

A study of the care of disabled elderly parents in
the community by single daughters and sons

A thesis submitted for a Ph.D degree

by

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Abstract

The thesis looks at the effect of the social policy of community care for infirm elderly parents on their supporting single daughters and sons. It is a small empirical study of a sample of 58 carers whose parents were on the district nursing records of one area health authority. Most of the parents were in their eighties or nineties and all had multiple impairments. The daughters and sons (the carers) were themselves usually approaching or above retirement age. Common problems arising from parental dependency included broken sleep, few leisure activities outside the home, difficulties in taking a holiday and in maintaining friendships. The majority of the women below retirement age were unable to maintain a full-time job outside the home; but it was rare for a son's employment to be so affected.

Several issues were highlighted by the research findings. In practice the policy of community care meant that the burden of care usually fell on one person. Not only did a substantial number of the single men and women totally lack supportive kin, those who had kin were usually given little support by such kin in coping with the parent. Although neighbours gave some form of practical support to about half the carers, the more infirm the parent the less likely were they to be supportive. As far as the statutory health and personal social services were concerned, the carers received relatively little support in the form of counselling or advice from district nurses or social workers. Although the social services departments often gave practical support such as Meals on Wheels or home help, services which would effectively share the burden of care, such as day care or short term places in residential Homes, were not readily available.

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Chapter 1: INTRODUCTION

Community care for infirm old people has become an important social policy issue. Undoubtedly, for many infirm old people living in the community, family members are the principal source of support and care. The primary purpose of this study is to provide a picture of the effect of giving support on a sample of family members and to evaluate the relative contribution made by the wider community and the statutory health and welfare services.

This small exploratory study was restricted to unmarried women or men living in the same household as at least one infirm parent. A sample of 58 single carers was selected from their parents' names being on district nursing records in one area health authority.

This introductory chapter has three sections. The first discusses the meaning attributed to the phrase 'community care'. Secondly, the demographic background to community care policies for the infirm elderly is examined. The third section briefly reviews relevant empirical studies of the elderly.

Community Care

Although community care has frequently been described in government documents as the principal social policy objective for the infirm elderly, the term does not have a simple meaning. Contradictory definitions have been offered in various discussion and command papers. For example, the 1963 Blue Book, 'Health and Welfare: the

Development of Community Care', which documented both the current state of health and local authority services and the plans for future development, offered a definition of community care which included living in residential homes;

'The first aim of the health and welfare services is to promote health and well-being and to forestall illness and disability by preventive measures. Where illness or disability nevertheless occurs, their aim is to provide care in the community- at home, at centres, or where necessary, in residential accommodation - for all who do not require the types of treatment and care which can be given only in hospitals.'(1)

But the Scottish command paper, 'Social Work and the Community', published two years later, considered residential homes to be outside the community;

'It is desirable that whenever possible old people should remain in the community rather than go into residential care, and if they are to do so, a wide range of help from public and voluntary services is needed'.(2)

An example of a definition of community care including both living in residential homes and hospitals occurred in the 1977 D.H.S.S. consultative paper, 'The Way Forward: Priorities in the Health and Social Services';

'In this document, the term 'community' covers a whole range of provision, including community hospitals, hostels, day hospitals, residential homes, day centres and domiciliary support. The term 'community care' embraces primary health care and all the above services, whether provided by health authorities, independent contractors, voluntary bodies, community self-help or family and friends'.(3)

If there is one common meaning which can be attached to the term community care in official documentation, it appears to be a negative one, i.e. not being in the geographically remote, large institutions which characterised the social care of dependent groups in the late nineteenth and early twentieth centuries.

The word community became an integral part of social policy vocabulary in the 1960s. Community care was described not only as the policy objective for the infirm elderly but for the mentally ill and for the mentally handicapped as well.⁽⁴⁾ As far as education was concerned, the 1967 Plowden Report on primary education recommended the development of community schools.⁽⁵⁾ In the same year, a Central Housing Advisory Committee Report on new towns was given the title 'New Communities'.⁽⁶⁾ A year later, the Seebohm Report on the reorganisation of the local authority personal social services, concerned to encourage citizen participation in the social services, devoted a chapter to considering the concept of community.⁽⁷⁾

However, the concept of community defies definition in a universally acceptable way. As Bell and Newby commented,

'The concept of community has been the concern of sociologists for more than two hundred years, yet a satisfactory definition of it in sociological terms appears as remote as ever.'⁽⁸⁾

Underlying many definitions is an assumption that a community must have a territorial basis. For example, McIver and Page observed,

'Community is the term we apply to a pioneer settlement, a village, a city, a tribe or a nation. Wherever the members of any group, small or large, live together in such a way that they share, not this or that particular interest, but the basic conditions of a common life, we call that group a community. The mark of a community is that one's life may be lived wholly within it The basic criterion of community, then, is that all of one's social relationships may be found within it.'⁽⁹⁾

Yet other definitions reject the necessity for a territorial element.

Nisbet, for example, asserted that a community could be,

'all forms of relationship which are characterised by a high degree of personal intimacy, emotional depth, moral commitment, social cohesion and continuity in time. Community is founded on man conceived in his wholeness rather than in one or another of the roles, taken separately, that he may hold in a social order'.⁽¹⁰⁾

The Seebom Report, accepting the primal significance of relationships, offered two definitions,

'although traditionally the idea of community has rested upon geographical locality, and this remains an important aspect of many communities, today different members of a family may belong to different communities of interest as well as the same local neighbourhood. The notion of community implies the existence of a network of reciprocal social relationships.....'(11)

Enthusiasm for searching for an appropriate definition is attenuated by the knowledge that Hillery, in a 1955 article, described finding no less than 94 different definitions of community in the existing literature.⁽¹²⁾ He concluded,

'There is one element, however, which can be found in all the concepts..... all of the definitions deal with people. Beyond this common basis, there is no agreement'. (13)

In a 1969 article, Stacey, like Hillery, doubting whether the concept of community referred to a useful abstraction, preferred to use the expression 'a local social system'.⁽¹⁴⁾ She used the phrase 'a social system' to mean a set of interrelated social institutions covering all aspects of social life, familial, religious, juridicial, and the associated belief systems of each. 'A local social system' was described as occurring when such a set of interrelations existed in a geographically defined locality.⁽¹⁵⁾

Although Stacey's refusal to use the word community is undoubtedly sound, it is, nevertheless, necessary to attempt to understand the way in which the word has been used in statements about government policy. Community is a word which evokes feelings of warmth and of belonging. As Titmuss commented, in a 1961 lecture, delivered at the Annual Conference of the National Association for Mental Health,

'Does it not conjure up a sense of warmth and of human kindness, essentially personal and comforting, as loving as the wild flowers so enchantingly described by Lawrence in 'Lady Chatterley's Lover'? (16)

Tonnies use of the dichotomy Gemeinschaft: Gesellschaft conveyed a similar essence to the word community:

'All intimate, private and exclusive living together is understood as life in Gemeinschaft (community). Gesellschaft (society) is public life - it is the world itself.... A young man is warned against bad Gesellschaft (society), but the expression bad Gemeinschaft (community) violates the meaning of the word.....Gemeinschaft (community) is old; Gesellschaft (society) is new as a name as well as a phenomenon.... All praise of rural life has pointed out that the Gemeinschaft (community) is stronger there and more alive; it is the lasting and genuine form of living together'. (17)

Labelling a policy community care, therefore, ascribes certain of these qualities to it. By definition, such a policy must be good. Pursuing a precise definition of actual objectives and how these are to be achieved becomes almost indecent. Butterworth and Weir rather neatly described this element:

'Community tends to be a God word. In many circumstances, when it is mentioned, we are expected to abase ourselves before it rather than attempt to define it'. (18)

Despite the underlying connotations, some kind of definition is necessary. For the purpose of this chapter the word community is simply taken to mean 'home'. Therefore, the term community care means care at home as opposed to care in hospital, residential home or hostel. On this basis, it can be argued that the principle of community care for the infirm elderly was recognised by central government about 1890, when, according to Beatrice Webb, there was a significant change of direction in the treatment of the aged under the Poor Law.⁽¹⁹⁾ In the preceding twenty years, the accepted policy had been to offer a place in the General Workhouse to those old people who had become too infirm or destitute to maintain themselves in their

own homes. Outdoor relief was only given by a few Boards of Guardians.⁽²⁰⁾ From about 1890 the policy became to distinguish 'between the deserving and the undeserving poor, and in the amenities of institutional treatment'.⁽²¹⁾ Webb identified the change in policy as being, 'in obedience to the wishes of Parliament and in compliance with widespread public opinion.'⁽²²⁾ Following the recommendations of the Royal Commission on the Aged Poor in 1895, the Local Government Board, which administered the Boards of Guardians, issued a circular. The following extract describes the general policy followed at the turn of the century,

'We are convinced that there is a strong feeling that in the administration of relief there should be greater discrimination between the respectable aged who become destitute, and those whose destitution is distinctly the consequence of their own misconduct; and we recommend that Boards of Guardians, in dealing with applications for relief, should inquire with special care into the antecedents of destitute persons whose physical faculties have failed by reason of age or infirmity; and that Outdoor Relief should in such cases be given those who are shown to have been of good character, thrifty according to their opportunities, and generally independent in early life.....' (23)

Undoubtedly, the most significant policy change, enabling many old people to remain in their own homes was the introduction of the non-contributory old age pension in 1908 for those aged 70 or over.⁽²⁴⁾ Without such a pension the threat of destitution and recourse to the Boards of Guardians with their powers to determine eligibility must always have been present for those old people who were no longer able to work and lacked private means. Flora Thompson, in her autobiography, 'From Lark Rise to Candleford', attempted to convey the significance of these pensions from her experience as a post office clerk at their introduction;

'Then there were one or two poorer couples, just holding on to their homes, but in daily fear of the workhouse. The Poor Law authorities allowed old people past work a small weekly sum as outdoor relief; but it was not sufficient to live upon, and, unless they had more than usually prosperous children to help support them, there came a time when the home had to be broken up. When twenty years later, the Old Age Pensions began, life was transformed for such aged cottagers. They were relieved of anxiety. They were suddenly rich. Independent for life. At first when they went to the Post Office to draw it, tears of gratitude would run down the cheeks of some, and they would say as they picked up their money, 'God bless that Lord George! (for they could not believe one so powerful and munificent could be a plain 'Mr'.) and God bless you, miss! and there were flowers from their gardens and apples from their trees for the girl who merely handed them the money.' (25)

In a study of nineteenth century Lancashire, Anderson argued that the introduction of old age pensions also had the effect of strengthening kinship ties by increasing the support adult children felt able to give to elderly parents.

'It was probably only after the introduction of the old age pension transferred much of the economic burden of old age from kin, and above all in the interwar period when economic problems caused by other critical life situations began to be eased by the beginnings of that bureaucratised system that we now call the Welfare State to the point where kinship aid was not very costly per capita in cash terms that a really strong effective and non-calculative commitment to the kinship net could develop and traditional community solidarity become possible.' (26)

But it was not until the National Assistance Act of 1948, which signalled the end of the Poor Law, that local authorities were given very limited powers to provide support for old people living in their own homes. They were allowed to make contributions to voluntary organisations, 'whose activities consist in or include the provision of recreation or meals for old people'.⁽²⁷⁾ If the elderly people were classified as 'substantially and permanently handicapped by illness, injury or congenital deformity the local authority was given the

power 'to make arrangements for promoting' their welfare.⁽²⁸⁾ Most local authorities did exercise their powers to some extent under the National Assistance Act. In a history of social work in Britain, Younghusband gave the figure of 83% of them cooperating with voluntary organisations in providing services by the mid-1950s.⁽²⁹⁾

Central government reports relating to the elderly in the 1950s, continued to emphasise the desirability of their remaining at home. Two arguments in tandem were generally put forward in support of this view, one economic and the other humanitarian. Thus, long term admission to a hospital or a residential Home was considered undesirable both because of the high economic cost to central or local government and because of the distress caused to an old person in leaving a familiar environment. The possibility of such a policy causing strain to supporting relatives or neighbours was largely ignored. Thus, the 1954 Phillips Committee Report on the economic and financial problems of provision for old age made the following simplistic recommendation;

'The broad aim should be to enable old people to live in their own homes where they can continue to be happy and useful members of the community, in touch with their relatives and neighbours'.⁽³⁰⁾

This recommendation was reiterated with little additional comment by the Guillebaud Committee Report on the costs of the National Health Service two years later.⁽³¹⁾

Policies for the infirm elderly must be seen in the context of those for other dependent groups. Major changes occurring in the policies relating to the mentally ill and the mentally handicapped were particularly significant. In the late 1950s the emphasis was switched from hospital to community care. The 1957 Report of the Royal Commission on Mental Illness and Mental Deficiency devoted a

chapter to the potential development of community care.⁽³²⁾ Local authorities were given considerable powers to increase their support services for the mentally disordered in the ensuing legislation.⁽³³⁾ The real impetus to a change of policy direction was given in a 1961 speech which the Minister of Health, Mr. Enoch Powell, made to the Annual Conference of the National Association for Mental Health.⁽³⁴⁾ He announced plans for halving the number of hospital beds for the mentally disordered in the next fifteen years, for gradually eliminating the geographically separate asylum system and for eventually treating all such patients in the wards or wings of general hospitals. A necessary corollary to these plans was that responsibility for large numbers of the mentally disordered should be accepted within the community.

As far as the elderly were concerned, it was not until 1962 that local authorities themselves were given the power to provide support services such as meals or recreational facilities.⁽³⁵⁾ Before this they had been limited to making contributions to voluntary organisations providing these services. The 1963 Blue Book, 'Health and Welfare: the Development of Community Care', gave a strong directive for local authorities to develop adequate support services to forestall long-term hospital admissions for the elderly infirm, the mentally disordered and the physically disabled.⁽³⁶⁾ It described the current state of the services and summarised the separate local authority plans for their development. A conspicuous omission was that the central government did not set targets which should be achieved. In contrast the preceding 1962 Hospital Plan had very specific figures for the proposed reduction of hospital beds, including geriatric, for the next ten years.⁽³⁷⁾ Only in 1968, under the Health Services

and Public Health Act, were local authorities given the general power 'to make arrangements for promoting the welfare of old people'.⁽³⁸⁾

Not surprisingly local authority support services for old people in many areas were described, in a government report, as 'underdeveloped, limited and patchy' in the late 1960s.⁽³⁹⁾

The 1968 Seebohm Report on the reorganisation of local authority and allied personal social services provided a significant stimulus to community care policies.⁽⁴⁰⁾ As far as old people were concerned, for the first time in a government document, considerable emphasis was laid on assisting their supporting family members,

'In particular, of course, services for old people in their own homes will not be adequately developed unless greater attention is paid to supporting their families who in turn support them. The problem of old people living alone have attracted much attention, but many of those who are most dependent live with younger relatives who are themselves getting on in years..... If old people are to remain in the community, support and assistance must often be directed to the whole family of which they are members.'⁽⁴¹⁾

The need to give support to the whole family and not just the old person was one of the reasons given for recommending that services for the elderly should be an integral part of a social services department.⁽⁴²⁾

There was also an attempt in the report to consider the potential relationship between the proposed social services department and the community. Three specific recommendations were made. Firstly, departments should be made responsible for community development, creating 'conditions favourable to community identity and activity'.⁽⁴³⁾ Secondly, citizen participation in the 'planning and provision of the social services should be developed'.⁽⁴⁴⁾ Finally, voluntary work should be encouraged both by supporting voluntary organisa-

tions and by enlisting 'the services of large numbers of volunteers to complement the teams of professional workers'.⁽⁴⁵⁾

Major organisational changes were also suggested. These included replacing the fragmented welfare services by one social service department and the setting up of area teams. The Seebohm Report argued that the fragmented welfare services had produced separate spheres of responsibility with areas of neglect.⁽⁴⁶⁾ A single department would provide a clear and comprehensive pattern of responsibility over the whole social welfare field.⁽⁴⁷⁾ It would meet needs which were being neglected, adapt to changing conditions and be more accessible and comprehensible to consumers.⁽⁴⁸⁾ The 1970 Local Authority Social Services Act enacted the basic changes recommended in the Seebohm Report.⁽⁴⁹⁾

It can be argued that in some respects the Seebohm Report was detrimental rather than instrumental to the promotion of community care for old people. For example, a decline in social workers' attention to the elderly client group appears to have taken place. Before reorganisation social workers employed by a local authority welfare department, or in some areas a local health department, had a specific responsibility for old people. Since reorganisation old people have become just one of several client groups for whom the social services departments have a responsibility. Stevenson has suggested that one of the factors disturbing the balance of social work skill and attention offered to the elderly has been the anxiety generated by the pre-occupation of the general public, of the media and of the government with cases, or potential cases, of non-accidental injury to children.⁽⁵⁰⁾ The Seebohm Report did not anticipate a situation of different client groups competing for social workers' time.

Before the new social services departments were actually set up, further legislation significant for the elderly was passed by parliament, the 1970 Chronically Sick and Disabled Persons Act.⁽⁵¹⁾ As nearly 60% of impaired people are estimated to be above retirement age, this considerably widened both the powers and duties of local authorities in respect of the infirm elderly.⁽⁵²⁾ Several powers which had previously been permissive became mandatory. Amongst these were providing practical assistance in the home; providing recreational facilities both inside and outside the home; giving help, where needed, in adapting a disabled person's home 'to secure his greater safety, comfort or convenience'; and in providing, where necessary, a telephone.⁽⁵³⁾ Two duties which were innovatory were that the local authority had to find out the number and needs of disabled people living in the area and had to publicise the available welfare services.⁽⁵⁴⁾

It can be argued that the Chronically Sick and Disabled Persons Act has been more significant in raising consciousness of the needs of the disabled than in having a substantial impact on their lives. A private member's act passed in the dying days of a Labour government, it was not backed by any special financial provision from the Exchequer.⁽⁵⁵⁾ Although the act appeared to be greeted initially with enthusiasm by many local authorities, the public expenditure cuts of the 1970s soon affected their implementation of it. Aids for the disabled and housing adaptations appeared to be particularly early targets for savings.⁽⁵⁶⁾

Since 1970 there has been a dual and interrelated emphasis in government papers on the potentiality of volunteers for giving support in the community and on the public expenditure restrictions

inhibiting the development of adequate support services. For example, the 1981 command paper, 'Growing Older', exhorted,

'Whatever level of expenditure proves practicable, and however it is distributed, the primary sources of support and care for elderly people are informal and voluntary.... Voluntary and religious organisations already providing support can increase their effectiveness by working with each other and with public authorities to coordinate service and meet particular needs....(57)

There have also been government initiatives to stimulate voluntary activity. The Volunteer Centre, financed both by government and by voluntary trusts, was set up in 1973 to disseminate information on voluntary involvement, to advise on training volunteers and to take initiatives in extending voluntary participation. In 1976, the Good Neighbour campaign, to stimulate community support of the elderly, was launched by the Secretary of State for Social Services, David Ennals.⁽⁵⁸⁾

At least in the 1970s, there has been a consistent acknowledgment that supporting families may be strained by a policy of community care. The 1981 command paper, 'Growing Older', for example, comments that families

'are usually best placed to understand and meet the wide variety of personal needs which arise, and their support is irreplaceable. It may involve considerable personal sacrifice, particularly where the 'family' is one person, often a single woman, caring for an elderly relative'.⁽⁵⁹⁾

Three influences become readily apparent in the acceptance of community care as a policy objective for dependent groups; the humanitarian, the idealistic and the economic. Humanitarian feeling were engendered both by the evidence presented by sociologists and others that institutional care could be damaging and by the evidence emerging from a number of legal inquiries into allegations concerning staff ill-treatment of patients in certain mental hospitals. Barton's 'Institutional Neurosis', published in 1959, had a considerable

impact.⁽⁶⁰⁾ Its main contention was that long stay patients in mental hospitals had two illnesses: the one with which they had been admitted and an institutional neurosis which the hospital had given them. Goffman's 'Asylums: Essays on the Social Situation of Mental Patients and Other Inmates' was published two years later.⁽⁶¹⁾ His concept of the total institution has undoubtedly been highly influential. It was argued that seemingly dissimilar organisations such as mental hospitals, prisons, old peoples' homes, boarding schools and barracks share certain common characteristics.⁽⁶²⁾ For example, the barriers ordinarily separating the three basic spheres of life, sleeping, playing and working, are broken down. All aspects of life are conducted in the same place and under the same single authority. Each phase of a member's daily activity is carried on in the immediate company of a large batch of others. All inmates are treated alike and required to do the same thing together.⁽⁶³⁾ Goffman summarised total institutions as 'forcing houses for changing persons; each is a natural experiment on what can be done to the self'.⁽⁶⁴⁾

The concept of the total institution had a significant impact on several British studies of social organisations in the 1960s.⁽⁶⁵⁾ Amongst them, Townsend's 1962 survey of residential homes for the elderly, 'The Last Refuge', has been particularly influential on attitudes towards the appropriate policies for the infirm elderly.⁽⁶⁶⁾ Based on interviews with new residents in a random sample of residential homes in England and Wales, the study portrayed a bleak picture of their lives:

'We found they tend to experience loss of occupation, isolation from family, friends and community, difficulty in forming more than tenuous relationships with members of the staff and other residents, loneliness, loss of privacy and identity and collapse of powers of self-determination. These experiences vary in severity from one type of Home to another but seem to exist in some measure everywhere'.⁽⁶⁷⁾

A major conclusion of the study was that the majority of new residents could have continued to live in homes of their own if a small amount of support had been given by the domiciliary social services.⁽⁶⁸⁾ They had entered Homes for reasons of poverty, lack of housing, social isolation and absence of secondary sources of help from relatives and friends.⁽⁶⁹⁾ Townsend's proposals for future policy were sweeping. Residential homes should be gradually eliminated, being replaced partly by sheltered housing and partly by a slight extension of the hospital system.⁽⁷⁰⁾

Doubts about institutions as an acceptable form of social care were further exacerbated by a spate of inquiries beginning in the late 1960s into alleged staff ill-treatment of patients in several mental hospitals.⁽⁷¹⁾ These inquiries received enormous publicity. As Jones pointed out in a history of the mental health services, 'the effect of a number of isolated incidents has been to arouse disquiet about the whole mental hospital system.'⁽⁷²⁾ The publication of Robb's 'Sans Everything: A case to answer', in 1967, particularly strengthened the case for community care.⁽⁷³⁾ It contained sworn evidence from nurses and social workers of appalling ill-treatment of geriatric and psycho-geriatric patients in several hospitals, and a diary recording the deprivations suffered by an elderly friend of the author in a geriatric ward. An appendix contained an abridged version of a speech, given in the House of Lords, which summarised the conditions described in the book. This is an extract from it:

'In hospitals of this kind, of which I believe there are six or seven in the country, old people, it would be no exaggeration to say, are treated worse than in the old-fashioned type of Victorian workhouses. They are treated worse because they are regarded as mentally deficient as well as merely poor. There is, for example the practice of what is known as 'stripping'. This means

that on entry all personal belongings are removed, including spectacles, deaf aids and dentures. There are no personal lockers. The food is appalling. In some cases the last meal is served at half past three in the afternoon. Electro-convulsive treatment is given, I believe, to almost every old person, irrespective of whether it is needed or not'.⁽⁷⁴⁾

In addition to publicising the deprivations being suffered, 'Sans Everything' resulted in no less than seven inquiries in which papers were forwarded to the Director of Public Prosecutions.⁽⁷⁵⁾

The second influence apparent in formulating policies of community care has been the idealization of voluntary action. Encouraging voluntary action, in all its forms, is regarded as a positive contribution to a healthy society and, conversely, discouraging such action is to be deplored as a destructive act. This is an underlying theme in Titmuss' comparison of blood donor systems in several countries.⁽⁷⁶⁾ At one point he said,

'the ways in which society organises and structures its social institutions - and particularly its health and welfare systems - can encourage or discourage the altruistic in man; such systems can foster integration or alienation; they can allow the 'theme of the gift' (to recall Mauss' words) - of generosity towards strangers - to spread among and between social groups and generations.'⁽⁷⁷⁾

In the late 1950s and early 1960s, when community care was becoming increasingly regarded as a desirable policy objective, there was also a marked upsurge in voluntary activity.⁽⁷⁸⁾ During the fifteen or so years since the end of the Second World War, the voluntary sector appeared, in some ways, to have been marking time.⁽⁷⁹⁾ Part of the upsurge was the establishment of many new voluntary groups including pressure groups such as the Disablement Income Group, Shelter, and Child Poverty Action Group; mutual aid groups such as the pre-school playgroup movement and organisations for one parent families; and organisations for young volunteers such as Community Service Volunteers, Task Force, and the Young Volunteer Force Foundation.

The formulation of community care policies and the upsurge of voluntary activity appear to be interrelated processes. In addition to the initiatives previously mentioned, of contributing to the Volunteer Centre and launching a Good Neighbour campaign, both central and local governments throughout the 1960s and 70s have attempted to stimulate voluntary activity by giving grants to voluntary organisations.

The humanitarian and idealistic arguments for community care have gained support on economic grounds. Care in the community has been generally regarded as cheaper than institutional care. Restrictions on public expenditure and a substantial increase in the number of people aged 75 and over, the age group which makes most demands on places in geriatric hospital wards and residential homes, have encouraged the pursuit of community care.⁽⁸⁰⁾ As far as local authorities are concerned residential homes are expensive to run. In the financial year 1976/77, residential care of all types absorbed almost half of the social services departments' expenditure.⁽⁸¹⁾ For the elderly as a separate group, residential care cost approximately 57% of the total budget allocated to them.⁽⁸²⁾ (The figure does not take into account any administrative costs and assumes that all recipients of home help, meals, adaptations in the home, aids, telephones and holidays are above retirement age when, in fact, some of them would be physically disabled people below it). As far as hospitals are concerned, elderly patients are more likely than younger ones to create problems by blocking beds. As the 1979 report of the Royal Commission on the National Health Service commented,

'They frequently remain in hospital long after any investigation or active treatment has been completed because they are not fit to go home and there is nowhere else for them to go.'⁽⁸³⁾

It can be argued that the comparison between high cost institutional care and inexpensive community care is a fallacy. Standards of care in institutions are usually high but the standard of support services in the community is likely to be low. Calculations about the cost of community care generally ignore the indirect social and economic costs of transferring the burden of care to families, neighbours and voluntary organisations. Indeed, a note of caution has crept into government documents in respect of this point. The report of the Royal Commission on the National Health Service commented,

'it is argued that care in the community will relieve pressure on the hospital services and may be cheaper. There are, however, a number of difficulties about comparing the costs of treating or caring for patients in hospitals and at home. The degree of dependency of patients may vary, the quality of treatment and care may be different and is difficult to measure, the outcome or effectiveness of the treatment is hard to assess, and treatment at home may impose heavy burdens on relatives and neighbours'. (84)

A Scottish Home and Health Department report on the elderly, in 1980, made a similar point,

'Community care is not necessarily a direct and cheaper substitute for 'residential' care; indeed, for the more dependent, it may use more resources in manpower in that the services of many people from several disciplines may be needed to enable an old person to stay in his own home rather than in a hospital or residential home. (85)

Demographic factors

All Western industrial societies in the twentieth century have experienced an unprecedented increase in the proportion of the population which is aged 65 and over. In Britain the proportion of the population in this age group has risen from 6.3% in 1901 to 14.8% in 1979. (86) The number of people aged 65 and over is projected to continue increasing until the mid 1980s both in absolute terms and as a proportion of the population. (87) But, in Britain, as in

many other Western industrial societies, a drop is then anticipated as the children, born in the low fertility period between the two world wars enter this age group.⁽⁸⁸⁾ The relatively large proportion of the population aged 65 and over in the early 1980s can be attributed to the high fertility rate combined with improved environmental and health conditions of the late nineteenth and early twentieth centuries being followed by a decline in the birth rate commencing in the late 1920s and continuing for about twenty years. From approximately the mid 1980s until the end of the century a decline in the elderly population is anticipated and, by 2001, it is projected that 14.1% of the population will be in this age group.⁽⁸⁹⁾ However in the early years of the twenty-first century, a further increase in the elderly population is expected as those born in the relatively high birth rate period after the Second World War reach retirement age.⁽⁹⁰⁾

Because of the reduced infant mortality rates and relatively high birth rates around the turn of this century, the anticipated trend for people aged 75 and over is quite different from that of the elderly population as a whole. Both in terms of absolute numbers and as a proportion of the population, this age group is expected to increase substantially in the next thirty five years. In 1977 there were estimated to be 2.9 million people aged 75 and over and by the end of the century the number is expected to rise to 3.6 million, an increase of 25%.⁽⁹¹⁾ The anticipated proportional increase of those aged 85 and over is even greater. In the same period an increase of nearly 60% is expected. There will thus be about 800,000 people in this age group by the turn of the century.⁽⁹²⁾ As the Office of Population Censuses and Surveys'1977 demographic review pointed out, these figures were based on the assumption that mortality rates would continue to fall.⁽⁹³⁾ Even if mortality rates remained constant at

the 1977 level, the number of people aged 85 and over could still be expected to increase by over 30% by the turn of the century.⁽⁹⁴⁾

A substantial increase in the numbers of very old people has profound social policy consequences because, at least at present, ill-health and difficulties in performing personal care or housework tasks are more likely to occur at an advanced age. Hunt's 1978 government survey of people aged 65 and over living in the community illustrated this point.⁽⁹⁵⁾ All the respondents were asked about their ability to perform each of eleven tasks involving personal mobility. The difference between the youngest and the oldest age groups was frequently very great. For example, 4.4% of the 65-69 age group were unable to bath without assistance compared with more than half the 85 and over age group and similarly 4.4% of the former were unable to go out of doors on their own compared with almost half the oldest age group.⁽⁹⁶⁾

The frailty of people aged 85 and over is reflected in the heavy demands they make on the health and welfare services. Hunt's survey provided numerous examples; they were twice as likely as people in the 65-74 age group to have had at least one home visit from a general practitioner in the six months preceding the interview; 19.6% of them had been visited by a district nurse in the preceding six months compared with 7.8% of all the elderly; 27.3% of them had been visited by a home help in the preceding six months compared with 8.9% of all the elderly; and 11.3% of them had received Meals on Wheels compared with 2.6% of all elderly people.⁽⁹⁷⁾ Residents in local authority residential homes are generally the very elderly. About 80% of those admitted are over 75 and almost 35% over 85.⁽⁹⁸⁾ In 1981 the average age of admission approached 82.⁽⁹⁹⁾

An increase in the number of very elderly people has far reaching consequences not only for the health and welfare services but also for the family as a social institution providing support for its members. At a simple statistical level far more middle-aged and elderly people are likely to experience the dependency of one or both aged parents. But, in addition, there are at least four significant social changes which could affect the role of the family in providing support. One is the low number of children judged by the standard of family size in the nineteenth century, actually available to assist their infirm old parents. Those parents now aged 75 or more belong to a generation with exceptionally low fertility.⁽¹⁰⁰⁾ The consequences of this low fertility were spelt out by Abrams in a 1978 Age Concern survey in four areas of people aged 75 and over; 30% of the respondents were childless and another 45% had had only one or two children.⁽¹⁰¹⁾

A second significant social change is the substantial growth in the number of women undertaking paid employment outside the home. For those women in the age group 45 - 59 years, this being the most likely age at which to be involved in supporting an aged parent or parent-in-law, the growth has been quite striking. In 1951 their economic activity rate was 21.5%.⁽¹⁰²⁾ By 1971 this had virtually trebled to 61.9%.⁽¹⁰³⁾ Although a relatively high proportion of these women, almost half, were in part-time jobs the significance of this change cannot be underestimated.⁽¹⁰⁴⁾ Rising unemployment is likely to have some impact on this trend. However, the drop in employment for married women in the 45-59 age group does not appear to be substantial; the decrease between 1978 and 1979 being by only 1%.⁽¹⁰⁵⁾ A high proportion of middle aged women now have an expectation of

working outside the home which may well affect their willingness to look after dependent elderly relatives.

The third significant social change is the decline in the number of unmarried women in their fifties. These women have generally been considered to have a traditional caretaking role with infirm aged parents. As the following table shows, a far higher proportion of women in their fifties were single thirty or more years ago than at present. In 1931 approximately one in six were single but by 1978 the proportion had dropped to approximately one in fourteen. (106)

Table 1 Proportion of the female population who were single (per 1,000 in each sex-age group)

Age	1901	1911	1921	1931	1951	1961	1971	1978
50-54	136	150	159	159	150	121	83	70
55-59	117	135	155	157	155	137	96	74

Extracted from Marriage and Divorce Statistics 1978 England and Wales, table 1.1(b), p.5, Office of Population Censuses and Surveys (H.M.S.O. 1980).

On the basis of marriage rates for the younger generations, the proportion of women in their fifties who are single can be expected to drop even further in the future. (107)

The relatively high proportion of women in the 50-59 age group who were unmarried in the first half of the century can be attributed both to a marriage rate which was considerably lower than in the 1970s and to a distorted sex ratio in the population in which females outnumbered males. (108) Significant factors in this distorted sex ratio were that fewer males than females survived the womb and childhood; far higher numbers of males than females emigrated to the

colonies and the male population was decimated in the First World War.⁽¹⁰⁹⁾ The present relatively low number of single unmarried women in their fifties arises both from the increased popularity of marriage and a sex ratio which is more favourable to males for all age groups below the age of about fifty.⁽¹¹⁰⁾ (For approximately half a century the male birth rate has been about 6% higher than for females but the mortality rate is greater for males than for females in all age groups and for the age groups above the age of fifty females outnumber males.)⁽¹¹¹⁾

An implication of the decline in the number of unmarried middle aged daughters is that the burden of support for more infirm old people will either fall on married children or on the statutory health and social services.

The fourth significant social change with implications for the support role of the family is the marked growth in the number of divorces since 1971.⁽¹¹²⁾ Remarriages also became more common in the 1970s with the proportion of marriages involving the remarriage of one or more partners increasing from a fifth to a third between 1971 and 1978.⁽¹¹⁸⁾ By 1978 a tenth of all marriages were remarriages for both partners.⁽¹¹⁴⁾ The sharp upward trend may not continue. 1979 was the first year in the 1970s in which there was not a substantial increase on the previous year's divorce figures; there was, in fact, a drop of 4%.⁽¹¹⁵⁾ However, it cannot be concluded from this that the upward divorce trend had been reversed.⁽¹¹⁶⁾

A rising divorce rate does not necessarily indicate an increase in marital breakdown. Many marriages end in separation. There are no precise figures for the number of separations occurring either in the past or in the present. The 1974 Finer Committee Report on One-Parent Families was certainly wary of concluding that the rate of marital breakdown had increased:

'there are at present no reliable means of relating de facto and de jure breakdown. The increasing incidence of divorce may merely reflect higher rates of transfer from the former to the latter category. On the other hand it may indicate a greater amount of breakdown'.(117)

Although the real number of separations cannot be known, the Office of Population Censuses and Surveys did estimate that there had probably been an increase of 10% between 1972 and 1976 in the number of lone separated mothers with dependent children.⁽¹¹⁸⁾ This figure was based mainly on claims for supplementary benefit. There are no means of estimating the number of marriages without dependent children which end in separation.

Divorce and separation are likely to lead to confused feelings of obligation towards parents-in-law, in respect of support in infirmity or old age. If the divorce or separation is followed by remarriage or cohabitation then the confusion of feeling is likely to be greater because people will experience relationships with more than one set of in-laws as a result of changing partners.

Research into the costs to the family of community care

There have been numerous British empirical studies of the elderly population in the past thirty years. Between them a wealth of data has been provided on old people's incomes, expenditure, health, housing conditions, leisure activities and use of the health and welfare services. Many of these studies deal with some aspects of the care of the elderly infirm in the community by their adult children. But, generally, little consideration has been given to the cost borne by these children in providing that care. Studies with relevant data on family support can be divided into four categories; the first includes those based on national samples of the elderly population; the second, those based on local samples of the elderly population; the third consists of sociological studies of kinship

ties in local areas using samples of both the elderly population and of younger generations and the fourth encompasses studies both of infirm old people and their supporters in the community.

There have been two national surveys of the elderly living in the community. The first, carried out in 1962, was reported in Townsend and Wedderburn's 'Aged in the Welfare State', published in 1965, and in Shanas et al's 'Old People in Three Industrial Societies', published in 1968.⁽¹¹⁹⁾ A sample of more than 2,500 was drawn from Britain.⁽¹²⁰⁾ The second study, a government one, was also based on a sample of more than 2,500 in 1976 and was reported in Hunt's 'The Elderly at Home', published in 1978.⁽¹²¹⁾ The sample was drawn from England only.

Townsend and Wedderburn's study was concerned particularly with information considered relevant to immediate policy decisions.⁽¹²²⁾ It, therefore, concentrated mainly on topics such as the income and assets of older people, their use of the health and welfare services and the evidence of need for an expansion of these services. The role of the family in situations of illness and infirmity was also discussed. They found that adult children, both in and outside the old person's household, played an important supportive role. For over a third of the respondents, who had been ill in bed during the previous year, their children had been the main source of help with housework, shopping and meals.⁽¹²²⁾ They were equally important in other difficult situations. A third of the men and women, who had difficulties in bathing, doing heavy housework and in preparing a hot meal, were helped by their children.⁽¹²⁴⁾ This emphasis on the importance of children's support of elderly parents in the community reiterated, from a different perspective, some of the findings in Townsend's 1962 survey of new residents in residential Homes, 'The Last Refuge'.⁽¹²⁵⁾

The new residents differed strikingly from the general population in marital status and in having available children. The proportion of unmarried people admitted was much greater than the proportion of widowed or divorced people and many times greater than the proportion of married people.⁽¹²⁶⁾ A disproportionately large number of those who were married or widowed were childless.⁽¹²⁷⁾

Shanas et al's comparative study of old people in America, Britain and Denmark focused on their health, their use of the health and welfare services, their work patterns and financial resources.⁽¹²⁸⁾ A central concern of the study was to show the extent to which old people were integrated into industrial societies. In order to facilitate greater understanding of the family life of old people, data was collected on topics such as family structure, family size, the physical proximity of relatives and the frequency of contact between family members. A wide diversity of family structures was found. At one extreme a substantial minority of old people were single or childless. But, at the other extreme, a large minority had both grandchildren and great-grandchildren as well as at least two children.⁽¹²⁹⁾ A substantial number of the old shared a household with at least one child. This living arrangement was far more common in Britain than in the other two countries; 42% of those with children sharing a household compared with 20% in Denmark and 28% in America.⁽¹³⁰⁾ Contact with children was shown to be frequent. Three out of four old people with children lived either with, or within thirty minutes journey, of at least one of them.⁽¹³¹⁾ In all the countries, half of all those who had children, but lived apart from them, had seen a child within the last twenty four hours before the interview.⁽¹³²⁾ The study particularly emphasised the reciprocal nature of supportive relationships. About two in three old people in Britain reported receiving help of

some kind from their children and about half reported giving help.⁽¹³³⁾
In all three countries there was little class difference in the reported frequency of contact between old people and their children and in the patterns of giving and receiving help.⁽¹³⁴⁾

Although an important source of data on the elderly population's income, expenditure, housing, employment, health and leisure interests, Hunt's government study had far less material on old people's relationships with their children than the Shanas et al study.⁽¹³⁵⁾ Nevertheless, there was corroboration of some fundamental points. Children outside the household were an important source of help when the old person had difficulties in shopping or going out of doors.⁽¹³⁶⁾ Contact with relatives appeared to be generally frequent. On average more than half the old people interviewed saw a relative from outside the household at least once a week, although there were marked differences in frequency between the different geographical regions.⁽¹³⁷⁾

As 60% of the impaired are estimated to be elderly, Harris' government survey of the handicapped and impaired in Britain, published in 1971, had much data relevant to the elderly population.⁽¹³⁸⁾ Although containing little detailed information on family support, the point was made that more than one in four of the impaired, over the age of 65, lived with either a married or an unmarried child.⁽¹³⁹⁾

The second category of studies with relevant data on family support contains local surveys of both healthy and infirm old people. Sheldon's 1948 survey of the elderly of Wolverhampton, 'The Social Medicine of Old Age', has been frequently referred to in later studies.⁽¹⁴⁰⁾ Based on a sample of 583 people, it is probably unique in having a sampling frame of a ration card register.⁽¹⁴¹⁾ Food rationing was

introduced during the Second World War both because of a shortage of vital foodstuffs and because of the need to ensure a balanced diet for the working and fighting population. Local registers of ration card holders were kept. Although Sheldon was mainly concerned with the mental and physical state of the elderly respondents, his comments on 'domestic structure' have particularly attracted attention;

'Contact with old people in their homes immediately brings to light the fact that the family is of fundamental importance.....It is immediately obvious that old people have to be regarded as an integral part of the community, and cannot be considered merely as individuals by themselves. Whether married, widowed, or single they live, wherever possible, under the influence of family ties.'(142)

Sheldon recognised that caring for ill old people at home could prove excessively difficult for the daughters.⁽¹⁴³⁾ He commented,

'There is in general a steady development of strain in association with the age of the subject; but the really important fact is the sudden steepness of the increase of severe strain on younger relatives when the subject reaches ages of 80 and over Indeed, at the ages of 85 and over, one quarter of the subjects were the cause of heavy strain on the younger generation.'(144)

Townsend's 1957 classic study of the family life of old people in Bethnal Green, based on a sample of 203 people on general practitioners' registers, had quite a different focus from the previous study.⁽¹⁴⁵⁾ The main concern was with the extended family and the kinship network rather than the physical and mental states of the respondents. Grandmothers were described as dominant central figures in the family networks of relationships, having special bonds with their daughters and grandchildren. Old people had close contact with kin. The respondents reported an average of thirteen relatives living within a mile. Three in four of all their children, both married and unmarried, were seen at least once a week, as many as a third of them every day.⁽¹⁴⁶⁾ As in Sheldon's study, elderly infirm respondents usually relied on their daughters for care.⁽¹⁴⁷⁾ Although Townsend admitted that this could cause strain, his emphasis was on reciprocity;

'We found old people getting a great deal of help, regularly and in emergencies, from their female relatives, particularly their daughters, living nearby. The remarkable thing was how often this help was reciprocated - through provision of meals, the care of grandchildren, and in other ways. The traffic was not all one-way. This exchange of services seemed to be an essential feature of the relationship between the generations; this is one of the main conclusions of the book.' (148)

Tunstall's 1966 study, 'Old and Alone', based on a sample of 195 names drawn from general practitioners' lists in four areas, has the same emphasis as Townsend's study on the supportiveness of existing children.⁽¹⁴⁹⁾ For example, nearly half of the housebound were helped by their children with heavy housework and shopping.⁽¹⁵⁰⁾ Of the housebound who had had car rides in the last year 'overwhelmingly the main providers ... were children and children-in-law'.⁽¹⁵¹⁾ Having a child alive made an old person less likely to be isolated.⁽¹⁵²⁾

Although an important source of data on the need for home helps, Meals on Wheels, rehousing and residential care, Harris' 1968 government survey of the elderly living in thirteen areas had virtually nothing on the relationship with, and support from, children.⁽¹⁵³⁾

However, Abrams' 1978 and 1980 Age Concern reports, based on interviews with 1,643 old people in four areas, did contain data on relationships with children.⁽¹⁵⁴⁾ The conclusions drawn about the supportive role of the family were rather different from those drawn by Townsend in 'The Family Life of Old People' and by Shanas et al in their comparative study of old people in three societies.⁽¹⁵⁵⁾

'The findings of the present survey indicate that for a large minority of the elderly in this country family members are certainly not available and that even where they are available the family bonds are sometimes so fragile as to be almost non-existent'.⁽¹⁵⁶⁾

An important difference between the studies was in the proportion of old people with a surviving child. Abrams found that only 65% of the respondents had a child who could potentially give support.⁽¹⁵⁷⁾ But Shanas et al found that 76% of British old people were in this

situation.⁽¹⁵⁸⁾ Abrams found that 17% of the respondents aged 75 and over and 15% of those aged between 65 and 74, who had a surviving child, shared a household with one or more of them.⁽¹⁵⁹⁾ Shanas et al found that 42% of British old people with children were in this situation.⁽¹⁶⁰⁾ The difference was sustained for contact with children. Nearly three in four old people with children, in Abrams study, saw at least one of them once a week. At the other end of the spectrum, nearly one in four elderly parents only saw a child once a month or less.⁽¹⁶¹⁾ In Shanas et al's study, 85.6% of British parents had seen at least one child in the last week and 6% had only seen a child once a month or less.⁽¹⁶²⁾

There are difficulties in comparing a four-area survey with a national one. However, as Abrams was careful to point out, the Age Concern survey had very similar findings to Hunt's 1978 government survey for such characteristics as marital status, dwelling tenure and household composition.⁽¹⁶³⁾ One significant difference was the proportion of women aged 75 or more who were living alone; Hunt's survey put this at 48% while the Age Concern figure was 60%.⁽¹⁶⁴⁾ The difference between the findings of the Shanas et al and the Age Concern surveys may be due to differences in sampling procedures. But, if the differences are real ones, then there has been a significant decline in the supportive role of the family for old people in the past twenty years. Such a change would have many implications for social policy.

The third category of studies contains local surveys of both old people and those of younger generations. The first of these, Young and Willmott's 1957 survey, 'Family and Kinship in East London', based on a sample of 933 people, was complementary to Townsend's study of old people.⁽¹⁶⁵⁾ Similar points were made about the proximity of kin, the central role of the grandmother and the support kin

members gave each other. As in Townsend's study the possible costs to children of caring for infirm parents was given little consideration. It was assumed that aid would be reciprocal;

'In their declining years they can call on their descendants to complete the circle of care by easing the strain of infirmity, illness and bereavement. In a three-generation family the old as well as the young both receive and give services; the aid is reciprocal'.(166)

In their 1960 survey of a middle class neighbourhood, 'Family and Class in a London suburb', based on a sample of 939 people, Willmott and Young found striking similarities with Bethnal Green;

'perhaps the greatest surprise of the whole report, is that the two places are so alike. More people in Bethnal Green have a married child living within five minutes walk, more in Woodford have one elsewhere in the same borough. Otherwise, the differences between the places are not at all sharp. If we consider how often people see their children, rather than where they live, even these differences virtually disappear'.(167)

One difference reported between Bethnal Green and Woodford was that in the former the proportion of people with a married child in the same house or within five minutes walk was much the same before and after pension age but in Woodford the proportion doubled after pension age.⁽¹⁶⁸⁾ Both widowhood and infirmity were likely to precipitate joint households being set up. In Woodford the older the parents the more likely they were to live in the same dwelling as a married child.⁽¹⁶⁹⁾ Although the fact that 'strains and worries' might arise from this situation was acknowledged there was no further discussion of what these might be.⁽¹⁷⁰⁾

Rosser and Harris' 1965 survey of the middle and working classes in Swansea, 'Family and Social Change', based on a sample of just under 2,000, had striking similarities with the Bethnal Green and Woodford studies.⁽¹⁷¹⁾ Despite a wider dispersal of the extended family, the proportion of old people who had seen a child in the twenty four

hours before the interview was the same as in Bethnal Green.⁽¹⁷²⁾ There was no difference in this respect between the classes. However, they argued that an effect of the wider dispersal of the extended family was to concentrate the responsibility for caring for an infirm parent on one child; the nearest daughter.⁽¹⁷³⁾ Despite a chapter entitled 'The Final Phase' with a section headed 'The burden of old age', little was said about the effect of the burden on the daughter involved.⁽¹⁷⁴⁾

The fourth category of studies encompasses surveys both of infirm old people and their supporters in the community. Two of them compared the burden imposed on families by both elderly and younger psychiatric patients. Hoenig and Hamilton's 1966 sample survey of 89 elderly patients at referral to two psychiatric units and four years later, concluded that a considerable burden was imposed on other members of the household.⁽¹⁷⁵⁾ This appeared to be heavier than for a comparative sample of younger patients.⁽¹⁷⁶⁾ Similarly, Sainsbury and Grad de Alarcon, in a 1974 publication, assessed the burden imposed on families of 410 mentally ill patients at referral to two different types of service, one hospital-centred and the other community-centred.⁽¹⁷⁷⁾ Follow-up interviews with the nearest relative were held two years later. Burden was not related to the sex of the patient, but it did increase with age, 40% of patients over 65 being rated as a severe burden at referral compared with 11% of those below 40 years.⁽¹⁷⁸⁾ Both the community-centred and the hospital-centred services were equally effective in relieving the burden on the family for elderly patients.⁽¹⁷⁹⁾

Other studies have concentrated on the characteristics of the supporters and the nature of the problems arising in providing care at home. Cresswell and Pasker's 1972 pilot study of 45 highly

dependent old people being nursed at home, concluded that most of the supporters were themselves elderly and often almost as vulnerable as the person being nursed.⁽¹⁸⁰⁾ As far as the structure of care was concerned, the responsibility for three in four infirm old people was contained wholly within one household. For two thirds of the old people all the care was provided by just one person.⁽¹⁸¹⁾

The following three studies offer a retrospective picture of the difficulties encountered by the principal supporters of infirm old people living at home.

Isaacs, Livingstone and Neville's 1972 study of geriatric patients 'Survival of the Unfittest', based on several surveys in Glasgow, drew similar conclusions.⁽¹⁸²⁾ In one survey of 280 patients admitted to the geriatric unit, it was assessed that half the supporters at home were labouring under 'undue stress', defined as, 'a state of exhaustion in the helper, occasioned by the patient's illness, which threatened the helper's own physical or mental well-being'.⁽¹⁸³⁾ Two groups of patients were most likely to cause strain, those aged 85 and over being looked after by either a very elderly spouse or a daughter herself above retirement age, and those under the age of sixty five being cared for by a daughter with dependent children.⁽¹⁸⁴⁾ A sample survey in which the relatives of 250 people who had died in Glasgow in 1968 were interviewed showed that the caring burden fell largely on elderly spouses and middle-aged daughters.⁽¹⁸⁵⁾ Very few were assisted by the home help or district nursing services and in a large number of cases relatives experienced great strain.⁽¹⁸⁶⁾

The previous survey had many similarities with Cartwright, Hockey and Anderson's 1973 study, 'Life Before Death', based on a sample of 960 people who had died in 12 areas of England and Wales.⁽¹⁸⁷⁾

The majority of these people, 83.3%, were aged 60 or more.⁽¹⁸⁸⁾ Information about the last year of their lives and care was collected from next of kin or neighbours. The focus was on the experience of care from hospital and institutional services, general practitioners, district nurses, community services, relatives and friends. The supportive role of the family was again emphasised,

'Wives and husbands generally bore the brunt of caring for the married, daughters for the widowed, sisters and other relatives for the single'.⁽¹⁸⁹⁾

The person who had borne the brunt of care was almost always a family member and generally a woman.⁽¹⁹⁰⁾ A brief mention was made of the effect on people's lives of being a 'brunt bearer'. A quarter of those who had been employed outside the home gave it up to look after the person who had died.⁽¹⁹¹⁾ 'Life Before Death', containing a wealth of data about that last year, focused on the experiences and situations of the people who had died rather than on those who had looked after them.

Sanford's 1975 study, based on interviews with the principal supporters of 50 elderly people admitted to a geriatric ward, was concerned with the problems which had become intolerable at home.⁽¹⁹²⁾ As in other studies, most of these supporters were women, almost half being spouses and almost half offspring.⁽¹⁹³⁾ Intolerable problems included sleep disturbance and faecal incontinence. Many other problems were not considered intolerable by the supporter. These included urinary incontinence and the inability to wash or dress unaided.⁽¹⁹⁴⁾

Green, Creese and Kaufert's 1979 study similarly examined the structure of support within the community.⁽¹⁹⁵⁾ A sample of 92 frail elderly people, selected by a non-random method from general practitioners' lists, were interviewed mainly about their ability to perform 13 activities of daily living, whether they needed any help in performing them and, if so, from whom the help came.⁽¹⁹⁶⁾ The formal

domiciliary services had only a minor part in providing help. Most respondents depended on just one helper to meet all their needs. Again these helpers were mainly women, the largest single category of helpers being daughters.⁽¹⁹⁷⁾

Finally, a 1980 Equal Opportunities Commission report looked at the effect on employment and social life of another's dependency.⁽¹⁹⁸⁾ A sample of 116 people with a dependent relative was drawn in West Yorkshire. As far as elderly dependants were concerned, the responsibility, as in the other studies, usually fell on the nearest female relative. Their dependency usually had an adverse effect on that relative's health, employment and social life.

Although this latter category in particular contains studies with valuable insights into the difficulties of supporting elderly infirm people in their own homes, there is still a dearth of studies systematically exploring in depth the cost to a family member of implementing a social policy of community care. This dearth has been acknowledged from many sides. At the official level, the Department of Health and Social Security, in 1978, considered that the topic should have the highest priority for research funding.⁽¹⁹⁹⁾ More recently the Social Science Research Council launched a research initiative to examine the caring capacity in the community arguing, 'changing family relationships and changing ideas of the reciprocity to be expected between members of a family are affecting this important source of community care.'

This neglect has also been identified by individual authors. For example, Stevenson, in a 1978 Age Concern Occasional Paper, pointed out, 'we have done remarkably little to define and analyse what goes on in families who care for the elderly'.⁽²⁰¹⁾ This view was echoed by Mark Abrams in a 1978 overview of current British social

research on the elderly.⁽²⁰²⁾ Identifying neglected research areas he asked, 'how much and what kind of aid would be of most help to those families which include an elderly member who needs above normal care?.'⁽²⁰³⁾ In a discussion of research problems and priorities in community care Philip Abrams commented, 'the derived needs of domestic caring agents are a peculiarly unexplored territory which should, if the extension of community care is a really major commitment, rapidly be explored.'⁽²⁰⁴⁾

This study focuses on one type of domestic caring agent, the single child in the same household as an infirm elderly parent. Single children in this situation have been curiously neglected in studies of intergenerational relations. For example, Young and Willmott's 1957 study of family and kinship in Bethnal Green contained no reference to adult unmarried children.⁽²⁰⁵⁾ Their 1960 study of family and class in a London suburb did contain one brief paragraph which focused on their numerical incidence rather than their significance. In a chapter headed 'Are the parents deserted?', they commented,

'Before we look at old people's relationships with their married offspring, and ask where these live, we should just say a word about their single children. Are they living with their parents? Of the 210 people in the old age sample, 47 had at least one unmarried child, and they had 58 unmarried children altogether between them The majority of these bachelors and spinsters turned out to be still at home with their parents..... The proportion of single people living at home was almost exactly the same as in Bethnal Green. In so far as they benefited from having children at home, old people in the suburb were as well off as those in the East End. Now for the married children.'⁽²⁰⁶⁾

Rosser and Harris in a 1965 study of working and middle class families and kin in Swansea were equally dismissive. Although commenting that more elderly people lived with unmarried than married children, they then focused exclusively on the latter.⁽²⁰⁷⁾ Even when posing the question 'Do children care for their parents in

old age?' they only discussed the role of the married children.⁽²⁰⁸⁾ Townsend's 1957 study, 'Family Life of Old People', did have some acknowledgement of the supportive role of single children but nevertheless restricted comment to a few brief paragraphs.⁽²⁰⁹⁾ Similarly, Shanas et al's 1968 study of old people in three industrial societies gave single children very cursory treatment.⁽²¹⁰⁾

This neglect of single children is particularly striking in view of their significant supportive role with elderly parents. For example, Harris 1971 government survey of the handicapped and impaired estimated that 27% of the impaired aged 65 or over lived in the same household as a child, approximately half of these children were single and half married.⁽²¹¹⁾ In view of the fact that married people far outnumber the single between the age of 50 and 59, the age group most likely to be involved in parental care, this figure illustrates the particular significance that the single have in this area. The ratio of women who had ever been married to single women in this age group was about 14:1 in 1978.⁽²¹²⁾

CHAPTER 2 A DESCRIPTION OF THE STUDY

Despite the notion of community care having been so overtly central to government thinking about social policy for the disabled elderly for more than twenty years, there is still a remarkable dearth of knowledge about the caring capacity of the community. One determinant of that caring capacity is the effect which providing support and care has on the lives of the carers. Such carers are not a simple single category of people. They may be wives or husbands, married or unmarried offspring, more distant kinsfolk, neighbours, friends or voluntary workers. A research project examining the impact of caring on all types of carers would clearly be substantial, involving considerable resources and a large scale survey. This would have been beyond the scope of a single researcher with very limited financial resources. It was, however, possible to examine some of the problems experienced by a particular type of carer by studying a small sample of unmarried daughters and sons living with an elderly disabled parent.

It is far more common in our society for women rather than men to occupy the role of carer whether the dependant is a child, a disabled adult below retirement age or a disabled elderly person.⁽¹⁾ One of the basic objectives of this study, therefore, was to draw comparisons between the caring experiences of men and women in a superficially similar situation because it was hypothesised that there would be substantial gender differences between certain crucial elements of their situations.

The dependency of a disabled person is conditional on complex psychological and social factors as well as the underlying physical impairment. A significant factor for a disabled woman is that looking after a son or a husband is seen as integral to the feminine role. Therefore, a first hypothesis in the study was that there would be a

relationship between the extent of parental dependency and the sex of the carer. Mothers living with sons would be less dependent than those living with daughters. The second hypothesis, arising from the first, was that caring for a parent would have far more effect on a daughter's employment than on a son's.

Any study of care in the community must be interested in the extent to which care is actually given by the community. Once again, it is likely that the gender of the carer has an impact on the amount and nature of community support. A third hypothesis, then, was that sons would get more support than daughters from the community. However, supportive acts can only be evaluated in the context of the total caring burden which may often involve constant attendance on the disabled parent throughout the day and night for many years. A fourth hypothesis, then, was that when kinsfolk and neighbours gave support it would generally be slight in relation to the total burden of care and that the overall caring burden would primarily rest on one person, the single carer.

Although community care has for so long been accepted as highly desirable, local authority social services departments have failed to develop an appropriate partnership with those families caring for a disabled elderly parent in the same household. Over half the social services departments' expenditure on the elderly is spent on institutional care which is a service for a relatively small segment of the elderly population.⁽²⁾ Local authority services are directed primarily at the disabled elderly living alone or with a spouse. Several studies show that families with a disabled elderly parent in the same household receive little or no support.⁽³⁾ Therefore, a fifth hypothesis was that the majority of the single carers would also receive little or no support from social services departments.

The sample

There are considerable difficulties in obtaining a represent-

ative sample of a special population group. Ideally such a group could be located by sampling from the general population and sending an interviewer to each of the households selected to ascertain whether anybody in the special population group lived there. A very large sample from the general population would generally be needed to locate a small sample of the special population group. This would involve a team of interviewers and a substantial research budget. The cost of this process is lessened by locating the special population group through a postal survey of a sample of the general population. Nevertheless the process is still costly and there is a problem of obtaining an adequate response rate. As Moser and Kaltom pointed out, in 'Survey Methods and Social Investigation', a response rate of 10% to a postal survey is not unknown.⁽⁴⁾ A 1980 Equal Opportunities Commission study of carers with handicapped and elderly dependants had this particular problem of a low response to this type of survey. A two stage survey was used, and a postal survey of 2,500 households was followed by an interview survey. Despite the subject matter, it was only possible to get a response rate of 36% to the postal survey.⁽⁵⁾ A crucial factor in stimulating a public response does appear to be the sponsorship of a survey. It is not unusual for a Government Social Survey using postal questionnaires to have a response rate of 90% or more.⁽⁶⁾

There were pragmatic considerations in the present study. The research project had to be feasible for one person living on a Social Science Research Council postgraduate award for two years with research expenses limited to £100. In the event further financial support was given at the end of the two years through a Marjory Warren award.⁽⁷⁾

A pilot study was conducted with ten female carers contacted through the National Council for the Single Woman and her Dependents.⁽⁸⁾

In the main study reported here, the names of 108 carers were obtained indirectly by examining district nursing records in one area health authority. These nursing records provided a useful sampling frame because they contained details of household composition, patients' disabilities and ages. For various reasons 16 of the 108 single carers, identified from these records, proved to be ineligible. The most common reason was that the parent had died. In all, 30 carers refused an interview.

Interviews were successfully completed with 58 carers:

No longer a carer	16
Wrong address	4
Refused an interview	30
Interviewed	<u>58</u>
	<u>108</u>

Interviewing for the main study took place between November 1977 and March 1978. As the district nursing records contained the names of far fewer parents living with sons than of parents living with daughters, there were difficulties in obtaining as many interviews with male carers as female carers. Interviews were completed with 36 daughters and 22 sons. Undoubtedly it would have been more satisfactory to have interviewed as many sons as daughters. One possibility was to attempt to obtain more male names from district nursing records in another area health authority. But this presented practical difficulties. It had taken six months to get research permission from the first area health authority. Not only was it quite possible for research permission to be refused by a second area health authority, it would probably have taken the research committee at least as long to reach a decision. In any case sampling just male names from another area health authority could have been a source of invalidity. The

district nursing service or the social services departments in that area could have pursued quite different policies towards this type of caring situation. In practice, the sample was large enough to allow for some of the comparisons necessary to test the hypotheses about gender differences. Although there were fewer males, they represented almost the entire group of unmarried sons whose parents were receiving district nursing services in the area. While there were more females in the sample, they represented a larger group of unmarried daughters whose parents names were on district nursing records.

Indubitably a sample of 58 single carers is rather small. However, the size is adequate for an exploratory study which describes basic characteristics and processes and suggests explanatory hypotheses which could be tested in larger studies of caring situations. In 'Theory and Methods of Social Research', Galtung considered that a minimum sample of 50 was adequate for an analysis on the basis of two variables.⁽⁹⁾

Important contributions to sociological knowledge have been made from the data derived from small samples. Bott's 1955 study, 'Family and Social Network', which has been influential on thinking about the relationship between conjugal roles and kinship networks, was based on interviews with 20 couples.⁽¹⁰⁾ Oakley's study of housework was based on interviews with 20 working class and 20 middle class housewives.⁽¹¹⁾ Bayley's 1973 study of the structure of care in the community for mentally handicapped adults was based on interviews with 54 mothers.⁽¹²⁾

The boundaries of the area health authority were such that it included three outer London boroughs. The names of the health authority and the London boroughs remain unspecified and the names of the respondents have been changed to preserve anonymity.

It is not possible to know how representative the sample is of single carers in the general population. As far as the source of the sample is concerned, being on district nursing records becomes more likely at an advanced age. Hunt's 1978 government survey of the elderly living at home found that while 7.8% of all elderly people had been visited by a district nurse in the past six months, the figure rose to 19.6% of those aged 85 and over.⁽¹³⁾ Not unexpectedly such visits become more likely in cases of severe disability; one in three of the bedfast or housebound were being visited in Hunt's sample.⁽¹⁴⁾

There is no way of knowing whether the fact that there were more single daughters than sons with an infirm parent on district nursing records reflects the situation in the general population. Harris' 1971 government survey of the handicapped and impaired estimated that about 13% of impaired people over the age of 65 lived in the same household as a single child.⁽¹⁵⁾ But there was no indication of what proportion of these children were sons or daughters. The 1971 Census showed that there were 413,410 households containing a single son with one or more elderly parents and 309,000 households containing a single daughter with one or more elderly parents.⁽¹⁶⁾ But the existence of this type of household does not necessarily mean that the parent is infirm or dependent. Nor did the Census figures include those households in which both the child and the parent were beyond retirement age.

Non-response

Non-response is a difficulty likely to be encountered in both large and small surveys. Refusals are less likely to occur if an interviewer approaches a potential respondent directly and makes it clear that answering a few questions is all that is required. Moser and Kalton suggested that in this situation a typical non-response rate would probably be about 20%.⁽¹⁷⁾ But the rate is often higher than

this. For example, Abrams' 1978 Age Concern survey of elderly people in four areas which had interviewers calling at selected households to request an interview, had a non-response rate of 25.8%.⁽¹⁸⁾

When respondents are approached indirectly by being sent a letter requesting an interview, the non-response rate is usually much greater. For example, in his study of motherless families, Marsden had a non-response rate of 44% when writing to a sample of mothers dependant on supplementary benefit to request an interview.⁽¹⁹⁾ As far as the present study was concerned, the two research committees of the area health authority made it a research condition that the single carers could not be approached directly and a letter had to be sent requesting an interview. To minimise refusals, a 'contracting out' letter was sent to each potential respondent explaining the research objectives and suggesting a time for the interview. A reply was only needed to refuse an interview or to suggest a more convenient time. (A copy of this letter appears in Appendix One). People who were employed outside the home were offered interview times in the evening and at the weekends.

The non-response rate for the men was 40% and for the women 29%. Although this non-response rate seems high, it compares favourably with that of similar studies such as Marsden's 'Mothers Alone', or George and Wilding's 'Motherless Families' which had a non-response rate of 38% when using a 'contracting out' letter to approach a sample of fathers.⁽²⁰⁾

The possible reasons for each carer's refusal were discussed with the district nurse who normally visited the parent. Several people also wrote to explain why they felt unable to take part in the study. Those who were employed outside the home were more likely to refuse despite being offered interview times at the weekend and in the evening. As more men than women were in employment this appears to

be one of the factors in the sex difference in non-response. Working carers often experienced not only long commuting journeys but also weekends and evenings which were more than fully occupied by domestic and caring tasks. An extract from a letter apologising for refusing an interview illustrates the pressures which could be generated by a caring situation.

'I have to leave home at 7.30 a.m. in order to reach my office by 9. I don't get home until after 7 in the evening. I have to cook mother a meal, tidy up, wash up, and put her lunch ready on a tray for the next day. It all takes such a long time because I am a multiple sclerosis sufferer. I don't know how much longer I can keep it up really. Saturdays are my busy days because mother wants me all the time... I am sorry I am too busy to meet you.'

Several district nurses suggested that certain of the men and women declining to be interviewed were rather mentally disturbed in some way. Usually the person concerned appeared to the district nurse to be generally anti-social, leading a very isolated defensive existence. The following typical comment was made,

'Really, I am not surprised she refused to see you. She really keeps herself to herself. I could not get in at first. I had to call at the house several times. They only let me in because the old lady needs the ulcer on her leg to be dressed. You would not believe how dirty the house is and it's dropping to pieces. That daughter is really dirty as well. Apparently she works part-time in the civil service but I am really surprised that she can hold a job down.'

As carers in employment were more likely to refuse an interview, the study may well underestimate the problems they experienced. Also not interviewing several men and women considered somewhat mentally disturbed by the district nurses may mean the loss of significant data in areas such as relationships with neighbours, relatives and professional helpers.

The Interviews

The average interview took about two hours to complete. A tape recorder was usually used and notes were rarely taken during the

interview. The guided interview schedule used appears in Appendix Two. Questions were not always asked in the same order because it was felt that the most effective sequence was determined by the respondents' willingness to take up topics. Sometimes it was necessary to respond early in the interview to the carer's need to vent strong feelings on topics such as a sibling's inattentiveness, a neighbour's unfriendliness or a doctor's brusqueness. Looking after an elderly parent can be an extremely frustrating and lonely experience. Often there is little opportunity to express the strong feelings generated by parental dependency. One indication of the strength of these emotions is that several women broke down and wept in the interview and were only able to continue after giving vent to their feelings.

Basic characteristics of the sample

The youngest parent was aged 60 and the oldest 99. Only a few were below the age of 80. Three quarters of the parents were aged 85 or over and a third of them were aged 90 or more. Their mean age was 84.5 and the median age was 85. The inter-quartile range was from 84 to 91.5. There were 51 mothers and 7 fathers in the final sample. Women predominated partly because of the sex difference in mortality; they outnumber men by 4:1 in the 85 and over age group.⁽²¹⁾ They are also more likely than men to be severely handicapped in old age. It has been estimated that although there are twice as many women as men aged 75 and over, there are three times as many women as men who are very severely, severely or appreciably, handicapped in this age group.⁽²²⁾ In addition, Cartwright et al's 1973 study, 'Life Before Death', indicated that women were far more likely than men to be visited by a district nurse.⁽²³⁾

The youngest carer was aged 30 and the oldest was 75. But there were very few carers in their thirties or forties. Most of them were themselves either approaching or above retirement age. Three quarters were aged 50 or more and a quarter were aged 60 or more.

Their mean age was 54 and the median age was 53. The inter-quartile range was from 48 to 63.

The phenomenon of infirm aged parents depending on children who are themselves in late middle age or elderly has been commented on in other studies. Isaacs et al's 1972 Glasgow study of a sample of patients admitted to a geriatric unit found that the average age of the supporting sons and daughters in the community was about 50, but many were aged more than 60.⁽²⁴⁾ Similarly, Goldberg's 1972 study of a field experiment in social work with the elderly remarked on a number of single daughters living with parents who were themselves near, or above, retirement age.⁽²⁵⁾

Although the majority of households consisted of a daughter or son and an infirm elderly parent, several were larger than this. In two households the respondent was an unmarried mother with a child at school. Seven households, approximately one in eight, contained a sibling as well as the carer. In all cases the daughter or son interviewed was clearly the person who was mainly responsible for tending the parent. Six households had two infirm elderly parents. Sometimes one of the parents was supportive. As one woman explained,

'I only feel able to go off to work still because father is in the house with her during the day. She has really gone peculiar in the past six months. She will strike matches and throw them round the room. She actually stood at the kitchen door and just threw as much china as she could lay her hands on out into the garden. Father is 89 now and she is 85. But, at least, he can use the phone to get help if there is an emergency. His hip is quite bad and he has arthritis so he can't do very much really; but he can stop her doing really silly things. Really, I suppose they are my two children.'

But then there were cases where the two parents could be equally highly dependent. One woman was interviewed shortly after her parents had been admitted to a geriatric ward for two weeks because she needed a rest;

'Both Mum and Dad are nearly 90 and they have both been pretty bad for about five years. Dad can wash and dress himself but his sight is getting bad and he doesn't always

know what he is doing. He will leave taps running. I came back once to find the kitchen flooded and another time the bathroom. Mum is the worst of the two. She is totally blind and diabetic. She has had four strokes and more heart attacks than I can count. She wants to die and she is always asking me to give her something to finish it all off. But I could not do anything like that. I have slept on a settee outside her bedroom door for five years now and I get up several times a night for her. I had what you would call a bit of a nervous breakdown last week. I came back from shopping and they were both just lying there on the floor. Mum had fallen down, Dad went to help her and he fell over too. When I found them I just started screaming. I can't really remember anything that happened. One of the neighbours got the doctor in and he got them both into hospital for two weeks to give me time to pull myself together. It's the first time I've had a day without them for years.'

Although only six people had two infirm parents in the household at the time of the study, others had experienced this situation in the past. Altogether 11 people, about one in five of the sample had either past or current experience of a period when both parents were infirm and dependent.

As the people interviewed were scattered throughout three outer London boroughs, it is not possible to give a simple description of the geographical location. A few people, 16%, lived in council flats. These were usually modern and on the ground floor. A few people, 14% lived in privately rented accommodation. Sometimes the conditions there were very poor. One man lived with his mother in a very damp top floor flat. The landlord refused to spend money on maintenance and a leaking roof had not been repaired. But there were instances of a private landlord or landlady being very supportive. One man lived with his mother in a very pleasant 1930s maisonette. The landlady who lived in the maisonette above regularly did some of the washing created by the mother's incontinence.

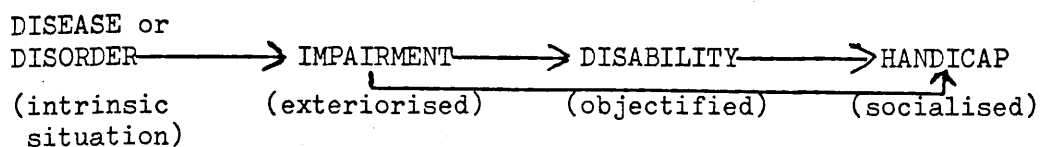
A majority of the respondents, 70% of them, lived in a house which either they or their parents owned. The most common type of housing was in a terrace dating from the 1920s or 1930s. Typical to the study area were seemingly identical rows of bay fronted terraced or semi-detached houses with small front gardens.

Chapter 3 THE PARENTS

This chapter describes the parents of the single women and men in the study, concentrating particularly on their physical capabilities.

'Impairment', 'disability' and 'handicap' are key concepts in such a discussion. But they are concepts which tend to be used ambiguously. 'Disability' and 'handicap', in particular, are often used interchangeably both in everyday speech and at governmental level. Thus the Department of Employment maintains a register of the disabled but local authorities are obliged to maintain registers of persons who are 'substantially and permanently handicapped'.⁽¹⁾ The 1980 World Health Organisation conceptual framework for the consequences of disease attempted to avoid some of the ambiguities.⁽²⁾ The key definitions it offered will be followed in this chapter. An 'impairment' was defined as 'any loss or abnormality of psychological, physiological, or anatomical structure or function'.⁽³⁾ A 'disability' was defined as 'any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being'.⁽⁴⁾ A 'handicap' was defined as 'a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal for that individual'.⁽⁵⁾

The concepts were linked in the following sequence.⁽⁶⁾



This sequence can be interrupted at any stage. Thus a person can be impaired without being disabled, and disabled without being handicapped.⁽⁷⁾ It cannot be predicted that a certain degree of impairment will produce a similar degree of disability or of handicap.

This chapter outlines firstly the parents' impairments and secondly the disabilities arising from these. In conclusion some of the problems inherent in a concept of handicap in relation to very elderly people are considered. Although the W.H.O. conceptual framework is used, it was not considered appropriate to attempt an assessment of the status of individuals on each of the dimensions of handicap suggested in the classification manual.⁽⁸⁾ As only the daughters and sons were interviewed, the chapter necessarily relies on their reports of parental capabilities. However, there is no reason to suppose that these would be any different from the parents' own reports. As part of an evaluation of a set of tests for measuring motor impairment, Jefferys et al interviewed a sample of impaired people about their activities and also obtained independent accounts from key relatives. There was remarkable agreement between the impaired person and the key relative on most activities.⁽⁹⁾

Impairments

All the parents had multiple impairments. The most common cause of impairment, as in Harris' 1971 survey of the handicapped and impaired and Hunt's 1978 survey of the elderly in the community, was arthritis or rheumatism.⁽¹⁰⁾ As Table 2 shows, it affected more than half the parents. The second most common cause of impairment was a

stroke which had been suffered by about one in five. Other common causes were Parkinson's disease, heart trouble, diabetes and pernicious anaemia.

Table 2. The reported causes of parental impairment

<u>Causes of impairment</u>	<u>No. of parents affected</u>	<u>Percentage of parents affected</u>
		%
Arthritis	30	52
Stroke	11	19
Heart trouble	7	12
Prolapsed womb	5	9
Chest condition	5	9
Pernicious anaemia	4	7
Diseases of circulatory system	4	7
Ulcerated legs	4	7
Parkinson's disease	3	5
Diabetes	3	5
Cancer	2	4
Shingles	1	2
Prostate trouble	1	2
Thyroid deficiency	1	2
Epilepsy	1	2
Trigeminal neuralgia	1	2

Deterioration of the sensory organs was common. Eight parents, one in seven of the sample, were either deaf or very hard of hearing and fifteen of them, one in four of the sample, were either blind or partially sighted. Three parents were both deaf and blind.

Incontinence was a considerable problem. More than a third of the parents were described by their children as either occasionally or frequently incontinent. The loss of control was more likely to be of the bladder only but as Table 3 shows a considerable number of the parents also lost control of the bowels.

Table 3. Common impairments in parents

<u>Impairment</u>	<u>No. of parents affected</u>	<u>Percentage of parents affected</u>
		%
Blind / partially sighted	15	26
Deaf / very hard of hearing	8	14
Incontinent (bladder)	21	36
Incontinent (bowels)	11	19
Confusion / forgetfulness	28	48
Limb amputated	3	5
Broken bones which had not healed	7	12

Incontinence has many possible causes such as a prolapsed womb, a bladder infection, an obstruction resulting from prostate enlargement, psychological feelings of rejection or depression, or just sheer physical difficulties in reaching a toilet or a commode quickly enough. Some medical authorities believe that incontinence is rarely a symptom of senility. Newman, for example, argued,

'it is my belief that mental decay, senile or otherwise, plays practically no part in the genesis of incontinence'.
(11)

Other geriatricians hold the opposite view. In a 1972 study of geriatric patients in Glasgow, Isaacs et al, for example, argued,

'In most old people the condition is caused by irreversible damage to the cerebral mechanism controlling bladder and

bowel evacuation and is accompanied by other manifestations of brain damage, notably disturbance of balance and intellectual impairment'.⁽¹²⁾

The high incidence of incontinence in the present study reflects the fact that the sample was drawn through district nursing records. However, the incidence is comparable with that found in two retrospective studies of the last phase in life of a sample of adults. Isaacs et al found that a third of a sample of elderly people dying in Glasgow in 1968 had been incontinent at some time before death.⁽¹³⁾ There was no difference in the frequency of occurrence between those dying at home and those dying in hospital. Cartwright et al's 1973 national study, 'Life Before Death', had similar findings.⁽¹⁴⁾ They showed that the likelihood of incontinence in the year before death increased with age. In the oldest age group, of people aged 85 or more, 42% lost bladder control and 43% bowel control in this period.⁽¹⁵⁾

Apart from these retrospective studies, there are others indicating that incontinence can cause considerable difficulties. Sanford's 1975 research into the circumstances leading 50 supporters to seek an elderly dependant's admission to a geriatric ward found that the old person's incontinence was problematic in more than half the cases.⁽¹⁶⁾ In view of the evidence about the current incidence of incontinence, it is somewhat paradoxical to recall Sheldon's comments in the 1948 survey of the elderly in Wolverhampton.⁽¹⁷⁾ Finding there were 'unsatisfactory faecal habits in one subject only' and 'unsatisfactory urine habits in two subjects only', he observed,

'The answers probably reflect to some degree the difficulty in obtaining accurate answers to questions involving matters such as personal cleanliness, but they also indicate the fact that severe grades of defect cannot be cared for at home. Such cases usually have to be moved to an institution.'⁽¹⁸⁾

Sheldon's assumption that people are likely to be reluctant to admit to their own incontinence is undoubtedly sound. (The studies quoted earlier, showing a high incidence of incontinence, were based on the reports of relatives). However, it is highly likely, given the evidence in Cartwright et al's 1973 survey of the higher incidence of incontinence of people in the oldest age groups, that the substantial increase in the number of people aged 75 and over has also meant an increase in the number of people living in the community who are incontinent.⁽¹⁹⁾

Nearly half the parents in the present study were described by their children as either forgetful or confused. A wide range of behaviour was described in considerable detail. At one extreme relatively mild confusion gave little cause for anxiety. For example, Mr. Green described his 76 year old mother as suffering from arteriosclerosis. One physical effect had been gangrene developing in a toe which had had to be amputated. Even so, Mrs. Green still managed to cope with most of the shopping, cooking and housework. During the past three years she had suffered noticeable mental deterioration. Shopping had previously been managed competently, but she became unable to cope with money and simply had to hand her purse to shopkeepers for the right amount of money to be extracted. Any change of routine made her totally confused.

At the other extreme several of the parents appeared to be severely confused. Some common characteristics were losing all sense of the passage of time; being confused at the identity of other household members; and being unable to remember the main features of the home. Mrs. Challis' behaviour was similar to that of several parents. Her daughter said,

'My mother has not recognised me as her daughter for several years now. On her good days she thinks I am her sister but on her bad days she thinks we are both passengers waiting at a railway station. She thinks Queen Victoria is on the throne. She does not think this is her home and we have lived here for 47 years. When she is downstairs, she worries away about whether there is an upstairs and bedrooms, but when she is upstairs, she thinks she lives in a flat and keeps on looking for the kitchen. She spends hours waiting for her father to arrive with his dog cart to take her back to her brothers and sisters in Camden Town.'

Aggressive behaviour was not unusual. Miss Hunter gave this description of her mother;

'My mother is 94 and has been very senile for about seven years. She really hurts me by not recognising me. She will say 'When is Maureen coming home?' and there I am with her. She will scream out that I have hurt her and will do things like shout 'Murder, Murder' at the top of her voice. She will throw cups of tea at the wall when I am out of the room and if I say 'What do you think you are doing?' She will just reply 'I saw you do that'.

Often the parent's confusion was a constant source of anxiety on safety grounds. A common problem was the possibility of the parent turning a gas cooker on and forgetting to light it. One solution was for the son or daughter to turn off the gas when leaving the house and lock up the cupboard which contained the gas meter. One son had fitted a padlock to the kitchen door to keep his mother out during his absence. In another case, the children living outside the household organised themselves in a rota so that their mother, who had become very senile in behaviour, was never left alone with access to a fire or cooker while the unmarried daughter with whom she lived was at work.

There were numerous examples of the danger and damage caused by forgetfulness. One woman had burnt out a couple of electric kettles by heating them on the gas cooker. Another had ruined three fan fires by trying to light them with matches and spills of paper. In this situation it became difficult to leave the parent alone for even half an hour to go shopping.

Confusion or forgetfulness in elderly people can arise from various causes. Such behaviour may simply be a continuation of established personality traits, but it may be symptomatic of an underlying psychiatric disorder. These disorders in the elderly are generally divided by psychiatrists into two broad types, the functional syndromes and the organic syndromes. The former includes affective disorders such as depression, the neuroses and paraphrenias.⁽²⁰⁾ Organic syndromes include delirious states and the dementias. Delirious states can arise directly from a physical illness or as a side effect from drugs being used to treat a physical illness, from a metabolic, biochemical or endocrine disorder or from an acute cerebral disease.⁽²¹⁾ There are two main types of dementias, senile dementia and arteriosclerotic dementia. They are generally ascribed to physical changes in the brain or in the blood flow through the brain. The theory that the dementias have underlying physical causes is not universally accepted. On the basis of a study of 329 old people in several residential homes and chronic geriatric wards, Meacher concluded that senile dementia should not be regarded as a pathological condition but as an attempted adaptation,

'to an environment which is inauspicious in terms of the needs of the pre-existing personality pattern, which has itself been moulded by the steady accretion of earlier experiences which cumulatively tend to strengthen or weaken the reaction on each subsequent occasion to adverse or alien surroundings'.⁽²²⁾

Whatever the underlying causes, the prevalence of mental disorders in old people is high. The 1964 findings of Kay, Beamish and Roth are generally accepted as an indicator of national prevalence rates.⁽²³⁾ Based on a sample survey of households, hospitals and residential Homes in five wards of Newcastle on Tyne, the study found that about one in ten people aged 65 and over with a home address in the study area had an organic brain syndrome and almost one in three a

functional syndrome.⁽²⁴⁾ Fewer than a fifth of those with an organic syndrome and fewer than a tenth of those with a functional syndrome were being cared for in a hospital or Home.⁽²⁵⁾ Discussing the possible medical and social causes of mental disorders in old age, Kay, Beamish and Roth concluded that in the case of the functional syndromes various constitutional and environmental factors appeared to interact together.⁽²⁶⁾ In the case of the organic syndromes the only factor which could be identified with any certainty was chronological age.⁽²⁷⁾

Disabilities

All the parents had several major or minor impairments and these had varying, but mostly serious, disabling consequences. There were four particular kinds of disabilities which had significant implications for other household members; disabilities in communication, in performing domestic and personal care tasks, and in mobility.

Communication

Defects of sight and hearing can create great difficulties in communication. Many old people suffer from some degree of deafness. In Abrams 1978 Age Concern survey in four areas, more than a third of the respondents aged 75 or over described themselves as hard of hearing.⁽²⁸⁾ Although a hearing defect can often be corrected and cause little or no disability, many old people appear reluctant to seek advice about it or to wear a hearing aid. Williamson et al's 1964 survey, of the unreported needs of a sample of 200 patients drawn from the lists of three general practices in Scotland, found that 40% had a hearing defect. In most cases the general practitioner was unaware of it.⁽²⁹⁾

Eight parents in the present study were deaf to some degree. Some were so deaf that there was virtually no communication with any other human being. This was either because a hearing aid could not

be used or because the parent refused to use one. A son, in the present study, ruefully described such a situation;

'Don't mind my mother being here. We don't need to go into another room to talk because she has not heard a word for the past five years. It's a worry really because she can't even hear the doorbell when I am at work. Nobody comes to see her any more. You can't blame them because there would not be a lot of point. She never replies to anything that is said to her. It used to get me down because we can never talk about anything. But really I've got used to it now. I do get annoyed when I take her to get a hearing aid refitted every year. For two whole hours she can hear lovely. Then as soon as we get home, off it comes. She says 'I am not wearing that thing'. It stays in its box for a whole year until the next appointment.'

At least his mother was able to watch television and to respond to facial expressions. She might be unable to hear jokes but at least she could still try to crack them. At the end of the interview she was teasing her son about his inability to find a girl friend.

A few parents were both deaf and blind. One woman, deaf, blind and crippled by arthritis, simply spent all her time sitting in a wheelchair in the corner of a room. The only communication with her daughter was to ask for food or drink or to be lifted onto a commode. Her daughter, who had given up a job ten years earlier because of her mother, described the situation;

'Mum is 93 and has been blind for sixty years. She has had arthritis for thirty years and her hearing started to go about eleven years ago. A hearing aid is no good to her. She can't even hear shouted conversation any longer but she can just hear the radio if it's turned up full blast next to her. It's awful having the radio on so loud. It can be heard right at the bottom of the road. I would give anything to hold a conversation with her. People used to come to talk to her but the worse her hearing got the less they came. Even the Jehovah's Witnesses stopped coming in the end.'

Loss of sight in itself can, of course, be highly restrictive. A partial loss of sight can make it difficult to pursue normal activities such as going for a walk, watching television or reading.

Miss Pearce's father had recently lost his one interest in life;

'Father is 89. His sight has been getting worse for years and he can't see to read any more even with a magnifying glass. That really upsets him because reading those geology books meant everything to him. He used to work in the Natural History Museum. He can't really go out any longer so reading was the one thing left'.

A blind person with appropriate training, determination, a convenient environment and suitable employment may be only slightly disabled or handicapped. But, for an old person, who is also likely to have other impairments, a loss of sight may be permanently devastating, virtually severing communication with the outside world. Blindness is a significant cause of old people being housebound.⁽³⁰⁾ Miss Willett described the effect of blindness on her mother's life;

'My mother can hardly move with arthritis and her hearing has been poor for years because the hearing aid is so awkward to adjust. But at least I used to get her out in the wheelchair. There is not a lot to see round here admittedly, a load of traffic really. But at least we got out. When her sight went she did not want to go out any more. The only pleasure she has left really is in the summer when the sun shines and I sit her in the kitchen with the door open and she can feel the sunlight on her face.'

Loss of sight and hearing have been linked to mental deterioration. Kay, Beamish and Roth, in an analysis of the possible medical and social causes of old age mental disorders, concluded,

'It is possible that these defects of sight and hearing may have sometime played a part in the production of mental symptoms by reducing the subject's contact with the outside world, for the association of sensory defects with organic mental states seems to be too strong to be wholly explicable by the advanced age of the subject.'⁽³¹⁾

From his study of confused old people in an institutional setting, Meacher drew a similar conclusion. He argued that not only may deafness give a false impression of confusion but that confused behaviour is significantly correlated with deafness.⁽³²⁾

Domestic activities

Three sorts of potential parental domestic activities were discussed with the daughters and sons; shopping, cleaning and cooking. There were seven fathers in the study, two living with sons and five with daughters. Given the sex role division in our society, it is rather unlikely that they had ever had much responsibility for such domestic tasks.⁽³³⁾ But the situation in respect of the mothers was quite different, for only a minority of women escape a housewife's role. Defining a housewife as the person wholly or mainly responsible for running a household, Hunt's 1968 government survey of women's employment concluded that 84.5% of women aged 16-64, in a national sample, were housewives. The majority of the non-housewives being full-time students.⁽³⁴⁾

Shopping appeared to be the most difficult of the domestic activities. Only two of the 51 mothers did any and this was with some difficulty. Shopping was also found to be one of the most difficult tasks for impaired housewives in the 1971 government survey of the handicapped and impaired.⁽³⁵⁾

Mothers living with daughters were far more likely to be disabled in respect of domestic activities such as cooking or cleaning than mothers living with sons. As Table 4 shows, two, or 6%, of the mothers living with daughters and ten, or half, of those living with sons did some or all of the cleaning. But this was often with considerable difficulty. For example, Mrs. Thomas, who was 83, was severely crippled by arthritis and had badly ulcerated legs. She could hardly walk and was described by the district nurse as having become very senile in her behaviour, chatting non-stop about events in her life 75 years ago. Nevertheless, she managed to vacuum, dust and cook. When met at the end of the interview, Mrs. Thomas expressed

Table 4 Domestic Activities of Mothers

	<u>Mothers living with sons</u>		<u>Mothers living with daughters</u>	
	<u>No.</u>	<u>%</u>	<u>No.</u>	<u>%</u>
Shopping				
Done	1	5	1	3
Not done	19	95	30	97
Cleaning				
Done	10	50	2	6
Not done	10	50	29	94
Cooking				
Done	9	45	2	6
Not done	11	55	29	94

concern that she could no longer look after her son well enough. She was upset because he now had to do some of her 'jobs' such as getting the vacuum cleaner out of the cupboard ready for use.

Two, or 6%, of the mothers living with daughters and 9, or 45%, of those living with sons prepared and cooked an evening meal. According to the government survey of the handicapped and impaired, mentioned earlier, cooking is the domestic task that an impaired housewife is most likely to be able to do.⁽³⁶⁾ Preparing a meal was often a laborious task. Mrs. Green, aged 93, lived with her son who was in his late fifties. Crippled by arthritis for many years, she had also suffered a stroke two years earlier which had limited movement in the left arm and leg. Walking was very slow and with the aid of a zimmer frame. Her son said that it took her almost an hour to get from the sitting room to the kitchen. Nevertheless, she managed to prepare an evening meal for her son by spending most of the day on it.

Personal Care

There were also significant sex differences between the male and female carers in certain of the personal care tasks which had to be done for the parent. Table 5 shows that there was little difference between parents living with sons and those living with daughters in the incidence of incontinence or in needing help with bathing. However, there was a significant difference in respect of three personal care disabilities. Parents living with daughters were approximately twice as likely as those living with sons to need help in going to bed or in getting up; approximately four times as likely to need help in dressing or undressing; and three times as likely to need help in using the toilet or commode.

Table 5 Personal Care Disabilities of Parents Analysed by Sex
 of carer

<u>Parents disability</u>	<u>Parents living</u> <u>with daughters</u>		<u>Parents living</u> <u>with sons</u>	
	<u>No.</u>	<u>%</u>	<u>No.</u>	<u>%</u>
Incontinence (urine and/or faeces)	16	44	9	41
Need help in bathing	33	91	18	81
Need help in going to bed/getting up	29	61	7	32
Need help in dressing/undressing	24	67	4	18
Need help in using commode/toilet	20	55	4	18

Two hypotheses can be suggested for the fact that mothers living with sons were both more active domestically and had less personal care disabilities than those living with daughters. The first is that sex role expectations are one important factor in the extent of disablement. A daughter living with a father or mother would be expected to assume a traditional female caring role as the parental

impairment became worse. However, a mother living with a son would be likely to struggle against an impairment in order to maintain a female caring role herself in relation to a male. She would also be more reluctant to accept help in dressing or using a toilet if living with a son than if living with a daughter. Thus, the point of dependency would be likely to be reached earlier for a mother living with a daughter. The relationship between sex role expectations and the employment patterns of the daughters will be discussed in Chapter Five.

The second hypothesis is that a mother with a really severe impairment would be more likely to be admitted to a geriatric hospital or residential home if living with a son than if living with a daughter. Because such high significance is attached to male employment, both the son and mother would be reluctant for a job to be given up if full-time attention became necessary. Equally the parent would be more likely to be offered such a place if a son rather than a daughter were providing care. Townsend's study of the characteristics of a sample of new residents in Homes for old people does provide evidence in support of this point.⁽³⁷⁾ Demonstrating the effect of family structure and composition on the likelihood of an old person's admission, he showed that a disproportionate number of new residents were unmarried, widowed or childless. When there were surviving children a disproportionate number had sons rather than daughters.⁽³⁸⁾ Unfortunately no distinction was made between married and single sons in Townsend's study.

A personal care disability which is particularly trying for the carer is incontinence. Some of the parents in the present study appeared to be oblivious of their own incontinence. A daughter described the problem,

'I know poor mother cannot really help it. There is a commode in her room and I try to get her to use the incontinence pads and sheets. But she is so absent-minded that she just wees or does the other thing over the chairs or the bed or the floor. If she realises there is an incontinence pad in her pants or something in her bed, she will just pull it out and put it on the floor. Every day, morning and evening, I scrub the furniture and the floors with disinfectant. I find I really spend money on toilet waters and perfumes just to help me get over the stench.'

Most parents tried to be more cooperative. Nevertheless, nightly incontinence usually imposed a daily burden of washing bedclothes on the son or daughter. Mr. Harmer was phlegmatic about the difficulties;

'Mother does wet the bed every night. But its not too bad. The mattress has a plastic sheet over it. I just use nylon sheets and nighties for her and drop the lot in the washing machine. I do have to keep an eye on her in the day because she has 'accidents'. I put one of those special sheets on the chair. That does usually catch everything.'

Because it is considered so socially unacceptable, even occasional incontinence can have serious repercussions. When her 87 year old father developed prostate trouble, soaking himself and the bathroom floor about twice a week, Miss Roberts decided that she had no option but to stop work and look after him;

'It was the last straw. He was getting so shaky that I needed to get somebody in to keep an eye on him. But when he started having 'accidents' that was out. How could I ask anybody else to clean up a mess like that?'

There was only one instance in the study in which the incontinence could be described as 'controlled'. Mr. Harker commented,

'People are surprised at how well I manage. Dad had a stroke three years ago and his waterworks are gone. It doesn't really cause any trouble. I put an empty urine bottle on him when I go out in the morning at 5.30 and I empty it again when I get back at 2.0. No problem'.

Almost half the parents needed help in using the toilet or commode. Sometimes this help was only needed at night but, more often, help was needed all the time. This situation was difficult for both the carer and the parent, as one of the sons explained;

'My poor mother cannot move out of that chair. I lift her out of bed onto the commode in the morning, and then I leave her sitting in a chair for the morning while I am at work. She sits on one of those pads. I dash back at lunch time and put her back on the commode again. She has not been able to stand up since her hip was broken three years ago. It just didn't heal up well enough'.

It could be very arduous preventing a parent from being incontinent.

Mr. Borley had quite an elaborate strategy to cope with a blind, arthritic, greatly overweight, mother;

'I have given up trying to get her to the toilet when she wants to go. There were too many accidents. I now keep a bedpan on a chair in each room - even in the kitchen. I just rush her to the nearest one when she wants to go'.

A daughter, herself 65, had a particularly difficult time lifting a 98 year old mother onto a commode. The mother, very arthritic and overweight, had become obsessed by urinating;

'The only interest my mother has left is in going on the commode. All I get all day long is, 'I want a wee wee'. I just have to lift her on to shut her up. Once upon a time I used to try and be discreet about it, in case anybody saw her. But I have given that up and she just sits there on it in the sitting room. It does not matter who comes in. It goes on all night too. I often put her on the commode six times a night'.

Mobility

Mobility was considered at two levels, inside and outside the home. As far as mobility within the home was concerned those living in flats, or, in two cases, bungalows, were undoubtedly the best off. This was the type of accommodation for 22% of the parents. Although movement was slow, most of these parents were able to walk to the toilet, the kitchen or a bedroom without assistance. Because stairs were so difficult to manage, those living in houses were in quite a different situation. Less than half of these parents were able to climb the stairs and this was likely to be with considerable difficulty. Often the stairs could only be tackled twice a day. More than half the parents living in a house had become marooned on one floor. As this

was usually the ground floor; a back or front room had to be turned into a bedroom. One of the difficulties arising in this situation was the lack of a toilet on the ground floor. Only three parents marooned on the ground floor had access to a toilet. In most cases a commode had to be used and the carer had the chore of emptying it. There were also problems for the carer, with a bedroom on the floor above, hearing the parent call out at night. It was a common comment in the interviews that the carer tended to sleep badly through a fear of missing the parent call out for assistance in using the commode.

A relatively small proportion of the population is permanently housebound. Hunt's 1978 survey of the elderly gave the figure of 4.5% permanently, and 2.6% temporarily, housebound.⁽³⁹⁾ These findings were somewhat lower than those in previous studies. Shanas et al's 1968 comparison of old people in three industrial societies estimated that 13% of those in Britain were housebound.⁽⁴⁰⁾ No distinction was made between being temporarily and permanently housebound. Tunstall's 1966 four area study of old people living alone gave a lower figure of 8.4% being housebound using a different definition from that used in the Shanas et al study.⁽⁴¹⁾ People were only classified as housebound if they had not walked out of the house for a minimum of six months.⁽⁴²⁾ However, Tunstall's definition of housebound was broader than that used in Hunt's survey because it did not exclude people who could reach a car which was standing at the kerb outside the house.⁽⁴³⁾ Hunt's figures of 4.5% then, represents the really immobile. A further factor in the difference between Tunstall's and Hunt's figures is the growth in car ownership which has occurred in the 1970s and has probably enabled some people to go out who would previously have been considered housebound.

The incidence of immobility is greater for the older age groups, 17.7% of the people aged 85 or over in Hunt's survey being permanently housebound.⁽⁴⁴⁾ The figures in the present study were far higher than this. As the table below shows, half the parents were permanently housebound. A few were able to go for a walk or were taken out in a wheelchair. Altogether 38% of them were taken out in a car. This might be as infrequently as a few times a year or as often as several times a week.

Table 6 Mobility of the parents outside the home

	<u>No.</u>	<u>%</u>
Housebound permanently	28	50
Housebound winter only	1	2
Goes out in wheelchair	4	7
Ambulant	3	5
Goes out in car	<u>22</u>	<u>38</u>
	<u>58</u>	<u>102*</u>

*The percentages were rounded up

Complex factors contribute to a lack of mobility. A housebound person may have virtually no underlying physical impairment but may have psychological problems or attitudes which inhibit going out. Finding that a proportion of the respondents in the 1971 survey of the handicapped and impaired had only a minor handicap or no handicap at all and yet were housebound, Harris concluded, 'that age is an additional factor to physical handicap in limiting the mobility of impaired person'.⁽⁴⁵⁾ Some elderly people with formidable physical impairments refuse to become housebound. As Barker and Bury commented, an individual's capacity to overcome many of the barriers to mobility

'is determined not only by his health but also by his commitment to active life, his horizons and his readiness and ability to improvise or experiment'.⁽⁴⁶⁾ This was illustrated by the contrasting behaviour of two mothers in the study. Miss York described her 93 year old mother;

'There is no stopping mother. She has had osteo-arthritis for twenty years and then had to have one leg amputated two years ago. Well, I can't push her out in a wheelchair or lift her into a car. As soon as she got back from hospital she decided to get a motorised wheelchair. She sent off for all the details and it took some persuading to convince her she would never manage the kerbs. In the end she compromised and advertised in the local newsagent' for strong teen-agers to push her out in a wheelchair. A sixteen year old boy takes her out most Saturdays except when there is a special football match on. She also persuaded the social worker to fix something up and we often get two school girls come round on a Wednesday afternoon to take her out'.

Mr. Bedale gave quite a different description of his 92 year old mother;

'It's difficult to say what is wrong with Mummy really. She has got arthritis but I manage to get her up and down stairs. She had a bit of a stroke last summer. The main thing that's wrong with her is she is just old. She just sits in an armchair all day. She is not really interested in anything on the radio or the telly. She has not been out of the house now for nine years. That's not really true. She was in hospital for a week last year with the stroke. I soon got her home again, she hated it there. I've tried to persuade her to go out in my friend's car. We could take her out to the country. But she won't have any. She won't let me take her out in a wheelchair. She won't even leave the house to go into the garden. She just says she is going to die inside these four walls and she won't take any chance of dying anywhere else'.

Handicap

Assessing handicap, as defined by the World Health Organisation, is problematic in respect of very elderly people. Before discussing the disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal for that individual, it is clearly necessary to appreciate the normal role. What is the behavioural norm for a woman in her late eighties living in a household with somebody from a younger

generation? Would she expect to maintain the housewife's domestic role that she would almost invariably have had at an earlier age? What are the normal activities for people in their nineties? There is inadequate knowledge of the behaviour of the very old and other people's expectations of them, to answer these questions.

Cumming and Henry's theory of disengagement, postulating a predictable decline in roles and activities with advancing age, remains highly controversial.⁽⁴⁷⁾ They argued,

'aging is an inevitable mutual withdrawal or disengagement, resulting in decreased interaction between the aging person and others in the social systems he belongs to. The process may be initiated by the individual or others in the situation'.⁽⁴⁸⁾

Their basic premise is that as death is biologically inevitable, then the preceding disengagement of an old person from society is also inevitable;

'The anticipation of death frees us from the obligation to participate in the ongoing stream of life....By the end of his life, his bounds have been all but severed - disengagement is complete, he is free to die, and death is the last logical step in the process of living'.⁽⁴⁹⁾

The theory of disengagement has been widely criticised on various grounds. For example, on the evidence of the cross-national survey in America, Denmark and Britain, Townsend argued that there was only a small decrease in the proportion of people in the oldest age groups being engaged in various activities.⁽⁵⁰⁾ Arguing that the evidence for disengagement was based primarily on the facts of bereavement, he made the point that bereavement could not in any meaningful sense be said to be 'initiated' by the individual old person or society.⁽⁵¹⁾

A different line of criticism was put forward by Rose who argued that disengagement theory, with its emphasis on inevitability and universality, ignored significant trends in contemporary American

society.⁽⁵²⁾ Major changes were taking place. Amongst these were an ever increasing proportion of the elderly in good health; older people beginning to form a social movement to raise their status and privilege; and increasing numbers of elderly people taking up new roles in voluntary activity on retirement.⁽⁵³⁾

Another line of criticism was put forward by Neugarten, Havighurst and Tobin. On the basis of an empirical study of several hundred people aged 50-80, they concluded that there was a positive correlation between the extent of social interaction and psychological well-being which was even higher for people aged 70 and over than for those aged 50 to 70.⁽⁵⁴⁾

As Abrams pointed out in an overview of current research on the elderly, a longitudinal study of the process of aging, starting with a sample of those aged 50 or more and following them through the aging process, is needed to either challenge or support disengagement theory.⁽⁵⁵⁾

Certainly until disengagement theory is successfully challenged or supported, assessing handicap, as defined by the World Health Organisation, remains implausible for old people.

CHAPTER 4 THE DAUGHTERS AND SONS

This chapter discusses some of the common difficulties for the daughters and sons in the study apparently arising from the caring situation. Firstly, the health problems experienced by a substantial proportion of the carers are described. Secondly, the problems of sleep interruptions, are discussed and thirdly, common restrictions placed on the carers' social lives are examined. The last section of the chapter looks at the emotional disturbance experienced by almost half the carers. In the following chapter the impact of parental dependency on employment is considered.

Health

About one in three of the carers described themselves as having a noticeable health problem. Those with such problems appeared to fall into one of three categories. The first, comprising six carers, had illnesses concomitant with their age group, the majority of the carers being themselves near, or above, retirement age. For example, three women had arthritis of varying degrees of severity. Another woman, at an advanced stage of multiple sclerosis, was only able to move very slowly with the aid of a walking frame. One of the men, registered as disabled with the Department of Employment, had suffered a stroke nine years earlier which had left one side of his body permanently weakened.

The second and smallest category, comprising four carers, had disabilities which had existed since birth or early childhood. These included a dwarf, a woman with a heart condition, a woman crippled by polio and a woman who had had a leg amputated when she was eleven years old.

In the third category, comprising nine cases, were those whose problems could possibly be attributed, at least to some degree, to parental dependency. Sometimes the causal link was obvious as in several cases of back trouble resulting from years of lifting the parent out of bed onto a commode. One woman, very misshapen and looking as though she had been born with a deformed back, simply said,

'I look like this after 15 years of lifting my mother out of bed onto the commode. She is so much bigger than I am.'

Less straightforward in terms of causation were serious mental health and heavy drinking problems which had developed after years of caring for the parent. Several women suffered from serious neurotic obsessions. For instance, one woman had become totally obsessed by a need to cleanse the house. For several years she had followed a tortuous routine, rising at 5 a.m. and washing every interior wall in the house. All the walls were decorated in a washable paint. At night she was unable to sleep because of worrying about the state of the rooms. She had become agoraphobic and was afraid to go out, relying on a neighbour to do the shopping.

Three of the men drank very heavily. Having described how every evening was spent drinking, one man commented, by way of explanation,

'Well, what do you think its like, having to live the life of a very old woman?'

Another man had an attack of gout and was drinking whisky throughout the interview,

'The doctor said I got the gout from drinking too much of this stuff. I spend the attendance allowance on it; it's my wages for having to look after her'.

These mental health and heavy drinking problems could have resulted from the strains of parental dependency but might equally well have arisen without such a situation.

About a third of those with health problems were so severely disabled that it was a physical struggle to cope with housework and providing care for the parent. The situation was particularly difficult for those people who had been disabled since childhood. Their serious disablement from an early age could have contributed to them staying single and being very dependent on the parent in early adulthood. When the dependency is reversed by the parent's infirmities in old age, the son or daughter may find it extremely difficult to cope. One man, a dwarf in his fifties, was in this situation. Not only was he having to shop and cook for the first time in his life; he was barely able to cope with the needs of an obese mother of normal height whose sight and mobility had suddenly deteriorated.

These severely disabled men and women struggling to provide their parents with the necessary care were often permanently exhausted. Miss Hearst, in her early fifties, caring for a blind arthritic mother, described her difficulties,

'My left leg was amputated when I was eleven and, over the years, I have found it increasingly difficult to get about. My spine has gradually been giving me more and more trouble. It must be because I walk so badly. I have to do everything for mother now she has lost her sight and I have to keep my job going as well. It takes me a long time to do things in the morning. I have to get down some steps to fetch coal for the kitchen fire. I usually do a bit of shopping in the morning or go to the laundrette. I have to leave mother set up for the day with her snacks and I don't usually start work before 11. So I don't finish until 7 and I get home about 8. I really am worn out all the time'.

That woman's health problems were clearly being exacerbated by her mother's dependency. This was not at all uncommon. Two women in their sixties suffering from arthritis had each been advised to have hospital out-patient treatment, but as this involved travelling some distance and the parent could not cope with being left alone for any length of time, both women had had to refuse treatment.

It could well be difficult for the carer to recover from an illness or operation while having to continue giving the parent attention. One woman had had a severe attack of shingles which went on for several months. She reported that her general practitioner thought the continual strain of looking after a very senile mother was delaying recovery. It was only after a break of two weeks with her mother in a private nursing home at relatives' expense that the daughter began to make some progress.

In another case, the daughter had had a hysterectomy after developing cancer of the womb. During the operation and the short convalescent period, her mother had been admitted to a local authority Home. When interviewed a year later, the daughter felt she had never been able to recuperate properly after the operation because her mother, who had become very frail and helpless, needed so much attention in the evening and at the weekend. She worked a four day week and continually worried about her mother while at work. Several weeks after the interview the daughter wrote to say that she had collapsed from exhaustion. Her mother had been temporarily admitted to a local authority Home and she herself was on sick leave until she recovered some strength.

The high incidence of health problems in people caring for dependants has been remarked on in other studies. In a 1970 study of a field work experiment in social work with the elderly, Goldberg,

referring to single sons living with elderly parents in the sample noted, 'a comparatively high proportion of handicapped men. Presumably old people with a handicapped son are more likely to come to the attention of the welfare department and the sons are less likely to marry and leave home'.⁽¹⁾

In a 1974 assessment of the cost of community care for the mentally ill, Sainsbury and Grad de Alarcon found a particularly high incidence of health problems amongst supporting relatives. As many as 60% of them suffered mental health disturbances and 28% of them disturbances of physical health.⁽²⁾ Similarly, in a 1973 study of a sample of families with a mentally handicapped member living at home, Bayley found that only a third of the mothers were without health troubles.⁽³⁾ Hewett's comparable 1970 study, of a sample of mothers with a cerebral palsied child in the Midlands, concluded that only half of them had good health. One in four were described as being in moderate health and one in four in poor health or run down.⁽⁴⁾

Interrupted Sleep

A problem for a third of the carers was the parent interrupting their sleep. For many of them this had been a problem for several years. When such interruptions occurred, they had continued for an average of four and a half years. The shortest period of interrupted sleep claimed was two months and the longest, fifteen years. Sleep was rarely broken just once a night, the norm being three times. A few people regularly had to get up as many as seven times during the night.

The reasons given for the parent waking the carer fell into three broad categories. Primarily, help was needed for the parent to get out of bed to use the commode or toilet. Secondly, the parent

needed to be moved into a more comfortable position in bed. Thirdly, some of the parents, who had become senile, wandered about at night or called out. One daughter commented,

'I usually get up for mother seven times a night. She gets upset because she can't remember who she is or where she is. I just have to comfort her and give her a sweet to suck to get her back to sleep'.

Sometimes the problem had been solved by giving the parent sleeping tablets. One woman could not stand being woken up any longer and solved the problem by rearranging bedrooms;

'Mum used to wake me up about three times a night to go to the toilet. Her mind has gone really and she just could not remember where the toilet was. It really got me down because I had my job to do during the day. In the end, I bought a double bed and put it in my room. Now she sleeps with me and I leave the light on all night, so that she can see her way out to the toilet'.

As her mother occasionally wet the bed, the arrangement seemed quite a high price to pay for an unbroken night's sleep.

A few people were phlegmatic about the situation. One woman commented,

'Well, I usually get up about three times in the night and it must have gone on for about two and a half years. But I can't say it bothers me much. We sleep in the same room so I can jump straight out of bed when she wants the commode. Honestly, I am asleep before I get back into bed again'.

This woman was exceptional; most people found it a strain to be constantly woken up. In addition, there was a tendency to sleep very lightly, fearful of not hearing the parent call out. Such a failure could result in a soiled bed to clear up or the parent falling in trying to reach a commode unaided. The problem was accentuated for the seventeen parents who had bedrooms on the ground floor because they were no longer able to climb stairs. Their daughters and sons usually slept on the floor above. Surprisingly only one

woman in this situation had thought of using a 'baby alarm' and another woman had provided her mother with a bell to ring. All the others relied on hearing the parent's voice often from a considerable distance.

Broken sleep is a common difficulty reported in comparable dependency situations. Half the families with a mentally handicapped member in Bayley's study experienced sleep disturbance.⁽⁵⁾ In a 1972 study of patients referred to a geriatric unit, Isaacs, Livingstone and Neville identified sleep disturbance as a major source of strain for supporting relatives.⁽⁶⁾ A similar point was made by Sanford in a 1975 study of the home support of 50 people admitted to a geriatric unit because their relatives or friends could no longer cope with them at home. Broken sleep was both one of the most frequently occurring problems for those supporting relatives and friends and one of the least well tolerated.⁽⁷⁾

Three kinds of social life were often emphasised in the interviews as being particularly affected by parental dependency; leisure activities away from the home, holidays and relationships with friends.

Leisure activities away from home

Leisure activities are idiosyncratic. Many people do not want leisure activities away from the home. It may be perfectly satisfying to watch television, to pursue home hobbies or to entertain friends or relatives. However, leisure activities away from home are likely to have a heightened significance for a single carer. It affords an opportunity to meet other people and to have some kind of life independent of parental needs. One woman eloquently described the importance to her of leisure interests outside the home',

'In a tight domestic situation like this you really need to do something to keep your mind going because half the time you are leading the life of a very elderly woman. I do try to go out to an evening class and I do try to do something locally. We formed a little organisation to give support to prisoner's families. Seven of us got together and set it up. I feel there is a great similarity in the situation. I am in prison domestically'.

The men were more likely to have leisure activities away from the home than the women. Four out of five men in the sample went out at least once a month in the evening or at the weekend compared with three out of five women. This was partly due to a sex difference in the general population. According to the 1977 General Household Survey, men were far more likely than women to go out to a pub, or for a meal, or to take part in, or to watch, sport.⁽⁸⁾

However, part of the difference also appeared to be attributable to the parents' behaviour. Those living with sons seemed to be more likely to accept being alone for an evening. A daughter usually had to arrange a 'sitter' before going out. Mr. Harker's situation was typical of several of the sons,

'I go out several times a week to an ex-servicemen's club. My father can't get himself to bed since having that stroke, so I put him to bed at about 8.30 and then it does not matter what time I get back. He doesn't mind at all'.

Of course, not all the men found going out so easy. Mr. White was no longer able to leave his 79 year old mother alone in the evening;

'She would not like to be left alone in the house. She gets very depressed because she used to be so active and she is a prisoner inside four walls now. I thought she was going to die a couple of years back. She had collapsed at home and I had to get an ambulance. They said it was hypothermia. I leave work three times a day to ring her. If she doesn't answer I rush home. I used to go out to the pub most evenings but I never go now'.

Parents were also less likely to accept being left alone in the evening if the son or daughter were no longer employed outside the home. A substantial number of the carers were in this situation having retired or given up jobs to care for the parent. (As the

following chapter describes, daughters were far more likely to be in this position than sons). It was as though the carer on giving up paid employment had also forfeited the right legitimately to leave the house for leisure. Mr. Haig was in this situation. When he retired from a job as a self-employed decorator, his 90 year old mother suddenly refused to be left alone in the house.

'I used to go out just once a week, old time dancing. There was a bar and I got to know all the people. I used to have a laugh and a chat and I really looked forward to it. But it all had to stop when she said she wouldn't be left alone in the house any more. It wasn't that she got worse or anything it was just that she wanted me to keep in the house'.

It could be very difficult to find somebody to 'sit' with the parent. In the few cases where a sibling lived in the same household, it was likely to be easier to make some arrangement. But even in this situation there could be problems. A 75 year old carer living in the same household as her mother and sister had recently had to relinquish her last activity outside the home;

'I used to sing in the choir but I have even had to give that up. You see my sister has had a stroke and she has lost the strength in one arm. She just can't manage mother by herself'.

A married sister living in the neighbourhood could sometimes be relied on to act regularly as a 'sitter'. There was no case in the study of a married brother taking this role.⁽⁹⁾ Sometimes a neighbour 'kept an eye' on the parent for the evening and this invariably meant calling briefly at the house rather than spending the whole evening there.

A substantial proportion of the carers, two in five of the women and one in five of the men, had no leisure activities outside the home. A few people had little desire to go out anyway. One woman in her fifties, living with her 89 year old father, commented,

'Why should I want to go out? I like to sit by my own fireside in the evening. I am very happy at home. I like to do the shopping and cooking. I am the original little housewife'.

But this woman was exceptional; most people expressed considerable frustration at the situation. In the case of Miss Herbert, there had not been an hour's break in the evening or at the weekend from her very senile 94 year old mother for about seven years;

'Mother is at the day centre while I am at work. I can't leave her alone in the house because she would be quite capable of setting fire to it. She does not know what she is doing any more. If I even try to talk to anybody on the 'phone she starts shouting and carrying on. I suppose we do go out once a year; a cousin in North London usually asks us over on Boxing Day. I could go out with the people at work. They go out for a meal and a drink at Christmas. They don't understand why I can't go. If only there was somebody who would just sit in with her'.

Other people with a senile parent had experienced the same restrictions. One woman, herself retired, had been unable to leave her 95 year old mother even to go to the shop at the end of the road for several years.

'I have to take mother with me everywhere in the car. I just dare not leave her alone in the house because she does not know what she is doing. Her mind has gone. I have tried to go out by myself for a couple of hours twice in the last five years. The first time a friend, who is a sister in a hospital, was staying here and she said, 'go on - just get away from her for a little bit'. Well, I went and she had a dreadful time. Mother physically attacked her and landed quite a few punches. The second time I left mother with a neighbour from across the road. I just slipped off and left her having tea. Mother started to hit this poor woman with her handbag. Fortunately the husband was at home and they managed to push mother out of the house and get her across the road into this house. There is no way that I can ever have a break from her'.

Such excessive dependency could arise in situations when the parent was not senile. For several years Miss Rainer, also retired, had only been able to leave her 90 year old mother, who was blind and arthritic, for an hour on Friday afternoons to do the weekly shopping,

'My sister comes round, then, to sit with mother. It's her day off. The whole time I am out, mother keeps on at my sister to look out to see if I am coming back. My sister has a hard time of it because my mother just gets into a panic. What can I do? I can't go out for anything. My niece is getting married next week but there is no way I can go to the wedding'.

Holidays

Holidays are likely to be particularly significant for a person who has to cope with the strain of another's dependency. Two in three of the daughters and one in three of the sons normally had a holiday of some kind each year. Several of them had to take the parent. This could be a reasonably satisfactory arrangement;

'My sister helps and we manage to take my mother and father on holiday to a cottage. Somehow we have managed to do it for the last two years. It is much better than leaving them behind. Three years ago Dad went to an old people's Home and Mum went into a geriatric ward so that I could get away. She was in a dreadful state when I got back, covered in bedsores. There is no way I could leave her knowing she would be looked after like that. So we make the best of it and them too'.

Sometimes a married sibling from outside the household provided holiday care for the parent. As will be discussed in Chapter Six, sisters were more likely to stay with the parent, and brothers were more likely to arrange for the parent to stay in their own homes. When the carer was an only child or had a sibling unwilling, or unable, to provide such care rather more elaborate arrangements might be made. One woman whose two sisters refused to be involved in holiday care, let a flat in her house to a young couple. Part of their tenancy agreement was to look after her mother while she had a summer holiday. A number of the parents had been given holiday care places by the statutory social services. The health authority provided some temporary places in geriatric wards and the three local authorities some in residential Homes. Holiday care by the statutory authorities will be discussed more fully in Chapters Nine and Ten.

The everyday strain of looking after the parent was often so great that it was difficult to get much enjoyment from a holiday.

'My sister is very good to me. She gives up a week of her holiday to stay with mother. I spent a week in Devon with relatives last year. But I was in a dreadful state; I could not sleep and just kept on taking lots of sleeping tablets'.

Another woman commented,

'Yes, I had a holiday last year but I was too tense to enjoy anything. I knew everything would be all right at home. My brother lives here anyway and my sister was coming round to the house for the day as well. But I just felt sick with tension the whole time'.

A substantial proportion of the carers, one in three of the daughters and two in three of the sons, never had a holiday. Of course some had no such expectation. This was more likely to be true of the men than the women. For example, a greengrocer's assistant in his fifties living with a severely disabled mother in her nineties protested,

I've never had a holiday in my life. I would not know what to do with it if I had it. I've never had a day's sickness in my life and I've never had a day's holiday. I just work through my holidays as normal and get double pay'.

Occasionally a carer simply refused the opportunity to take a holiday. In one instance a 93 year old mother, who had been house-bound for ten years, decided that her son had become run down and needed a holiday. She herself arranged to be admitted to a nearby hospital where she had worked as a ward maid until retiring twenty years earlier. But her son refused to cooperate and would not take a holiday. He remained at home and spent hours visiting her each day.

But 72% of those people who had not had a holiday the previous year said it was because they were unable to make a suitable arrangement for the parent. Only children or lacking siblings or other relatives willing to accept the caring responsibility, they had not used the

holiday care places theoretically available through the health and local authorities in the study area. One of three reasons were given for the failure. Firstly, the carers concerned appeared to have no idea that such short term relief existed. They reported that neither the district nurse nor the general practitioner nor the social worker, in the cases where there had been contact with a social services department, had mentioned such facilities. It is possible that the information had been given and forgotten. But, that many professionals do not convey information about existing supportive services has been confirmed in other studies.⁽¹⁰⁾ For example, Bradshaw, in a 1976 study of the problems experienced by a sample of families with handicapped, incontinent, children, reported that contact with health visitors made no difference to knowledge about the available statutory services such as free incontinence pads.⁽¹¹⁾

Secondly, a few carers reported that at some point a request for a short term holiday place had been refused by the statutory authorities. Such a refusal might come from the individual general practitioner or social worker. A daughter, who had coped for several years with a very senile, doubly incontinent, mother without a break, said resignedly,

'I have asked my doctor several times if there is any chance of mother being admitted to hospital just for a week just to give me a break from it all. But she says there is no possibility'.

But the parent could be assessed as unsuitable. A consultant at a geriatric unit may decide an old person is not frail enough to be offered a temporary place. Local authorities set their own criteria and may consider an old person unsuitable for a temporary place on the basis of such problems as lack of mobility, senile behaviour or incontinence. One woman had the experience of her father being rejected

by both the local and the health authorities.

'Father is 87 and has had angina for years. He has had four strokes altogether. He also has problems with his waterworks because of the prostate gland. Anyway I reached the end of my tether last year and I felt I just had to get away for a week's holiday. My doctor arranged for me to take my father up to the hospital to see if they would accept him. Really he made a tremendous effort at that medical examination. He was determined to put up a good show. The doctor said he was too fit for a geriatric ward and should go to a local authority Home. But, of course, the local authority said he was too infirm'.

The third reason was that either the carer or the parent rejected using a short term place. It was not uncommon for the parent to suspect the carer's motive. One man commented ruefully,

'Mum was admitted to a lovely new unit when she had a lot of chest trouble about four years ago and they made a point of saying she could come back at any time for me to have a holiday. But will she agree to go? She thinks I will leave her in and never get her out again'.

A daughter had a more forceful reaction from her mother.

'I arranged for my mother to be admitted to a psychogeriatric unit for one week just to have a little joliday. I explained it to her but she could not take it in. Anyway, we went to the ward and I started to help mother put her things in the locker. She must have suddenly come to the conclusion I was putting her away because she started hitting me and carrying on. There was such a scene that I just turned round and brought her home again in the car'.

Some carers rejected using short term places on the basis of a previous bad experience. The most common complaint was that the parent had become more disabled through a stay in a residential Home or geriatric ward. Instances were given of parents becoming incontinent through lack of attention. It was alleged that nurses had not been prepared to spend enough time in assisting parents to reach the toilet. In some cases it was also alleged that parents' mobility had decreased as a result of being unnecessarily confined to bed,

'There was no problem with her walking when she went into the geriatric ward but when I got her out two weeks later, she could not walk at all. I had to teach her how to walk again. They found her behaviour difficult to cope

with and gave her drugs which made her keep in bed the whole time. She lost the use of her legs. It's just not worth it when you have to face that'.

Friends

Although friendly social contact is important to everybody, it is particularly so for a single person who does not have the additional social relationships created by marrying and having children. Many of the women and some of the men spoke of a sense of social isolation. They felt that caring for the parent had had a significant impact on social contact outside the home. A few people had friends who came round to the house. Miss Warren commented,

'I make a point of keeping up with friends and regularly invite them round. I know a man who devoted everything to his mother. He gave up everything; going out, all his friends, the lot. When she died he had nothing left and he was very lonely. So I think it's important to think of the future and keep up with friends'.

But, some parents made it virtually impossible to invite anybody home;

'I just had to stop asking people round to the house in the end. She drives me mad enough by continually asking the same question. She just did the same to them. She would start up, 'Why are you here? Who are you?' No matter what was said to her she would keep on saying that until they left the house'.

If there was regular contact it was usually away from the home. Such arrangements tended to be infrequent because of the difficulties of leaving the parent. A typical arrangement was;

'I meet my friend about once every three months. We meet somewhere for a meal. I am only away from father for about an hour and a half. She never comes back here afterwards and I don't have time to go to her flat'.

A substantial number of the people in the study described themselves as having no friends at all. They generally attributed this to the dependency situation. Carers who were working frequently found it difficult to go out socially in the evening or at the weekend. But those who had stopped going out to work often found it even more

difficult, because the parent, used to the carer's presence during the day, became even more likely to protest at being left alone in the house.

Employment would seem to be an important potential source of friendship. But many of those with jobs stressed the sense of loneliness they felt in relation to others because of their abnormality in remaining single. They had no spouse or children to talk about. A civil servant, with a very senile mother in her nineties, described her sense of separateness from colleagues;

'When I am at home, I never stop dashing round. There is always faeces or urine to clear up....When I am at home, I worry about how late I am going to be for work. When I am at work, I worry about what is happening to Mum at home. At work you just have to pretend to lead the sort of life that other people lead. You simply can't let on what life is really like at home. Other people would hate to know about it'.

Certainly there were several anecdotes about the lack of sympathy shown at work towards the problems of a single carer. One woman was particularly distressed by the reaction of the other women in her office to a crisis in caring for her parents;

'It was getting difficult to look after both parents and keep the job going. Father got very awkward indeed. He got very confused and aggressive. He would do things like get up at 2 a.m. and come and demand that I got up to cook his breakfast. The only way to keep him quiet was to get up and do it. I was having to leave him and my mother alone during the day. Mum got frightened because she never knew what he would do next. I did not want to give up my job because I had worked there for thirty years. Well, I broke down several times at work and had a good cry. None of the women gave me any sympathy. They turned round and told me to give up my job. Really it was a big mistake talking about my problems at work. All they wanted to talk about were husbands and boy friends. Nobody wanted to know about a spinster and her problems'.

Emotional disturbance

Not surprisingly caring for a highly dependent adult or child can prove to be an emotionally disturbing experience. A scale

developed to measure this emotional disturbance has been used in several studies examining the impact of physically disabled children on their families. Called the malaise inventory, it was developed by Rutter and Graham for a comparative study of 'normal', psychiatrically disturbed and physically disabled children and their families on the Isle of Wight.⁽¹²⁾ A shortened version of the Cornell Medical Index-Health Questionnaire, the malaise inventory is a self administered questionnaire containing 24 questions put in simple language. A copy of the malaise inventory appears in Appendix three. Fourteen of the questions appeared in the original Cornell Medical Index and ten were added by Rutter and Graham. 'The items refer to the emotions (Are you easily upset or irritated? Do you often feel miserable or depressed?) and to physical states which have important psychological components (Do you feel tired most of the time? Is your appetite poor?)'.⁽¹³⁾ The respondent circles 'yes' or 'no' as the appropriate response to the questions. A score of 1 is given for a 'yes' answer and 0 for a 'no' answer. The maximum possible score is 24. According to Rutter a score of five or six or more shows evidence of emotional disturbance.⁽¹⁴⁾

Both the validity and the reliability of the malaise inventory have been demonstrated in various studies. The Cornell Medical Index itself was found to yield accurate medical and psychological data in both American and British validating studies.⁽¹⁵⁾ In a 1970 neuropsychiatric study of childhood, Rutter et al state that both the Cornell Medical Index and the inventory are useful indicators of emotional disturbance agreeing fairly well with independent psychiatric assessments.⁽¹⁶⁾ Reliability was tested in the Isle of Wight study by asking 35 mothers, at a suitable interval, to complete the inventory on two separate occasions. Although they tended to acknowledge slightly fewer symptoms on the second occasion there was a very high

correlation between the scores.⁽¹⁷⁾ In a similar exercise, Bradshaw reports that 17 mothers from a sample of applicants to the Family Fund for assistance in coping with the needs of disabled children were asked to complete the inventory on two separate occasions.⁽¹⁸⁾ There was a high correlation between their scores.

Each respondent in the present study of single carers was asked to complete the malaise inventory at the end of the interview. Four out of every ten had a malaise score of five or more. The mean malaise inventory score for the women was 6.0 and for the men 2.5. More than half the women but less than one in five of the men had scores of five or more.

It is interesting to consider these scores in the perspective of some of the findings of the studies of mothers with highly dependent children. Bradshaw's 1980 study of the Family Fund reports a mean malaise score of 9.02 for a sample of 303 mothers with severely disabled children applying for financial help.⁽¹⁹⁾ This was a considerably higher mean than that reported by Dorner in a 1975 study of mothers with spina bifida children.⁽²⁰⁾ However, Tew and Lawrence's 1975 study of some sources of stress in 51 mothers of spina bifida children did find a difference in the maternal mean malaise score according to the severity of the child's handicap. In cases of mild handicap the maternal mean malaise score was 5.68 compared with 9.2 when the handicap was severe.⁽²¹⁾ But in the present study no relationship was found between the carer's malaise score and the parent's incontinence, degree of mobility or mental abnormality. Bradshaw similarly found no significant tendency towards high malaise scores in mothers of either less mobile children or children with little communication or children with a reduced ability to look after themselves.⁽²²⁾

In the present study of single carers several variables were tested to see if a relationship existed with malaise scores of 5 or more. It was hypothesised that a relationship might exist between malaise scores and employment outside the home. Bradshaw, in the study of a sample of applicants to the Family Fund, had found that mothers who were able to do paid work outside the home had lower malaise scores than all other mothers.⁽²³⁾ But no relationship was found either between high malaise scores and having a job or high malaise scores and not having a job in this study.

There were two variables in the current study which had a relationship with 'malaise'. One was associated with leisure. People who were never able to leave the parent to go out in the evening or at the weekend tended to score five or more. The relationship was clearly there although it was not a strong one. ($r = 0.243$)⁽²⁴⁾ More men than women were able to go out in the evening or at the weekend. However, the relationship was still there when the male and female scores were analysed separately. The second variable to have a strong relationship was the sex of the carer. ($r = 0.511$) This finding of mean female inventory scores higher than mean male scores has been demonstrated in other studies. Rutter et al's 1975 comparison of samples of children and their families in the Isle of Wight and an inner London borough measured the mean malaise scores of both fathers and mothers of 'normal' and psychiatrically disturbed children. The fathers' mean score was consistently lower than the mothers' for all groups.⁽²⁵⁾ The sex difference also emerged in studies using the Cornell Medical Index. For example, Hamilton et al's 1962 study of social and psychiatric data for 146 parents of children in the 5 - 11 age group found that fathers had a considerably lower average number of functional, somatic and psychiatric positive responses than the mothers.⁽²⁶⁾

A possible reason for the difference in mean scores is that both the malaise inventory and the Cornell Medical Index are inadequate instruments for measuring emotional disturbance in men. But, it is also possible in the study of single carers that the men tended to be under less pressure than the women. Their mothers were more likely to struggle against the effects of disabilities and to perform housework and self care tasks. As the following chapter shows, the men's employment outside the home was far less likely to be affected by parental dependency.

CHAPTER 5. EMPLOYMENT, HOUSEWORK AND CARING

This chapter examines the two spheres of work, employment outside the home and housework and caring tasks within it. Housework has not traditionally been treated as 'work' by sociologists but as an aspect of the female role within the family. But, as Oakley demonstrated, housework is analagous to other kinds of work undertaken outside the home.⁽¹⁾ It will be argued that for the men and women in this study a relationship existed between the two spheres of work. The first section compares their employment situation and, the second, their involvement in housework and caring tasks. Finally, the contribution of sex role expectations to the sex differences in employment and performance of housework and caring tasks will be discussed.

The following analysis is in terms of gender rather than class. This is because of the obvious sex differences within the two spheres of work and the difficulties inherent in a meaningful conventional analysis by class for a sample of men and women. The Registrar General's six fold classification of occupations is widely used in making social class assessments.⁽²⁾ Classes I and II (professional and managerial) are usually termed 'middle class' and classes IV and V (semi-skilled and unskilled), 'working class'.

Class III is normally divided into non-manual and skilled manual occupations, the former being assigned to the 'middle class' and the latter the 'working class'.

A high proportion of women have class III non-manual occupations. As Table 7 shows, the proportion of economically active, single, married and divorced, women in the 1971 census with occupations in this class was approximately four times greater than for men. Conversely, the proportion of men with class III manual jobs was approximately four times greater than for these women. If the conventional distinction were made between 'middle' and 'working class', 61.6% of these women but only 34.9% of the men would be considered middle class. The problem posed by sex differences in occupation are normally avoided for married women by assigning them to their husbands' class rather than their own. As the current study is of single people, this solution to the problem of sex differences in occupation was not available. However, the occupations of the single men and women in the study broadly reflect the sex differences between manual and non-manual occupations in the general population.

As Table 7 shows, a higher proportion of the women than the men in the current study were in 'middle class' occupations, 80% as compared with 41%. Also a higher proportion of the single women in the current study than in the 1971 census has class I occupations, 14% as compared with 1.2%. And the proportion of single men in the current study with class V occupations was higher than in the 1971 census, 40% as compared with 8.3%. Although the current study is based on a small sample, it appears to reflect a tendency Goode identified in a study of the family. He pointed out that, although people tend to marry into the same class, 'when women marry into a different

class, they are more likely to marry upward in class'.⁽³⁾ Consequently unmarried women are more likely to occur in the highest social class and unmarried men in the lowest social class.

Table 7 Social class of the single carers, by present or previous occupation, compared with economically active men and single, widowed and divorced women in the 1971 census

<u>Social class</u>	<u>Female</u>		<u>Male</u>	
	<u>Single</u> <u>Carers</u> N = 36 % 14 23 43 0 6 <u>14</u> <u>100</u>	<u>Unmarried</u> <u>women 1971</u> <u>census*</u> % 1.2 19.2 41.2 10.8 22.7 4.9 <u>100</u>	<u>Single</u> <u>Carers</u> N = 22 % 14 9 18 18 0 <u>41</u> <u>100</u>	<u>1971</u> <u>census</u> 5.2 17.8 11.9 39.0 17.8 8.3
I				
II				
III non-manual				
III manual				
IV				
V				

*Unmarried women means single, widowed and divorced

The source of the 1971 census figures was the Central Statistical Office, Social Trends 1975 (H.M.S.O., 1975) Table 1.1, p.11

Employment outside the home

The majority of carers in the study, 82% of the men and 72% of the women were below retirement age.⁽⁴⁾ As Table 8 shows, their employment situations were a stark contrast. All except one of the men had a full-time job. However, this was true for less than

half the women. Four women, 15% of those below retirement age, had part-time jobs. Altogether ten women, 37% of those below retirement age, and one man were without jobs. Almost all of them gave their parents' need for care as the reason. Three of the women, one in part-time work and two not working at all, said their own health problems had been a contributory factor. As the study is based on interviews at one point in what could be lengthy caring processes, it is likely to underestimate the full impact of parental dependency on women's employment. More of the working daughters could eventually have to give up work before reaching retirement age.

Table 8 Employment situation of the men and women below retirement age

	<u>Men</u>		<u>Women</u>	
	<u>No.</u>	<u>%</u>	<u>No.</u>	<u>%</u>
Working full-time	17	94	13	8
Working part-time	-	-	4	15
Not working	<u>1</u>	<u>6</u>	<u>10</u>	<u>37</u>
	<u>18</u>	<u>100</u>	<u>27</u>	<u>100</u>

The employment experience of the one in four carers above retirement age had been very similar to those who were younger. None of the men had either given up work before reaching retirement age or had felt forced to retire by the parent's disabilities. But about half the women had given up work before reaching retirement age. Indeed, one woman had scarcely worked outside the home at all. She had started work at the age of fourteen and had been persuaded to give it up two years later because of her mother's poor health. At

the time of the interview she was 75 years old and still looking after her mother who by then was 99.

On the whole, the women had given up secure white collar jobs to care for the parent. They included a social worker, two executive officers in the civil service, an administrative officer in local government, a computer operator, a nurse, a clerk and two secretaries. As most were in their late forties and early fifties when they stopped work, the chance of being able to return to an equivalent job, if the parent died before the daughter's retirement age was reached, was probably remote.

There were common elements in many of the women's accounts of the reasons why they had given up work. Often there was a precipitating crisis;

'Mother fell and could not get up because of her arthritis. She spent the whole day lying on the floor. When I got home from work, I could not get her up even with the help of a neighbour. In the end, I dialled 999 and some ambulance men came round to pick her up. Actually she was not hurt at all, but her nerve was broken. She begged me not to leave her at home alone'. (Former civil servant)

'I was working near home and I popped over for a cup of coffee. The ambulance was outside the door. My father had secretly arranged for mother to be admitted to hospital. He wasn't prepared to keep on coping with her. That was it. I gave up my job then and there'. (Former social worker)

Usually the strain of coping with a job and the parent's needs had been so great that stopping work was initially a relief. A common recollection was thinking that at the time stopping work was only temporary because the parent was unlikely to live long. But often the parent's condition seemed to improve,

'When I stopped work 11 years ago, I thought she would only last a year. But she did improve and now she is 93'. (Former clerical assistant)

'Quite honestly if I had known how long it would go on for I would never have had her out of hospital and given everything up'. (Former insurance collector)

Other responses to the parent's need for attention included working part-time, varying normal work hours and taking the days of annual leave as the parent needed extra attention. The four women who worked part-time all suffered a loss of income. This could be quite substantial. One woman thought she was very fortunate in her job;

'I work a 27 $\frac{1}{2}$ hour week instead of 37 hours. I work five days a week and it means that I never have to leave my mother alone for a whole day. I am really lucky because they let me use up my holidays as my mother gets bad turns. The pay is low but that's not the main thing'. (Clerical assistant)

It was more common for women than for men to vary normal work hours. Three of the women, but only one of the men, working full-time did so. The most common work pattern was to leave home relatively late in the morning and compensate by working later in the evening because the parent either needed lengthy personal attention or there was housework which could not be left until the evening. Mr. Reve described his daily routine;

'My employer lets me start a bit later because of the amount I have to do first thing. My mother wets the bed so I have to wash out sheets and her nightdress and put them in the spin dryer. She can't be left with the gas on any longer, so I make her a drink in a flask and put out food for her. Then I shut off the kitchen with a padlock on the door. I just work later in the evening'. (Garage mechanic)

Working flexible hours might have to be paid for in other ways. Miss Alexander had paid quite a high price;

'I used to have a very good job in the city but I gave it up two years ago. I just could not work the hours they wanted. I took my present job because I can go in late after I have seen to mother. I know I have to work late in the evening but she needs the attention in the morning. My pay is much worse than in my previous job and there is

no pension attached to it. Society is going to penalise me in the future because at present I am doing what society is telling me I should do. I will not have an extra pension in my own old age'. (Librarian)

Taking an official policy of 'flexi-time' literally and consistently arriving late for work could be felt to earn disapproval. Miss Baker, a woman in her late forties, commented;

'Because of all the things I have to do for mother I have arrived in the office after 11 in the morning for years. I work until after 7 in the evening but I know that the people I work with resent it. People are tolerant of those sort of hours for a short time but not when it goes on for year after year. I know I have never had any promotion because of it'. (Civil servant)

Several people who would have welcomed being able to start work later in the day were never given the opportunity to do so. According to these informants, their employers would not, or could not, tolerate flexible working hours. This kind of flexibility is more likely in white collar than blue collar jobs. Because they were predominantly in white collar jobs, the women in the study were more likely than the men to have the opportunity of flexible hours.

Housework and Caring tasks

Housework can be interpreted to mean a wide variety of domestic tasks. Three specific ones were discussed with the carers; cooking the main meal, cleaning floors and other surfaces and doing the main shopping. The women were significantly more likely than the men to be responsible for each of these three tasks. As Table 9 shows, almost all the women, 89% of them, cooked the main meal compared with 41% of the men. Only 18% of the men did the main cleaning of floors and surfaces compared with 61% of the women. Most of the women, 81% of them, did the main shopping compared with 45% of the men.

Table 9 Housework done by the carer

<u>Housework task</u>	<u>Women</u>		<u>Men</u>	
	<u>No.</u>	<u>%</u>	<u>No.</u>	<u>%</u>
Cooking the main meal	32	89	9	41
Cleaning	22	61	4	18
Doing the main shopping	29	81	10	45

There were three crucial differences between the two types of household. Firstly, as discussed in Chapter Three, mothers living with sons were far more active domestically than those living with daughters. This did not apply to shopping, only one mother living with a son and one with a daughter managed to do any. However, half the mothers living with sons did the main cleaning compared with only 6% of those living with daughters. Almost half the mothers living with a son cooked the main meal compared with only 6% of those living with a daughter.

Secondly, households with sons received far more support from the local authority home help service. Home helps assisted 55% of households with sons and only 22% of households with daughters. The difference is not so great if households with a working son or daughter are compared, 53% of the former being assisted by home helps and 35% of the latter. This sex bias repeated that found in a national study of the home help service. In the 1970 government survey, Hunt commented,

'There are indications that men are more likely to receive home help simply because they are elderly and living alone: for example, 98.1% of men were able to go out compared with 67.8% of the women: 29.1% of men compared with 8% of women, had no difficulty with any of the personal tasks involving mobility'.(5)

Working daughters in the current study were less likely than sons to apply for a home help. This was usually because it was believed that such an application would be turned down. Such a belief was not without foundation. Four daughters had been refused a home help at some point in their working careers; an experience not shared by any of the sons. One of the women recalled,

'I felt I could not cope with it all any longer. I had my job to do all day and then non-stop housework when I got home. Somebody at work suggested a home help and I rang up. They said they could only let me have a home help for a month, so I said there was no need to bother because that was not a lot of use. Somehow I managed to keep going until I retired. But I feel a bit bitter that there was no help at all'. (Former secretary)

Of course, home help organisers are not alone in assuming that female relatives can, and should, cope with the problems of dependency. In a 1976 study of the career of a sample of disabled people discharged from hospital, Blaxter commented that social workers and nursing staff assumed that if female relatives existed then no problem could arise;

'Some of the most obvious failures in ensuring necessary care arose because this assumption, that daughters, sisters and mothers will automatically provide it, was shared by the professionals whose job it was to recognise 'need'. (6)

The third difference between the two types of household was in the amount of personal care tasks needing to be done for the parent. As was described in Chapter Three, although parents living with daughters were as likely as those living with sons to be incontinent or to need help in bathing, there were three areas of personal care in which they were far more likely to need help; going to bed or getting up, dressing or undressing and using the commode or toilet.

The heavy burden of domestic work and caring tasks within the home borne by many of the women in the study clearly had an impact on their employment outside it. Conversely, the relatively lighter domestic burden of many of the men contributed to their continued employment. Sex role expectations were a crucial factor both in the different employment patterns and in the differing domestic burdens of the men and women.

Sex role expectations

In an urban industrial society a high moral value is attached to male employment. To quote Parsons,

'It is perhaps not too much to say that only in very exceptional cases can an adult man be genuinely self respecting and enjoy a respected status in the eyes of others if he does not 'earn a living' in an approved occupational role'.
(7)

This view has wide support. For example, Morse and Weiss, exploring the work attitudes of a sample of more than 400 employed men in America, asked who would continue to work after inheriting sufficient money to remove the necessity.⁽⁸⁾ The response from 80% of the sample was that they would continue to work. Morse and Weiss concluded,

'It is through the producing role that most men tie into society and for this reason and others, most men find the producing role important for maintaining their sense of well-being'.⁽⁹⁾

Similar conclusions have been drawn in studies of the unemployed. Hill et al's 1973 study of a sample of unemployed men in three English towns, concluded there was no evidence that many men remained unemployed because it was more lucrative than working.⁽¹⁰⁾ Nor did large redundancy payments encourage long-term unemployment. If the effects of age were taken into account, the recipients of redundancy pay experienced shorter than average periods of unemployment.⁽¹¹⁾

The strength of the moral value of employment for men is neatly illustrated in George and Wilding's 1972 study of motherless families.⁽¹²⁾ As part of the study, community attitudes were explored through a small sample survey. Respondents were asked their views on what a father should do to provide the best care for his children in the event of his wife dying or leaving. Generally in our society a high value is placed on caring for children under school age at home. But the situation of a motherless family produces a value conflict between the parental care of very young children at home and male employment. As far as the sample was concerned, a higher value was placed on male employment, and 78% thought a father with children under school age should go to work and 96% thought the same of a father of school age children.⁽¹³⁾ The strength of the male work ethos is further illustrated by the sex difference in the employment behaviour of lone parents. According to the Finer report on one parent families, at least 90% of lone fathers were in work, the majority full-time, in 1971, compared with 25% of lone mothers working full-time and 20%, part-time.⁽¹⁴⁾

The single men in the current study shared society's evaluation of the significance of male employment. In response to questions about whether time had ever had to be taken off work because of the parent, almost all of them stressed that the job had to have priority;

'I've never taken time off work because the job has to come first. If that folds up, everything folds up'. (Chartered accountant)

'The only time I have ever had time off work was when the council workmen were here and I had to check on what they were doing. If my mother had a fall I do not know what would happen as I would have to go to work'. (Machine room supervisor)

'If she ever gets so that I need to give up my job, she will have to go into a Home. I am not giving up my job and that's it'. (Clerk)

Sometimes a few hours had been taken off work because the parent had developed 'flu' or had had a 'bad turn'. But the sons were at pains to emphasise how slight the interruption had been.

'I've only ever had one morning off in my life and that was when I thought she had had a stroke. Well, the doctor came and said it wasn't a stroke so I went back to work in the afternoon. The neighbour kept an eye on her'. (Clerk)

'I've only had the one or two half days off because of her when the neighbours have rung me at work to say that she is poorly. But, I've seen how she is and gone straight back to work. She has insisted I do'. (Civil servant)

Three of the men said that if the parent were ill a married sister living in the district would take time off from her job to provide the necessary care. On the whole the parent's disabilities were not seen as threatening to the son's job. The one man, who was an exception in the study had given a job up to look after his mother, had problems himself which had probably contributed to his decision. He had a serious physical disability and had suffered mental health problems for several years.

That mothers living with sons managed to do far more domestic work than those living with daughters reflects both the deference given to male employment and the attitude that domestic work is inappropriate for men. These mothers appeared to be struggling against disabling conditions to themselves to maintain a female caring role within the family.

That the single sons in the study usually had less responsibility than the daughters for domestic and caring tasks needs to be seen in the general context of male behaviour in the domestic sphere. All the evidence from previous research relates to married men. There are two views of male domesticity. One is that the traditional male

disdain of domesticity is a phenomenon of the distant past. Young and Willmott advanced this view in the 1973 study, 'The Symmetrical Family';

'Husbands also do a lot of work in the home, including many jobs which are not at all traditional men's ones...There is now no sort of work in the home strictly reserved for 'the wives'. Even clothes-washing and bed-making, still ordinarily thought of as women's jobs, were frequently mentioned by husbands as things they did as well. The extent of the sharing is probably still increasing'. (15)

However, it can be argued that they had insufficient evidence to substantiate a view of such an extensive sex role change. Oakley, for example, thought that the one question on the division of labour used by Young and Willmott, 'Do you/does your husband help at least once a week with any of the household jobs like washing up, making beds (helping with the children) ironing, cooking or cleaning?', was poorly worded and provided an inadequate basis for a conclusion of marital symmetry.⁽¹⁶⁾ As she pointed out doing a task once a week is very different from doing it every day. A husband who irons his trousers once a week or who prepares tea on a Sunday or who puts the children to bed one day in the week is rather a long way from equally sharing household tasks. Oakley's conclusion from her own study of housewives was that,

'In only a small number of marriages is the husband notably domesticated, and even when this happens, a fundamental separation remains: home and children are the woman's primary responsibility.....But the importance of women's enduring role as housewives and as the main rearers of children continues'.(17)

This view finds support in Hunt's 1968 national survey of women's employment.⁽¹⁸⁾ Although 67.8% of the working wives interviewed had some help from their husbands, it was mainly in washing up or in drying up. Hunt commented;

'the general impression is given that the help received by the majority of working housewives is very limited in character'. (19)

Although in Oakley's view, women may not actually enjoy housework as such, there can be no doubt that working within the home and providing care for other family members, whether adults or children, is an integral part of the female role.⁽²⁰⁾ It remains an integral part for both single and married women. This responsibility within the home is so taken for granted that it seems pedantic to say that working women are also housewives; it is rather like saying women are women. This taken-for-granted quality of women's domestic responsibilities is illustrated by one of the questions used in Hunt's national survey of women's employment,

'Do you get any help with your household duties from your husband (other member of the household) or a paid help?'
(21)

As far as married women are concerned, a major social change has taken place in the effect of marriage on employment. Before the Second World War, most women gave up, or were forced to give up, their jobs on marriage.⁽²²⁾ In 1931 only 10% of married women were in paid employment.⁽²³⁾ Indeed many professions banned the employment of married women.⁽²⁴⁾ The prime responsibility of married women was considered to lie in providing full-time domestic care for their husbands. Since the war there has been a growing tendency for work to be given up at the birth of the first child rather than at marriage.⁽²⁵⁾ There has also been a consistent trend towards returning to work when the youngest child reaches school age. This work is more likely to be part-time rather than full-time. For instance, although 65% of women with children aged 10-15 were working in 1979, two thirds of them were in part-time work.⁽²⁶⁾ This fits in with domestic responsibilities far more easily than full-time work.

Although single women have been as socialised as married women into a strong sense of responsibility for providing care, there are strong pressures not to give up a job, not least because a job provides both a current income and usually some kind of occupational pension. Often for many such women continuously looking after the parent would mean living at supplementary benefit level and sacrificing part or all of an occupational pension in the future. The fact that under half the women below retirement age were in full-time employment illustrates the strength of this feeling of responsibility to provide care. All but one of the women who were working expressed strong anxiety about whether the parent's need for care would allow them to continue. The exception, a lecturer in adult education, asserted her job had to come first,

'To me my job is important. My mother knows this and knows it comes first. If I could not do it I would be finished. I am not domesticated and I could not get any satisfaction from just running a house'.

For the other women the future of the job was always in question.

'You are always worried about the future. It's a question of how much more mother will deteriorate and will the authorities do anything to help if she does. You don't have a career when you have domestic responsibility. You are always worried about whether you will be able to continue working'. (Civil servant)

'There are times when I think I should give up my job or at least go part-time or work one day less a week'.
(Personnel officer)

'What shall I do if my mother gets worse? Should my mother go into a Home or should I give up my job to look after her? But what sort of pension will I get if I give up work now?'.
(Secretary)

It was not unusual to experience considerable pressure to give a job up. Sometimes the parent could not cope with being alone any longer;

'My mother just kept ringing me up at work and asking me to go home to be with her. I felt I had to give it up then. I had already given up a full-time job and taken one in the mornings to fit in with her'. (Retired clerk)

'Falling like that made her lose her nerve although she was not really hurt. She begged and begged me to give up my job and stay at home. Actually she didn't think I was giving up anything when I stopped work. She thought I was lucky not to have to go out of the house and travel to the office every day'. (Former civil servant)

Sometimes other people at work suggested that the women should give up their jobs;

'I went to talk over the problems I was having with mum at home with the welfare officer at work and she turned round and told me to give up work. But I didn't really see why I should'. (Civil servant)

'I've been late for work a couple of times because I have such a time with my mother getting her ready for the day centre. She can't dress herself and does silly things like putting two legs in one knicker hole or her cardigan on back to front. The manager was dreadful to me about it and said I should give up work altogether to look after her'. (Cashier)

Just as there was a sex difference in the certainty that priority had to be given to the job, so there was a sex difference in taking time off work because of the parent. While most of the men insisted little if any time had been taken off, most of the women seemed to have behaved quite differently;

'I regularly finish an hour earlier than everybody else so that my mother is not left alone in the house. My employer has been very good about it and I still get the same wage at the end of the week'. (Wages clerk)

'I regularly have to take time off in the winter for my father if he gets 'flu or bronchitis. But it isn't any problem, I am so much part of the firm'. (Secretary)

'I have had several week special leave for a sick relative without it coming out of my annual leave'. (Civil servant)

This sex difference in taking time off work is partly a difference between blue and white collar jobs, a higher proportion of the male respondents being in the former. But the type of job in itself is not sufficient explanation of the differences; the men in professional and clerical jobs were as adamant as those working in factories that time could not be taken off work.

There was a complex interaction between sex role expectations, the carers' employment, the parents' ability to do some housework and personal care tasks, and the volume of housework and caring tasks done by the carer. The single women were far less likely than the men to have full-time jobs. When they were employed they usually had to cope with more housework and personal care tasks for the parent than the men. Their parents tended to be more disabled and dependent than those living with sons. Unlike the men, most of the working women felt under continual pressure from their domestic responsibilities.

CHAPTER 6 KIN SUPPORT

This chapter examines the extent of kin support for the single carers and discusses some of the key issues arising from these findings. The following chapter looks at the support experienced from neighbours, friends and volunteers.

A major sociological debate has revolved around filial feelings of obligation towards elderly parents in an urban industrial society. On the one hand it is argued that industrialisation has substantially weakened kinship ties. Within a rural economy not only does the family fulfil many functions, but kinship is often seen as the central form of organisation. Through it women and men expect to meet most of their needs whether these are social, occupational, economic or emotional. To quote Parsons, 'it is well known that in many 'primitive' societies there is a sense in which kinship 'dominates' the social structure; there are few concrete structures in which participation is independent of kinship status'.⁽¹⁾ Industrialisation and urbanisation are seen as processes eroding the significance of kinship. In a much quoted paper, Linton described what he saw as the effect of the current technological revolution:

'The outstanding feature of the present situation is the almost complete breakdown of the consanguine family as a functional unit.... breakdown seems to be directly correlated with the increased opportunities for both spatial and

social mobility which have been created by the current technological revolution... Colloquially speaking when a man can do better without relatives than with them he will tend to ignore the ties of kinship. At present the consanguine family retains its functions only in long settled rural districts and in the case of a few capitalist dynasties'. (2)

Writing in the 1950s, Parsons expressed a similar view of the consanguine family, coining the term 'isolated' nuclear family;

'Our suggestion is, in this perspective, that what has recently been happening to the American family constitutes part of one of these stages of a process of differentiation. This process has involved a further step in the reduction of the importance in our society of kinship units other than the nuclear family. It has also resulted in the transfer of a variety of functions from the nuclear family to other structures of the society, notably the occupationally organised sectors of it..... The first feature to be noted is on the level of kinship organisation as anthropologists ordinarily treat this; namely the 'isolation' of the nuclear family and its relation to 'bilaterality' with respect to the lines of descent. This 'isolation' is manifested in the fact that the members of the nuclear family, consisting of parents and their still dependent children, ordinarily occupy a separate dwelling not shared with members of the family of orientation of either spouse.....'(3)

On the other hand it has been asserted by other writers that, far from degenerating in an urban industrial society, the extended family has flourished. Broadly, three lines of argument have been put forward to demonstrate the strength of kinship ties. One is based on empirical contemporary research. Several such studies are concerned with the links between the generations. For example, Young and Willmott, in a study of family and kinship in Bethnal Green, emphasised the bond between 'Mum' and her adult daughters;

'The Bethnal Greeners whom we have been describing did not change their residence just because they got married. They have remained in their district, and consequently in their family of origin. The wife stays close to her mother because she already shares so many common interests and associations, and since she stays nearby, she keeps them alive and renews them'.(4)

Townsend's complementary study of the family life of old people in Bethnal Green, came to a similar conclusion;

'The network of kinship and the support system of reciprocal obligations spread outwards. Within the network the extended family was, to the individual, the most important group. As members of this family most old people in Bethnal Green found security, occupation and interest day by day'.(5)

Numerous other studies on both sides of the Atlantic, of both the middle and working classes, confirmed that reciprocal aid between the generations was not confined to an atypical east London working class area.(6) The largest of these studies, 'Old People in Three Industrial Societies' by Shanas et al, based on national samples in Denmark, America and Britain, drew the conclusion that links between the generations were strong;

'Our observations in the three countries lend support to the general hypothesis that in industrial societies family relations in later life have developed towards a modified extended family system rather than towards isolation and the breaking of family ties. The over-all pattern revealed in the relations between older people and their families shows clearly that most elderly people in each of the three countries are likely to maintain fairly frequent contacts with children as well as relatives'.(7)

The second line of argument against Parson's thesis is that an isolated nuclear family does not logically best meet the needs of an industrial urban society. Litwak, in particular, has developed this point, arguing that basically four generic types of kin relations have been described in sociological literature.(8) They form a continuum. At one extreme is the traditional extended family in which nuclear sub-families are entirely dependent on extended kin for most services in life. A second type is the modified extended family in which nuclear sub-families are partially dependent for services on extended kin and partially on formal organisations. The third type

is the isolated nuclear family structure in which families meet their own needs and the fourth is a 'dissolving' or weak family structure where needs are met entirely outside the family by large scale formal organisations. Litwak argued that of these four types, the modified extended family best met the needs of a modern democratic industrial society. It had the capacity to survive common recurrent crises more efficiently than an isolated nuclear family because of a greater pool of resources on which to draw in the form of kinsfolk help.

The third line of argument used against Parsons' 1955 thesis is based on historical material. Broadly, the argument is that kinship was not, in fact, the dominant form of social organisation in pre-industrial Western Europe. Rather a typical domestic group was small and centred on a conjugal pair. For example, Anderson argued from census material for 19th century Preston that the effect of early industrialisation was to strengthen rather than weaken kinship ties;

'... of the non-bureaucratic sources of support only the family had a framework within which reciprocation could occur which was sufficiently clearly defined to provide an adequate guarantee of assistance in the major crises situations. It was thus advisable, or even well-nigh essential, for kinsman to make every effort to keep in contact with, and to enter into reciprocal assistance with, kinsman, if life chances were not to be seriously imperilled'.(9)

In a reply to his critics, Parsons, in 1965, somewhat modified his earlier description of the nuclear family as isolated;

'The concept of isolation applies in the first instance to kinship structure as seen in the perspective of anthropological studies in that field. In this context our system represents an extreme type, which is well described by that term. It does not, however, follow that all relations to kin outside the nuclear family are broken. Indeed, the very psychological importance for the individual of the nuclear family in which he was born and brought up would make such conception impossible'.(10)

Clearly, in some respects, the debate between Parsons and his critics appears to stem from ambiguity over terminology. Such words as 'family', 'kinship', 'extended' and 'isolated' do not have a commonly accepted meaning. As Baric pointed out, there is no necessary contradiction between the views of Parsons and his critics.⁽¹¹⁾ When Parsons referred to an extended family, he meant kin of several generations, cooperating in productive activities and having a common ownership of assets. Such a family does not usually exist in an urban industrial society. But when a sociologist like Townsend referred to the extended family providing support for the elderly in Bethnal Green, he really meant something quite different, a set of extra familial kin. To quote from Townsend's study;

'The extended family may be said to consist of a group of relatives comprising more than an immediate family, who live in one, two, or more households, usually in a single locality, and who see each other every day, or nearly every day'.⁽¹²⁾

As Firth et al pointed out, the difference between the two types of kinship structure become quite distinct if the test of authority is exercised.⁽¹³⁾ Parsons referred to an extended family in which authority was exercised by the parents of the family of origin. No such authority was being exercised for the extra familial kin to which Townsend referred.

Siblings

The current study of single people caring for infirm elderly parents must be seen in the perspective of this debate. On the whole these elderly parents had a tremendous amount of support from at least one member of the younger generation. The crucial question to which we now turn is the extent to which the caring burden was shared by kinsfolk.

Generally if there was any assistance from kin, it came from the carer's siblings. However, a high proportion of the single carers completely lacked sibling support. Altogether 26% of them were only children and a further 10% had had no contact of any kind with existing siblings for years. The rest, 64%, had supportive contact of some kind with at least one sibling. Before discussing the nature of this supportive contact, it is relevant to look at where the siblings lived. If they lived nearby this obviously increased the possibility of sharing the day to day burden of caring.

Seven of the carers had an unmarried sibling living in the same household. All but two of the siblings living outside the carer's household were, or had been, married, and a substantial proportion lived quite close. Altogether 66% of the married sisters and 39% of the married brothers lived within a three mile radius. Broadly this is in agreement with the findings in other studies on matrilocality; married daughters being more likely than married sons to live near their mothers.⁽¹⁴⁾ For instance, in their 1965 study of family and social change in Swansea, Rosser and Harris reported that 42% of the married women and 26% of the married men had at least one parent living in the same locality.⁽¹⁵⁾ Social class differences were slight.⁽¹⁶⁾

Evaluating kin support is problematic. Firstly, there are difficulties in deciding what can be regarded as a supportive act. Social visiting was the most frequent form of sibling activity. On the one hand it could be highly valued. As one woman put it;

'My sister coming on Saturday afternoon is the one thing I have to look forward to in the week. I long for that day. It's the only day in the week I can really talk to anybody'.

But, on the other hand, a mere social visit could cause intense resentment. It often entailed extra work for the carer in preparing

a meal and really emphasised the differences between two life situations. Miss Randel, who was in her sixties and looking after her 90 year old mother, was very bitter about the lack of help from her two sisters;

'They take it in turn to come here each Saturday evening. I always have to prepare a meal with several courses and then wash up afterwards. I then manage to get out to my club for a little while. My sisters don't stay with mother for any length of time. They help her to bed and then go home. I still have to get home at 10 p.m. Mother is always awake and she goes on at me, 'Why don't you give me poison if you hate me so much and stay out so long?'

A second problem is the comparability of different forms of practical help. Shopping, washing soiled bed linen, taking the parent out for a summer Sunday afternoon drive, having the parent to stay for a week or two and 'parent sitting' to allow the carer to go out in the evening were all mentioned. Occasionally financial help was given particularly when the sibling lived far away. One example was of two sisters living in Canada who bought new furniture for their younger sister and also paid nursing home fees for their mother when the sister became too ill to cope for a couple of weeks. A similar example was a brother living in Switzerland who paid for a house extension with a downstairs toilet when his mother became unable to climb stairs to reach the first floor bathroom.

A third problem lies in evaluating the assistance given in relation to the total caring burden. Many of the carers had to provide support to the parent twenty four hours of the day and seven days of the week. The burden became particularly heavy in situations of parental incontinence, senile behaviour or needing continual attention at night. In this context the sibling's contribution could seem rather minimal. One woman, who had been unable to leave her very senile

mother alone for more than an hour at a time for the past seven years, commented ruefully,

'I have asked my brother and his wife just to have her for a week so that I can get away from it all. But they refused, they said they were not prepared to take the responsibility. They do let us use their holiday home for two weeks in the summer. But, of course, I have to take mother so it isn't much of a break'.

In view of these problems in assessing support only very broad generalisations can be made. A high proportion of the siblings, 40%, gave no practical support of any kind and did not visit as frequently as once a year. In larger families one sibling was often more supportive than the others. Thus, four out of five carers, with one or more siblings living outside the household, received either some form of practical support or a social visit more often than once a year from at least one of them.

The most help undoubtedly came from siblings living in the same household. The seven respondents in this situation were clearly mainly responsible for the care of the parent. Three of them were women with an unmarried brother who did few housework or caring tasks and four of them shared a household with a sibling of the same sex. As far as the latter were concerned, there were three instances of one sister giving up a job to look after the parent and one instance of a more domesticated brother taking responsibility for providing care. At least most of these respondents were able to go out for the evening without having to arrange for a 'sitter' for the parent and sharing some of the chores did mean that the burden of caring was less likely to become overwhelming.

There were only two instances in the study of all the siblings living outside the household trying to share the day to day burden of

care. Miss Fern, a civil servant with an 87 year old mother severely crippled by arthritis, commented,

'Both my older sisters are prepared to pull their weight so I feel very lucky. I employ an attendant to look after mother during the day so that I can continue working. My sisters each pay a third of her wages. - They each come here once a week with their husbands and cook Mum an evening meal. So that's two evenings in the week I go out. Then, at holiday time I share a holiday house with one of my sisters and her husband. We take Mum and share looking after her. Then, the other sister has Mum to stay for a week later on and I can get away by myself.

Miss Harris was only able to continue working because of elaborate support from a kin network;

'My three sisters all work part-time and they work it so that each of them spends a day with mother. She is so absent-minded because of pernicious anaemia that she could easily set fire to the house if she was by herself. Two of my nieces share one day between them and my brother drives over and collects mother each Friday and she spends the day there. This has been going on for a year. The family only rallied round to help when Mum was taken into hospital and nearly died'.

In both cases the carer was the 'baby' of the family and much younger than the other siblings.

The assistance from siblings was usually much slighter.

'My sister sits with Mum for an hour on Friday afternoons so that I can get away from the house'.

'My brothers and sister take it in turns to have Dad stay for one week in the year so that I can have a holiday'.

'My brother does a weekly shop for us at Sainsburys'. He has a car so he can bring back quite a lot'.

'My sister and her husband take my parents out for a car drive on Sunday afternoons in the summer'.

'My brother comes over and chops wood for us on Friday evening'.

'My brother is very good. He fixed up a bell so that Mum can call me in the night. I have to get up about four times and I have started sleeping too heavily to hear her call'.

Altogether approximately half the carers who had siblings living outside the household had practical support of some kind from one or more of them. In a small study such as this one, there are invariably difficulties in interpreting the pattern of sibling help. Variables such as socio-economic class, geographical locality and family size did not appear to explain why some brothers and sisters did or did not give any practical assistance. However, there was a clear difference between sisters and brothers. Just over half the sisters gave some form of practical help compared to only one in three of the brothers. This was not a simple sex variable. Married sisters were more likely to give help to all carers. But female carers were more likely than male carers to receive help. Thus, there was more likely to be help from sister to sister than from sister to brother. Seven out of ten married sisters of female carers gave some form of practical help compared with one in six married sisters of male carers. This seemed to indicate both that sisters were more able to call on each other for help and that the closest sibling relationships in the study were between two sisters.

Other studies have drawn the same conclusion. In a 1969 study of middle class families and relatives in North London, Firth et al commented that sisters were generally closer to one another than brothers.⁽¹⁷⁾ And Abrams, summarising the existing research on community care, concluded that,

'kinship remains the strongest basis of attachment and the most reliable basis of care that we have. This is especially true among women. Between mothers and daughters and between sisters to a lesser degree, almost any call for help is legitimate and will, if at all possible, be satisfied. In these relationships a productive balance of trust, dependency and reciprocation is most easily struck'.⁽¹⁸⁾

Other Kin

Assistance from kin other than siblings was relatively rare. The parent's own siblings were usually either dead or too frail to be able to visit or help in any way. Indeed they were more likely to need than to give support. Miss Bowles' aunt was typical of surviving siblings from the older generation.

'I do drive over to fetch my aunt occasionally. She is actually far worse than mum. Mum is forgetful but she is not really senile, not like that. Auntie can't remember where anything is in her flat. The place is filthy dirty. I am sure she will set fire to it one day. Really, I should have her to live with us'.

Assistance from secondary kin such as nephews, nieces or cousins was usually minimal. There were a few exceptions. One woman kept in contact with a cousin;

'My cousin lives in Suffolk and she does get across to see us every few months. She stayed here for a week last year with my sister and between them they managed to look after Mum for a week while I went away on holiday'.

Occasionally a nephew or niece gave some help;

'My nephews are very good. They often come round on a Saturday and pop up to the shops for me'.

'My niece lives the other side of London. She is always busy and has her own life to lead. She comes across to see us about once a month. She does things like help to sort out the bills or gives a hand with cleaning up'.

Exchange

The issues to which we now turn are, firstly, the reasons for the single men and women in the study looking after their infirm elderly parents and, secondly, the reasons why their contribution to that care was generally so much greater than that of their married siblings.

Abrams declared that 'reciprocity is the heart of the caring relationship in community care'.⁽¹⁹⁾ Exchange of goods and services

are seen as one of the bases of social life in both primitive and modern urban industrial societies. In a study of the forms and functions of exchange in archaic societies, Mauss commented that when gifts circulated in Melanesia and Polynesia, 'the return is assured by the virtue of the things passed on, which are their own guarantees. In any society it is in the nature of the gift in the end to being its own reward'.⁽²⁰⁾ Both Blau and Homans have written at length on exchange theory arguing that it is fundamental to an understanding of social behaviour.⁽²¹⁾ Blau described the basic principle of exchange; 'an individual who supplies rewarding services to another obligates him. To discharge this obligation, the second must furnish benefits to the first in return'.⁽²²⁾ For Homans, 'interaction between persons is an exchange of goods, material and non-material. This is one of the oldest theories of social behaviour and one that we still use every day to interpret our own behaviour'.⁽²³⁾

A social exchange must not be confused with an economic exchange. Firstly, an economic exchange is precise and the price to be paid is agreed before the exchange takes place. However, a social exchange involves, in Blau's words, 'a principle that one person does another a favour and whilst there is a general expectation of some future return, its exact nature is definitely not stipulated in advance'.⁽²⁴⁾ Secondly, a social exchange usually has an emotional value attached to it, because feelings of obligation and gratitude are likely to be generated in the person who is benefitting. In contrast, an economic exchange, involving a payment agreed in advance, is unlikely to involve feelings of obligation.

The obligation to reciprocate is usually assumed as a determinant of social behaviour in much of the sociological literature on

intergenerational relationships. For example, Townsend, discussing the reasons why elderly parents were helped by their children, commented,

'The essential answer is that they were members of a tightly-knit family group and as such they received help because they also gave it, or had given it in the comparatively recent past. In previous surveys the fact that old people perform services for others has had less attention than the fact that others perform services for them. What seems to be an essential principle of daily renewal of an intimate bond between adult relatives is the reciprocation of services between them'. (25)

Young and Willmott, in their study of family and kinship in Bethnal Green, made a similar comment,

'The daughter's labours are in a hundred little ways shared with the older woman whose days of child-bearing (but not child-rearing) are over. When the time comes for the mother to need assistance, the daughter reciprocates..... by returning the care which she herself received'. (26)

Adams, in a study of kinship in an American city, found that,

'Contact patterns indicate that a mutual affection and obligation dominate the relation of parents and their adult offspring, the relationship focusing in a basic concern for each other's welfare. This concern finds a tangible and intangible outlet in the various forms of mutual aid, either financial or services, which are shared periodically as well as when a specific need is perceived'. (27)

One of the most explicit and sophisticated developments of exchange theory appeared in Anderson's study of family structure in 19th century Lancashire. He argued that in the new cotton towns crises such as sickness, death, unemployment, the problems of old age and those resulting from a housing shortage, ensured that members of the working class were encouraged to make great efforts to maintain relationships with kin. Kinship provided a structured link and could thus form the basis for reciprocation. (28)

However, there are difficulties with exchange theory particularly in respect of intergenerational relationships. Not least of

these is the very breadth of the concept of exchange. It can be argued that reciprocation occurs in payment for past services or for current services or, indeed, in anticipation of future rewards. Thus, the assumption is that adult children give support to their parents either in repayment of the care given them as children, or in exchange for current services such as childminding, or in anticipation of some future repayment such as inheritance of property after the parent's death. At its vaguest, reciprocation can be argued to have taken place when the person giving the service experiences a 'good' feeling such as satisfaction at having done his or her duty by the parent. Litvak, arguing strongly for the validity of exchange theory, emphasised the significance of this type of reciprocation;

'These psychological kinds of exchanges should be remembered, because if one concentrates only on the more obvious forms of service or money exchanges, it will often seem that no reciprocal exchange has taken place, when in fact it has'. (29)

When exchange theory becomes as encompassing as this, it is difficult to imagine a situation in which an exchange of some kind, at some level, has not taken place. A notable exception to the assumption of the universality of exchange theory occurred in Firth et al's study of middle class families in North London;

'In a relatively abstract sense kinship is a structure. But it is also a flow. It is not even a flow of exchange of goods and services in any strict accounting 'transactional' fashion. The notion of generalised or diffuse reciprocity does apply to a considerable amount of kin relations. But it fails to take account of the fact that some kin services rest primarily upon the basis of response to obligation without anything comparable being involved in return then or later'.(30)

The amount of care the single daughters and sons gave to their infirm parents could be interpreted in terms of exchange theory. It could be argued that they were reciprocating the love and attention

shown to them in childhood by their parents. But, following Firth et al, it will be argued that rather this was a kin service resting primarily upon the basis of response to obligation.

Many of the daughters and sons appeared to have developed, when much younger, a strong sense of responsibility towards the parent. This had contributed to their failure to marry or leave home. For several people the commitment had arisen because the mother had been widowed. A woman in her forties explained,

'I was going to get married but then I wondered how all three of us would get on. I just wasn't certain how it would work out with mother. Father died when I was just a child. I could not have left mother to live by herself'.

Another woman had similar feelings,

'I am the youngest of five children. The baby of the family, that's me. My brothers and sisters are all a lot older than me. Dad died twenty years ago and I have lived on my own now with Mum for seventeen years. She has been ill with all sorts of trouble now for years. I've never thought about getting married. But I do love children, I would have liked some of my own'.

This phenomenon has emerged in other studies. Shanas et al, in a survey of the elderly in three industrial societies, commented,

'But in general the evidence suggests that at least one of the children of a widow or widower may postpone marriage, sometimes indefinitely, if the other parent dies at a time when the child is adolescent or in his or her's 20s'.(31)

Townsend made a similar point in the study of the elderly in Bethnal Green,

'The strong bond between a widow and her unmarried children, particularly her sons, was frequently mentioned in the interviews'.(32)

The situation of significance in the family could arise in other ways. There were several instances in the current study of the single daughter being an only girl in a large family of boys and apparently assuming unusual importance from childhood to the mother. Sometimes a caring role was thrust on a child at a very early age. This was the experience of Miss Brewer,

'I had to take over running the family when I was about twelve years old. That was when my mother went blind. I had an elder brother and a younger brother who were both blind. My sister was eleven years younger than me and could not help of course. I had to do the shopping, the cooking and the cleaning and look after the baby. I had to keep looking after my brothers until they were in their thirties. They did eventually get married and leave home. By then my father needed a lot of looking after as well as my mother so I never felt able to leave home'.

Significance in the family could also arise through disablement in early childhood or young adulthood. A minority of the carers were in this situation and it appeared that unusual dependence on the mother earlier in life had contributed to difficulties in leaving home. Goldberg drew attention to the same phenomenon in a 1970 study of a fieldwork experiment in social work with the aged. Referring to unmarried sons living with elderly parents, she commented,

'we observed a comparatively high proportion of handicapped men. Presumably old people with a handicapped son are more likely to come to the attention of the welfare department and the sons are less likely to marry and leave home'.
(33)

Not all of those interviewed had remained at home all their lives. Those in their fifties and sixties had usually been in the armed forces during the Second World War. Apart from war service, approximately one in four respondents had set up their own households and the parent, or parents, had joined them. The precipitating factor usually appeared to have been the parent's health problems.

The situation of an unmarried child living in the same household as an elderly parent, then, had arisen in a variety of ways. It will be argued that as the parent's infirmities grew worse, a daughter, in particular, had very little real choice about continuing to provide care. Two factors in particular appeared to contribute to this lack of choice.

Firstly, married siblings were unlikely to offer to take permanent responsibility for the parent. The single person would be assumed to have prime responsibility for looking after the parent because the first loyalty of the married siblings lay with the family of marriage not the family of origin. In Wilensky and Lebeaux's words, in modern industrial society 'the marriage bond is the key; the man or woman's first kinship loyalty is unequivocally to spouse and children'.⁽³⁴⁾ This was clearly illustrated in the behaviour of the married siblings. In most cases their contribution to parental care was small compared with that of the single carers. This in no way contradicts the evidence of strong supportive links between the generations. Rather it suggests that the supportive behaviour of one child is conditioned by that of others. A conclusion about kinship ideology drawn by Firth et al in their study of middle class families and relatives seems highly relevant.

'The obligation may be admitted but not performed because other kin - perhaps better placed - have been willing to carry it out instead.... The ideology of kinship in its moral aspect is not a series of one-to-one relationships, each with its separate moral content, but a constellation in which the moral responsibility of each party is regarded as relative to that of others in the field'.⁽³⁵⁾

In other words the amount of support given by the married siblings might have been much greater if an unmarried child had not been living in the same household as the parent.

Secondly, many of the daughters appeared to think that there was little likelihood of the parent being offered a place in a geriatric hospital or old people's Home because a female relative was available to provide care. Several of them had personally had a rejecting experience when seeking the parent's temporary admission to care. For instance, one woman was unsuccessful in arranging a holiday place for her very senile mother in a local authority Home;

'Over the past few years I have contacted mother's social worker by telephone to talk over the way things are going with mother. I have asked about mother going into a Home for a couple of weeks so that I can have a holiday several times but the answer is always the same, no chance'.

The social worker could have been acting on her own initiative rationing the available places or she could have considered the mother too infirm for a Home. A general practitioner has a similar role in controlling access to hospital places. It may genuinely be impossible to get a place in a geriatric hospital for a parent, but it may also be that a general practitioner is reluctant to spend the time trying to find one.

There were several anecdotes about parents being rejected by hospital staff. An example was of a very senile mother in her nineties who had slipped and fallen in the house. A hospital X-ray showed that no bone damage had been done. However, the daughter was very worried because her mother appeared to be hardly able to walk and asked that she be kept in the hospital overnight for observation. She reported that a member of the staff accused her of trying to 'dump' her mother on the hospital, saying, 'We are used to people like you. You will just disappear and never come back for your mother'.

In another instance a father had been admitted to a geriatric hospital for a fortnight to enable the daughter to have a holiday. She recalled that, after a week, the hospital contacted her to take her father home. He had developed pneumonia and the ward sister argued that it was the daughter's responsibility to look after him if he became ill.

In Chapter three it was suggested that a possible reason why mothers living with sons were more active domestically and had fewer personal care disabilities than those living with daughters was

that mothers with really severe impairments were more likely to be admitted to some form of institutional care if living with sons than if living with daughters. It was argued that because of the high significance attached to male employment both the son and the mother would be reluctant for a job to be given up if full-time attention became necessary. Equally an institutional place would be more likely to be offered if a son rather than a daughter were providing care. If this hypothesis is correct then a son is likely to have rather more choice than a daughter about continuing to look after an infirm parent.

The following chapter discusses the support the carers received from neighbours, friends and volunteers.

CHAPTER 7 NEIGHBOURS, FRIENDS AND VOLUNTEERS

There are inherent problems in distinguishing between the four potential support networks in the community; kin, neighbour, friend and volunteer. Kinship has the two bases of blood and marriage, although there is some ambiguity in 'step' and adoptive relationships. Neighbours are usually defined as people living in a neighbourhood, which could be either a small, or a relatively large, geographical area. Kinsfolk may also live in the neighbourhood and could thus equally well be described as neighbours. Summarising a wide range of sociological literature on working class life, Klein pointed out that 'kin living in the neighbourhood rather than unrelated neighbours are mainly responsible for what is loosely called 'neighbourliness'.⁽¹⁾

The concept of a friend is problematic because there is a class difference in the use of the word. In a study of friendship and kinship, Allan argued that both the working and middle classes have significant non-kin sociable relationships.⁽²⁾ Working class people are more likely to restrict these relationships to given contexts and settings such as the work place and would not usually describe them as friendships. However, middle class people are more likely to have non-kin sociable relationships which are not seen as specific to one particular setting or activity and are described as

friendships. Middle class people, therefore, tend to report having more friends than those in the working class. A further confusion also arises because a neighbour may be considered a friend.

The term volunteer similarly defies a simple definition. A volunteer may work for a statutory organisation such as a social services department or for some kind of voluntary organisation. In certain circumstances a volunteer may receive expenses or payment. But, as Leat pointed out, in a discussion of the problems of defining voluntary involvement, payment would lead many people not to define the work as voluntary.⁽³⁾ A neighbour may become a volunteer; a relevant example being a 'Good Neighbour' scheme in which a person is paid a modest sum by a social services department to 'keep an eye' on specific frail elderly people in the neighbourhood.⁽⁴⁾ A volunteer may also come to be regarded as a friend.

For the purposes of this study, the respondent's own definition of relationships was accepted. Although a theoretical confusion exists between neighbours and kin, in practice this was not the case in this study. This may be because secondary kin like aunts or cousins are more likely to exist in traditional communities than in an area of relatively high geographical mobility like Greater London. In the event too, there were very few instances of volunteer support. This support was mainly in the form of specific tasks for the parent such as providing transport to a club. Such a role was unlikely to lead to a volunteer being described by the carer as a friend.

Neighbour

There is conflicting evidence on the supportive role of neighbours; to quote Klein, 'there is as much evidence that people do not get on with their neighbours as that they do'.⁽⁵⁾ Evidence of

considerable neighbourly support was given in Bayley's 1973 study of a sample of families with a mentally handicapped member living at home.⁽⁶⁾ Three out of four families were helped by neighbours and the conclusion was drawn that neighbours were as helpful as relatives.⁽⁷⁾ In a 1970 study of a fieldwork experiment in social work with the elderly, Goldberg made similar comments,

'the concern and helpfulness of neighbours was very noticeable and it is quite possible that the old people underestimated the help they were receiving from neighbours'.⁽⁸⁾

Other studies have drawn somewhat different conclusions. Townsend's study of old people in Bethnal Green emphasised the lack of involvement;

'About their neighbours old people were usually emphatic. 'We very seldom see anything of them. We keep ourselves to ourselves'.... Nearly two-thirds of the old people claimed they did not go regularly into the home of a neighbour and a neighbour did not visit them'.⁽⁹⁾

And Abrams, summarising research studies of community care, had similar comments to make. Kinship was described as the most reliable basis of care, and second in strength were 'moral communities' associated with churches, races, friendship nets and certain kinds of occupations. However,

'Neighbours, or more broadly local communities, come a very poor third and the relationships within them provide at best a means of mediating larger processes of social care - they are the means of contact and communication rather than care as such'.⁽¹⁰⁾

In the current study of single carers, neighbours were certainly less significant than kin in giving help. Half the women and a third of the men reported having no social contact at all with neighbours. But, when there was contact there was often practical help. In all, half the men and a quarter of the women had regular practical help from one or more neighbours. Altogether one in three

of all the carers were assisted by neighbours. However, half of all the carers with siblings living outside the household reported some form of practical help from one or more of them. A simple numerical comparison is inappropriate because the two networks tended to give different kinds of help. Generally, neighbours shopped and 'kept an eye' on the parent during the carer's absence. That shopping was such a significant neighbourly function helps to explain why the men in the study were more likely to receive help from this source than the women. Shopping seems to be regarded as pre-eminently a female responsibility. Hunt's government survey of women's employment reported that few husbands of working wives did any shopping.⁽¹¹⁾ Hence women in the neighbourhood would be far more likely to offer to do shopping for a male than a female carer.

'Keeping an eye' on the parent usually involved calling briefly at the house rather than staying for any length of time. Neighbourly support rarely involved actual physical care of the parent. Such support seemed far less likely if the parent were senile in behavior. In some respects their role was similar to that reported by Townsend and Abrams. Calling briefly at the house was to check that the parent had not fallen or been taken ill. If such a thing had happened then the neighbour would contact the carer. Cartwright et al's 1973 study of the care of a sample of people in the year before death made a similar point about the kind of support given by neighbours; 'friends and neighbours generally gave less intimate types of care'.⁽¹²⁾

Shopping and 'keeping an eye' on the parent may not appear to be major supportive acts, but they could be very important to the carer. The working carer often seemed to worry incessantly about the parent when away from home and a watchful neighbour could remove some

of the anxiety. For the carer permanently at home, being able to go out for the evening occasionally or being able to rely on somebody else to buy a loaf of bread could prevent the situation from becoming intolerable.

Many of the parents could no longer prepare food or drink for themselves and either needed help to use a commode or toilet or were incontinent. Siblings or their spouses were far more likely to be called on to do these tasks in the carer's absence than were neighbours. If there were no available siblings, the carer might find it virtually impossible to be away from the house for any length of time because neighbours were either unavailable or because it was considered inappropriate to ask this kind of help from them. In the few exceptions where it was done, the neighbour was paid for her services either in money or in kind. A daughter in her sixties and an only child, described the following arrangement;

'The only time I get away from my mother is when I go shopping in the morning. I am away about an hour and a half altogether. My next door neighbour is very good and she comes in. She has to help mother on and off the commode, of course. I use the attendance allowance to pay her'.

In another case of a highly dependent mother, two single women were able to reciprocate caring arrangements;

'I usually get out one evening a week to an art class. I really enjoy it. It's my one bit of relaxation. The woman in the flat next door is in the same situation as me. She usually brings her mother in and they both sit with mum. I do the same for her when she wants to go out'.

As far as this study is concerned, Abrams' contention that neighbours are a poor third in providing care was not substantiated. Although giving practical support to fewer carers than did kinsfolk, they gave far more help than any 'moral communities' associated with churches, races, friendship nets or certain kinds of occupation.⁽¹³⁾

Unlike kin, they were rarely involved in actual physical care of a parent, nevertheless the support given contributed to the tolerability of the carer's life. However, because they were rarely involved in actual physical care of the parent or in 'keeping an eye' on parents who were senile in behaviour, neighbours were less likely to be supportive to carers with highly dependent parents.

The factors affecting the volume and kind of support from neighbours are far from fully understood. On the basis of the findings in the current study, it seems likely that one factor is the extent of the dependency involved in a caring situation. Another factor is likely to be the type of dependency involved. For example, handicapped children or young adults may evoke more sympathy from neighbours than the aged infirm. Bayley's finding that three out of four families with a mentally handicapped member in his sample had help from neighbours tends to support this point.⁽¹⁴⁾

The notion of reciprocity is frequently implicit or explicit in discussions about relationships with neighbours. For example, Jaenhig, in an unpublished thesis examining the experience of a sample of families with a mentally handicapped child, commented,

'about 60% of the families were participating in informal neighbourhood exchanges, paying the milkman for absent neighbours, picking up their children from school or running errands to the shops for elderly people'.⁽¹⁵⁾

It is likely that a single carer would be disadvantaged compared with a family of several members in entering into reciprocal relationships with neighbours. The larger family would be more likely to have both a wider variety of ways in which to repay services and more time available to make that repayment. In contrast a single carer would be limited both in the method of reciprocation and in having less time available. Neighbours may well be wary of offering help when the

caring burden is taken by one person because the need for support is so great. An offer of help in one sphere might well reveal needs in other spheres which the neighbour would be unable or unwilling to meet. In other words, a factor in hesitating to offer even limited help would be a fear of demands escalating. As Abrams pointed out, a closer understanding of the nature of reciprocity and the conditions governing it remains a highly important research task.⁽¹⁶⁾

The number of married women in the neighbourhood employed outside the home is highly likely to affect the probability of support from neighbours. Certainly in the present study of single carers, a common response to questions about help from neighbours was, 'Oh no, all the women round here are out at work'. A significant social change which has taken place in the past thirty years has been the increased economic activity of married women. A measure of this change is that, in 1951, 21.7% of all married women were employed; by 1979 this had increased to 49.6%.⁽¹⁷⁾ Although a considerable proportion of these women would be in part-time employment, this being the situation for approximately 40%, such a major change is likely to diminish the support available from women in the neighbourhood.⁽¹⁸⁾

A factor affecting neighbourliness suggested in some studies is the density of housing. Isaacs et al's 1972 study of a sample of patients admitted to geriatric hospitals in Glasgow, found that, 'of the patients who lived in old tenement houses with outside toilets, twice as many were helped by neighbours as was the case with patients in more modern houses'.⁽¹⁹⁾ A very similar point emerged in Rosow's 1967 study of the social integration of the elderly in an American city.⁽²⁰⁾ Care by neighbours in time of illness occurred with impressive consistency in dense housing areas, but scarcely at all in others.⁽²¹⁾

Marked regional differences in neighbourliness are apparent. Greater London, the locality of this study, is apparently relatively low in neighbourliness. Respondents in the 1978 government survey of the elderly living at home were asked whether they received calls from, or made calls on, neighbours. At one end of the spectrum, 56.6% of the elderly living in Greater London neither made nor received such calls. But, at the other end of the spectrum, only 27.9% of the elderly living in Yorkshire and Humberside region or half the Greater London proportion were in this situation.⁽²²⁾ Elements in these regional differences may well be related to geographical mobility; however, there do appear to be particular traditions of neighbourliness in some parts of the country which do not exist in others.

Friends

In comparison with kin or neighbours friends gave practical support to very few carers, assisting just one in ten of them. However, this practical support could be quite substantial. One carer was only able to continue working because a friend, who had retired, travelled a considerable distance each lunch time to feed her mother. Meals on Wheels had become inappropriate when the mother became too infirm to cope with feeding herself. Another example was of a friend who did all the shopping and sat with a chairbound mother for a couple of hours each afternoon.

The lack of practical support from friends has also been demonstrated in other studies. For example, Firth et al, in the study of middle class families in North London, found that friends were rarely asked for practical assistance because 'the friendship bond is looked upon as too frail to bear much tension and negative effect'.⁽²³⁾ In the 1978 government survey of the elderly, Hunt

reported slight help from friends. Only 8.3% of the respondents reported help from friends compared with 41.5% reporting help from relatives.⁽²⁴⁾ Similarly, Townsend in the study of the family life of old people in Bethnal Green, commented that only 5% of his sample received major help from non-relatives, this term including both friends and neighbours.⁽²⁵⁾

As was discussed in Chapter 4, friendship could be particularly significant for a single person lacking the additional social relationships created by marriage and having children. Sometimes a carer successfully maintained relationships with several friends. But this seemed to be rare. Those people who had friends were more likely to have just one who was met at infrequent intervals. For instance, one woman commented,

'I meet my friend about three times a year. Public transport would take too long, so I use the attendance allowance to hire a taxi. I just spend a couple of hours with her and that's it, home to mother'.

A substantial number of the men and women in the study described themselves as having no friends at all. As discussed at the beginning of the chapter, this may be partly due to a working class reluctance to use the word 'friend' to describe a non-kin sociable relationship. Often the lack of friends was ascribed to parental dependency. Carers who were working frequently found it difficult to go out socially in the evening or at the weekend. And those who had stopped work often found going out even more difficult because the parent, used to the carer's presence during the day, became even more dependent. As one man, who had recently retired, said,

'When I was working I used to get out to the old time dancing every week. I really enjoyed it. I could have a drink and a laugh and there were several people I got to know quite well. But my mother doesn't let me go any more. She kicked up and said she wasn't going to be left alone in the house'.

Volunteers

Volunteers appeared to be the least substantial source of help. There were just three instances of long term voluntary help. In one case a carer had advertised in a church magazine for somebody to sit with her mother for one evening each week so that she could attend an evening class. Social workers had arranged for volunteers in the other two caring situations. In both cases, several volunteers were involved and appeared to make a substantial difference to the lives of the carer and parent. One of the mothers was blind and had become very frustrated at being alone in the house during the day while her daughter was at work. Volunteers with cars taking her out to a club twice a week had greatly relieved the situation. In addition, a voluntary organisation had arranged for her to go out to tea at different volunteers' houses on Sunday afternoons. The other mother, who was confined to a wheelchair, was taken out by two school-girl volunteers each week. As the daughter was too physically disabled herself to push the wheelchair, this provided the mother with her only outing of the week. In addition, a Round Table volunteer took care of the garden with which the daughter had become too disabled to cope. A discussion of the potential role of volunteers appears in Chapter nine.

Substitution

The question to which we now turn is the extent to which neighbours or friends substitute for kin in giving support. The evidence in other studies is conflicting and confusing. Several have found no evidence of substitution. For instance, from a 1967 study of old people in an American city, Rosow drew the conclusion that,

'there is no general principle of compensatory association whereby parents see friends specifically to counteract any limited contact with children... Nor does neighbouring increase among those parents of non-local children who are the least accessible'.(26)

Similarly, Hadley et al found no data to support such a theory in a 1975 study of volunteers and the elderly;

'Family relationships, other friendships, and indeed contacts with the social services all appeared to be unrelated'.(27)

But other studies have found some evidence of substitution.

In a 1957 study of the family life of old people, Townsend commented,

'People without relatives intensified other associations. They exchanged visits more often with neighbours and friends and partly through mutual services, found a means of satisfying personal or social needs'.(28)

But he did add that the evidence was not decisive.

In a 1969 article on primary group structures and functions, Litwak and Szelenyi put forward a more complex theory of substitution.⁽²⁹⁾ Using comparative data from Detroit and two cities in Hungary, they argued that kin and neighbours had different functions. Crucial factors influencing these functions included the immediacy of the task and the geographical distance of kin from the nuclear family. Neighbours were more likely to be viewed as helpful in emergencies but kin were more likely to be called on for long term help.⁽³⁰⁾ No basic difference was hypothesised in the kind of task undertaken by neighbours and kin. But the difference lay in the speed at which help could be given. Neighbours tended to substitute for kin who did not usually live nearby, in giving immediate help.

The findings in the current study of single carers indicated that neighbours and kin had different functions. But, the difference appeared to lie in the nature of the task rather than in the speed at which it had to be performed. Kin could be called on to

substitute for the carer in performing personal care tasks for the parent. But, neighbours were rarely involved in such tasks, tending to give support by doing shopping or by 'keeping an eye' on the parent in calling briefly at the house during the carer's absence. In general, there was no evidence in the study to support a theory of neighbours or friends substituting for kin in performing personal care tasks for the parent. Consequently, those carers with highly dependent parents, who lacked supportive kin, were in an extremely difficult situation.

CHAPTER 8 THE DISTRICT NURSE AND GENERAL PRACTITIONER

This chapter discusses the support the carers obtained from district nurses and general practitioners. The first section looks at the respondents' views of the district nursing service and examines the part it played in family support. The second section discusses the general practitioner's role in relation to the social policy of community care for the infirm elderly. Thirdly, as the payment of the attendance allowance is dependent on the fulfilment of certain medical criteria, the primary health care team's role in the referral process is considered here.

The district nurse

Since its inception in the late 19th century, the district nursing service has been involved in the home care of the elderly. Approximately half their caseload in 1980 was of people aged 65 and over.⁽¹⁾ Contact with the service becomes far more likely with advancing age. Hunt's 1978 government survey of the elderly living at home found that, whereas, 7.8% of all the elderly had been visited by a district nurse in the past six months, the figure rose to 19.6% for those aged 85 and over.⁽²⁾ Among the bedfast and housebound elderly, 36.8% had received a visit.⁽³⁾

A district nurse was in contact with every household in the study. Over half the parents were visited weekly or fortnightly by a nursing auxiliary to be assisted in taking a bath. This nursing auxiliary was supervised by a district nurse who made the initial assessment for nursing need and remained ultimately responsible for the patient. In these circumstances, direct contact between the district nurse and the parent or carer was very limited. At the other extreme, a minority of the parents, about one in six, were visited at least once during the day by a district nurse. When this occurred the parent was either bedfast or needed a nurse's help to get out of bed, washed and dressed. A similar proportion of the parents were being visited temporarily by a district nurse for either post-operative dressings or for dressings to be put on leg ulcers. The remaining few parents were visited by a district nurse monthly or less often, usually for an injection to be given. The actual nursing care could contribute much to the continued viability of care in the community, particularly when given on a daily basis. For example, one woman only felt able to continue working because of the district nurse's help with her mother;

'I have to leave the house at 6.30 in the morning to travel across London to my job. It's too early to get my mother up before I go and my father can't manage to get her downstairs with his bad knee. I would have to give my job up if the district nurse did not come in every morning about nine o'clock to dress her and get her downstairs'.

Others, who were not working, found that daily nursing assistance made a very difficult situation more tolerable. A carer in her seventies said,

'The district nurses are wonderful. Two of them come in twice a day. Between them they can lift mother which I can't. She just lies there and does everything in the bed. They can get her out to the commode and change the bedding. I depend on them totally. I don't know what

would happen if they did not come in. I am not unusual in looking after my own folk but this has gone beyond what is reasonable. Mother has been in bed now for five years'.

A son would have found washing his mother each day embarrassing.

'Mother wets the bed. She just can't cope with things any more. It's a big help that the district nurse comes in first thing to wash mother and change the bed'.

On the whole, however frequently the parents were visited, the carers appeared to be very satisfied with the district nursing service, views which echoed those found in Blaxter's study of the career of disabled patients following discharge from hospital.⁽⁴⁾ Those of her respondents visited by a district nurse assessed the service as excellent.⁽⁵⁾

At the time of this study, a district nurse was regarded officially as having a far wider responsibility than just home nursing. The Report of the Royal Commission on the National Health Service in 1979, quoted a description of the role of nurses in primary health care given by the Chief Nursing Officer at the D.H.S.S.:

'The District Nurse is a SRN who has received post basic training in order to enable her to give skilled nursing care to all persons living in the community including in residential homes.....It is the District Nurse who is professionally accountable for assessing and re-assessing the needs of the patient and family, and for monitoring the quality of care. It is her responsibility to ensure that help, including financial and social, is made available as appropriate.....'(6)

In many instances in this study, however, the district nurse simply did not have the kind of contact with the supporting family which would have enabled her to make such an assessment of needs. For example, none of the working carers reported having met the district nurse responsible for visiting their parent or having discussed any caring problems with her.

As the district nurses themselves were not interviewed, it is difficult to assess the extent to which they were involved in ensuring appropriate support for the carer and the parent. The carers were sometimes very vague about how contact had been established with various welfare services. Indeed, they were being asked to recall an event which may well have taken place several years earlier. In any case, a referral for a service by a district nurse or general practitioner could easily have taken place without the carer being aware of it. Therefore, the respondents' reports of sources of referral must be treated with some caution.

Questions were asked about referrals for Meals on Wheels, home help, social worker visits, and aids and house adaptations for the physically disabled. The main referral pathway between the health and the local authority social services was undoubtedly through the hospital rather than through the primary health care services. In part, this reflects the high rate of hospitalisation among the parents in the study, two out of three of whom had been treated in hospital at least once in the previous five years. The hospital staff appeared to have made referrals to several support services, including the district nursing service, as the parent was being discharged. This clearly somewhat curtailed the district nurse's own role as a referral agent.

As table 10 shows, neither the district nurse nor the general practitioner were reported as making significant referrals for Meals on Wheels or home help. But, a district nurse was reported to be more likely than a general practitioner to make referrals to a social worker. Such a referral appeared to be generally for an assessment of a suitable aid or house adaptation for the physically disabled.

As Table 11 shows, the hospital was reported as a far more significant source of referral.

Table 10 Reported source of referral for Meals on Wheels
and home help

<u>Source of referral</u>	<u>Meals on Wheels</u>	<u>Home help</u>
	<u>No.</u>	<u>No.</u>
Self	<u>3</u>	<u>2</u>
District nurse	2	0
General practitioner	0	1
Social worker	0	2
Hospital	4	6
Other	<u>1</u>	<u>3</u>
	<u>10</u>	<u>15</u>

Table 11 Reported source of referral to a social worker

<u>Source of referral</u>	<u>No.</u>
Self	6
District nurse	6
General practitioner	0
Hospital	<u>16</u>
	<u>28</u>

However, there is evidence in other studies that district nurses tend to adopt a broader role than simply giving nursing care. In a 1973 national survey of the lives and care of a sample of people in the year before death, Cartwright et al commented,

'On the whole, district nurses seemed better informed about various services and made more use of them than general practitioners'.(7)

Blaxter, in a 1976 study of the career of a sample of disabled patients discharged from hospital, described the experience of thirty seven people in the sample visited by a district nurse;

'Many of them were in fact receiving services which might have been defined as social rather than medical, and beyond a nurse's function....Yet..of the thirty-seven people who had assistance from nurses, at least a third - and these the most demanding in time - were receiving help that had little to do with medical treatment. The nurse was going on errands, contacting agencies on the patient's behalf, bathing or washing the patient or giving other sorts of personal care'.(8)

The general practitioner

In the switch in emphasis that has taken place from treatment of the elderly infirm in hospital to care in the community, a general practitioner has a crucial role to play. A prime responsibility is to diagnose ill health. In the words of the definition given by the Royal College of General Practitioners to the Royal Commission on the National Health Service;

'His aim is to make early diagnoses. He will include and integrate physical, psychological and social factors in his consideration about health and illness. This will be expressed in the care of his patients. He will make an initial decision about every problem which is presented to him as a doctor. He will undertake the continuing management of his patients with chronic, recurrent or terminal illnesses'.(9)

Nevertheless, the wide extent of unmet medical needs amongst the elderly population has been well documented. At the level of minor disabilities, medical examinations, carried out as a part of Goldberg's study of a social work field experiment in helping the aged, revealed that many respondents suffered from such minor miseries as wax in the ear, out of date spectacles or foot troubles.⁽¹⁵⁾ A conclusion of the study was that, 'the identification of minor physical disabilities and discomforts and ensuring that they receive attention emerged as an important caring function'.⁽¹¹⁾

Evidence of more serious undetected medical conditions have emerged in other studies. Williamson et al's 1964 survey has been widely quoted.⁽¹²⁾ Psychiatric and physical examinations were carried out by a research team of doctors on a sample of elderly patients taken from doctors' lists in three practices. A large number of disabilities described as slight or moderately severe, but unknown to the general practitioner, were found among the respondents. Indeed, there were far more disabilities unknown to the general practitioner than known. Moreover, as the authors pointed out, the standard of care in all three practices was likely to be above, rather than below, the average given by general practitioners throughout the rest of the country. Arguing that the disabilities were mostly amenable to curative measures, they commented, 'preventive medicine is at least as important in old age as it is earlier in life, and there are few conditions in old people which medical and social measures, applied soon enough, will not help'.⁽¹³⁾

In 1970, Lowther et al took the argument a stage further by demonstrating the effectiveness of early preventive treatment.⁽¹⁴⁾ Three hundred 'high risk' elderly patients, drawn from several doctors' lists, were invited to attend an early diagnostic clinic. 'High risk' was defined as living alone, recently bereaved or recently discharged from hospital. Two thirds of the elderly patients were found to have major morbid conditions usually resulting in functional impairment. Treatment was given. At the follow-up, between 18 and 30 months later, there was clear evidence of improvement in half the patients who had carried out the clinic's recommended treatment. Altogether 23% of the elderly patients selected for the clinic could be said to have benefitted from early diagnosis.⁽¹⁵⁾

One major contributory factor to the unmet medical needs of old people is a reluctance to seek medical advice. Cartwright, in a 1967 study, 'Patients and their doctors', which was based on a national sample of patients, drew attention to this phenomenon;

'For one reason and another many old people were suffering from chronic conditions, which might have been alleviated by treatment but for which they had not sought any advice'.
(16)

In the 1973 national retrospective study of the lives and care of a sample of adults in the year before death, Cartwright et al made a very similar comment:

'one of the most disconcerting findings was the high proportion of symptoms for which apparently no one had been consulted. Over half of those suffering from an unpleasant smell and of those with a loss of bladder control, but not bowel control, were said not to have sought help from any professional person about it. Most of the people with these symptoms had seen their general practitioner since the symptom developed, but apparently had not asked him about it'.(17)

As Brocklehurst pointed out, one critical factor in this type of behaviour is that the old tend to attribute symptoms of pain, lethargy, dysuria and many others, not to illness, but to the fact that they are getting old.⁽¹⁸⁾ In other words symptoms are perceived as an inevitable accompaniment of old age rather than as remediable. Younger people tend to make the same pessimistic evaluation of ill health in the elderly. It was not unusual in the present study for the carer to deny that the parent was disabled rather than 'just old'. One of the women commented,

'I've looked after father for twenty years since mother died. There is really nothing wrong with him, he is just old. He is 87 now and, when he complains, I have to say to him, 'Well, at your age what do you expect. You are very fit for your age'. He has been epileptic for several years. The fits are not so bad now because he has tablets for them, but he does fall over quite a lot. In the last couple of years, he has managed to break an arm, a collar bone and his wrist. He does have arthritis and his hands are too twisted up to make himself a drink or anything like

that. He has angina too. I have to take him up to the hospital for his ulcers on the ankle. They have been there for months. His sight is not very good now because of cataracts. I've never registered him as disabled with the local authority because you would not really classify him as disabled. He has no real disability'.

In a 1969 study designed to investigate the feasibility of an enquiry to establish how many individuals in the population at any given time have motor impairments, Jefferys et al reported the same phenomenon.⁽¹⁹⁾ In reply to a postal screening enquiry aimed at identifying the impaired, 335 householders, randomly approached, indicated that there was no one living with them who had motor difficulties. When a random sample of these households was visited, about 10% were found to contain an impaired person. Negative answers had been given because the people concerned were aged 75 and over and their difficulties were attributed to the 'natural' limitations of old age rather than to physical impairment.⁽²⁰⁾

A further critical factor in old people failing to seek medical advice is the problem of access to the doctor. A research paper on access to primary care, produced in 1979 for the Royal Commission on the National Health Service, concluded that a proportion of old people stayed away from the surgery because of the physical effort involved in the journey. Aware of the pressure on doctors, they were reluctant to ask for a home visit. Minor disabilities were therefore tolerated and the doctor was contacted only for something serious and immediate.⁽²¹⁾

The reported frequency of general practitioner visits in the present study and the carers' reports of the support they had experienced needs to be seen in the context of this evidence about unmet medical needs in the elderly population. A separate medical assessment of the parent was not carried out for the study. About one in

six parents were visited regularly by the general practitioner at least as frequently as once every three months. There are no strictly comparable national figures. Hunt's 1978 government study of the elderly at home shows that 16.3% of those aged 85 or more were visited regularly by a doctor at least once a month.⁽²²⁾ However, the regional variation was considerable with far less regular visiting in Greater London than elsewhere, only 4.6% of the elderly being regularly visited at least once a month compared to a national average of 9%.⁽²³⁾ Such a regular visit was generally much appreciated by the carer and regarded as highly supportive. As one woman, whose mother was in her nineties and deaf, blind and severely crippled by arthritis, commented,

'The doctor comes to see mother every fortnight. He really does try to help me in looking after her. At the moment the problem is that she gets me up every night because she wants to wee. There has never been this problem before and I find it really terrible because it takes ages to get her onto the commode and back into bed again. It's really wearing me out and it's often twice a night. The doctor has suggested getting a special sort of sheet which she could just wee into and then I would have to wash it out in the morning. I haven't actually got one yet because it would mean so much extra washing. But, at least, the doctor takes an interest and has suggested a way of coping with it'.

Five out of every six informants said that the doctor would visit the parent at home when requested by the carer. This included all the cases in which the doctor made regular home visits. But, one in six carers reported that the doctor declined to make home visits in any circumstances. If the parent could not be taken to the surgery, which most could not, communication had to be by the carer telephoning, or calling at, the surgery to describe the parent's symptoms. This situation was usually resented. Miss Hargreaves was particularly bitter,

'I don't know how to look after mother really. She has diabetes and heart trouble and her colitis can be really bad. The diabetes has damaged her eyesight as well. Once, when I was washing her feet half her toe dropped off and they said that was something to do with the diabetes. She has these really bad turns and I stay off work for her but the doctor won't come round to the house and I can't get her round to the surgery. Mum has been rushed off to hospital in a coma now several times. You just do not get enough support from the medical profession. A couple of weeks ago, I went to see the doctor about mother and asked him to come round as she was so bad. After I left the surgery, the doctor rang the flat and mother managed to answer the phone. He just told her to spend the morning sitting on a chair until she felt better. I have now asked him to call several times and he has always refused'.

But some carers were philosophical about the lack of home visits. For example, a man looking after his mother who was in her late eighties and completely chairbound, commented,

'The doctor hasn't come round here now for five years. He would not even come round when she was discharged from hospital three years ago. That was a bad time, she had awful burns from falling against the fire when I was out of the house. Then, she broke her hip in hospital. It would be nice if he would visit like the old doctor used to. But I suppose you can't expect it nowadays. Anyway, he says there is nothing he can do for her any more. He won't come to see her but he does ask after her if he sees me up at the surgery collecting the prescriptions. She just has repeat prescriptions for pain-killers and things for her bowels'.

Two out of three carers described the parent's general practitioner as very helpful or helpful and one in three as unhelpful. The comments made suggested that one of the main criteria was the willingness of the general practitioner to make a home visit. Cartwright and Anderson, in a 1981 study of patients and their doctors, made a similar comment that the number of home visits patients had received in the last year was clearly related to their satisfaction with their care.⁽²⁴⁾ Typical comments made by carers in the present study who found the doctor supportive were,

'The doctor always insists on visiting if anything is wrong with father. I often offer to take my father down to the surgery in my car but the doctor will never hear of it'.

'The doctor is very good. He calls every three months and sometimes arranges for mother to go up to the hospital for day treatment'.

'Yes, the doctor has been very helpful. There has never been any problem in getting him it'.

'The doctor has never let us down. He comes when asked'.

Some of the carers who were critical resented the length of time it had taken the doctor to make a home visit. One man, himself retired and looking after a mother in her late nineties, said apologetically,

'I should not really say this but he is not really interested in old people. He is mainly interested in children. I've rung him up a couple of times to ask him to call round to see mother. But he has never rushed, he has always come round a couple of days later'.

Another man commented,

'On the whole we have not had any major support from doctor. She comes a couple of days after being called'.

Others resented a lack of visits for several years. One man coping with a senile, incontinent 92 year old mother felt let down;

'The doctor never visits and I really think it is the least he could do. Mother has been stuck at home now for eight years and I can't get her to the surgery. Last year she had a stroke and I telephoned the doctor, he still would not come round but he sent an ambulance. When she came out of hospital he would not come round either'.

It would be a gross over-simplification to attribute the frequent lack of direct contact between the general practitioner and the parent solely to the former's disinterestedness in the infirm elderly. However, just one indicator of British doctors' low estimation of work with the elderly is the high percentage of posts in geriatric medicine filled by overseas born doctors. At the time of the study, geriatric medicine had a higher percentage of posts at all levels filled by these doctors than any other specialty.⁽²⁵⁾

Like district nurses, general practitioners are frequently identified as potentially important referral agents for local authority and other support services. In the words of the 1981 paper, 'Growing Older',

'The family doctor is normally a person's first point of contact with the health service, and he may well be the first person through whom an approach is made to the social services. The role of the family doctor is therefore of crucial and increasing importance if more elderly people are to be enabled to live in their own homes....Much will depend on early diagnosis and rapid contact with the relevant community care services'.(26)

There was little evidence in this study, however, of approaches being made to the social services. The general practitioner seemed less likely to contact the local authority welfare services than did the district nurse. As Tables 10 and 11 show, only one referral for Meals on Wheels was reported and none for a home help or a visit from a social worker. Although the carers may not have always been aware whether such a referral had been made, the evidence from numerous studies in the past twenty years does confirm a frequent general practitioner reluctance to be involved in contacting the social services. From a 1965 study of the health and social services in Buckinghamshire, based on data collected in the early 1960s, Jefferys commented,

'Doctors did not seek help from the domiciliary social welfare services in dealing with social difficulties, sometimes because they were aware of the shortage of facilities, sometimes because they were not fully aware of the available services, and sometimes because they doubted the competence of the available staff'.(27)

A similar conclusion was drawn by Harwin, Cooper, Eastwood and Goldberg in 1970 from an interview survey of all family doctors in National Health Service practice in one London borough:

'Most doctors had no views on the local social services because their acquaintance with them was so scanty'.(28)

In a 1976 study of the career of a sample of nearly 200 disabled patients following discharge from hospital, Blaxter identified a range of attitudes and practices doctors displayed in connection with patients' social problems;

'At one extreme...they saw themselves as counsellors, concerned with both psych-social needs and the practical problems of daily life...Other doctors, however, deliberately restricted themselves to service 'on demand' for strictly medical attention, and believed that it was not their function, nor within their competence, to assess mental, social or financial stresses within a family. The majority of doctors, however, appeared to occupy an uneasy middle position. On the one hand they recognised how often social problems lay behind the medical problems presented to them, and they were willing and anxious to offer personal support. On the other hand, they did not see themselves as part of a larger network of services'. (29)

That the majority in Blaxter's study did not see themselves as part of a larger network of services, was illustrated by the fact that for the whole sample only two patients were referred to a social worker by their general practitioner. (30)

The attendance allowance

Introduced in 1971, the attendance allowance is a highly relevant social security benefit for the infirm aged living in the community. (31) Both the general practitioner and the district nurse, given their involvement with the infirm aged and their supporters are in a unique position to draw attention to this allowance.

A person may qualify for a full attendance allowance if a mental or physical disability is so severe that,

- a) frequent attention is needed throughout the day with bodily functions and prolonged or repeated attention is needed at night; or
- b) continual supervision is needed to avoid substantial danger to self or others.

The condition must have existed for six months or more. In 1972, the qualifying conditions were modified so that a part allowance was

payable if either the day or the night condition was satisfied.⁽³²⁾

The medical criteria are far from straightforward because phrases such as 'frequent attention', 'bodily function', 'continual supervision', 'substantial danger' and 'prolonged or repeated attention', are open to various interpretations.

The short history of the attendance allowance has been one of constant legal wrangling between the Secretary of State for Social Services and the National Insurance Commissioner. The Commissioner's interpretation of the legislation has been challenged several times in the courts by the Secretary of State. For instance, an early legal debate was on the meaning of 'night'. The time when night began and ended was at issue. A person needing attention by day and night is entitled to a full attendance allowance. But if the attention is only needed during the day the entitlement is just to a part allowance. In a 1974 judgement allowing an application by the Secretary of State for Social Services for an order of certiorari to quash a decision by a National Insurance Commissioner that undressing a paraplegic before he went to bed was a service rendered at night, the Lord Chief Justice recommended that Attendance Allowance Boards should reject the 'between sunset and sunrise' ordinary meaning of 'night' and look at 'night' as being that period of principal inactivity through which a household went in the dark hours. The beginning of night should be measured from the time at which the household closed down for the night.⁽³³⁾

Another instance of a legal debate occurred in 1981 over the meaning of 'attention needed....with bodily functions'. The Court of Appeal allowed an appeal by the Secretary of State for Social Services against a dismissal by a lower court of an application to quash a decision by a National Insurance Commissioner who had held

that cooking was 'an attention in connection with the bodily function of eating'.⁽³⁴⁾ The Commissioner had set aside a decision of an Attendance Allowance Board which had rejected a claim for an allowance based on an elderly person's inability to cope with cooking.

In addition to the continuous legal debate on eligibility for the allowance, a regional variation between the practices of the different Attendance Allowance Boards is also highly likely. In the first year of the allowance being paid, the government acknowledged that these Boards had varying standards.⁽³⁵⁾ That a substantial proportion of the appeals against refusals of the allowance by the Attendance Allowance Boards are successful each year suggests that this is still the case. In 1977, for example, two thirds of the appeals against the Boards' decisions were successful.⁽³⁶⁾

This decade of legal wrangling over the meaning of key words in the legislation, make it highly likely that general practitioners and district nurses are often uncertain about whether individual patients meet the appropriate criteria. Such uncertainty would be likely to make them hesitate about suggesting that a patient apply. In practice some of the parents in the study appeared to meet the attendance allowance requirements but had never applied for it. As Table 12 shows, a third of the parents received the attendance allowance at either the full or the part rate. A further 7% had made an application and were awaiting a decision. A third of the parents did not appear to meet the criteria for an allowance because they did not need assistance at night and could cope with basic self care tasks. But 28% of the parents in the sample did appear to meet the criteria for a full or part attendance allowance and had not applied. In two of these cases, the daughter involved said that the

parent was unwilling to apply considering the current income to be adequate. However, in all the other instances, the carers said that they had never heard of the attendance allowance.

Table 12 Number of parents receiving, or apparently eligible for
a full or part attendance allowance

	<u>No. of</u> <u>parents</u>	<u>% of</u> <u>parents</u>
Receiving full attendance allowance	14	24
Receiving part attendance allowance	5	9
Application made for allowance and decision awaited	4	7
No application made for allowance but parent appeared to be eligible	16	28
No application made for allowance but par- ent did not appear to be eligible	<u>19</u>	<u>33</u>
	<u>58</u>	<u>101*</u>

* The percentages were rounded up

The following two cases are typical of the parents who appeared to meet the criteria. In the first case, Mrs. Ritchie appeared to be eligible for a full allowance. She was 90 years old, blind, deaf and severely arthritic. It took about fifteen minutes for Miss Ritchie to help her mother out of a chair and a few feet across a room. Mrs. Ritchie was unable to use a commode without assistance. She could not prepare food or drink but did manage to feed herself with a spoon if the food were cut up into small pieces. Her daughter had to get up at least three times in the night because the mother needed to be moved to a more comfortable position.

In the second case one of the mothers appeared to meet the criteria for a part allowance. Mrs. Harmer was 75 years old and suffered from arthritis and pernicious anaemia. She had become very mentally confused and dangerous in her behaviour with fires and the cooker. Afraid that she would harm herself, her children and grandchildren organised a rota so that she was never left alone in the house. Continual supervision was needed for Mrs. Harmer to avoid substantial danger to herself.

There was the same lack of knowledge of the invalid care allowance. This is payable to a very restricted category of people who cannot work because of having to remain at home to look after a severely disabled relative receiving an attendance allowance. As married women and people above retirement age are ineligible, single women are the largest single category of recipients.⁽³⁷⁾ Only one woman in the study received the invalid care allowance. Three others below retirement age and unable to work because of looking after parents who received an attendance allowance should have been recipients. However, they were dependent on supplementary benefit and said they had never heard of the invalid care allowance. Although claiming this allowance would not have given them any immediate financial advantage because being less than supplementary benefit it would simply have been deducted from the latter, it would have preserved pension rights by conferring 'home responsibilities protection' on the individuals concerned.⁽³⁸⁾ When the basic pension is worked out, the number of years for which there was 'home responsibilities protection' is deducted from the number of qualifying years needed for a full pension. Knowledge of the invalid care allowance and the pension protection it gave might also have had an impact on the decision of some single carers in the study to continue working.

Table 13 Reported source of referral for an attendance allowance

<u>Source of referral</u>	<u>No.</u>	<u>%</u>
Self	5	20
District nurse	1	4
General practitioner	4	16
Social worker	3	12
Hospital	0	0
Friend	4	16
Relative	2	8
N.C.S.W.D.*	3	12
Other	<u>3</u>	<u>12</u>
	<u>25</u>	<u>100</u>

* National Council for the Single Woman and her Dependants

As Table 13 shows there was only one instance reported of a district nurse giving information about the attendance allowance. Four such initiatives were reported from a general practitioner and none from hospital staff. That so many parents in the study appeared to meet the criteria for an allowance and yet had never applied suggests that the primary health care team could have been far more active in making referrals.

CHAPTER 9 THE PERSONAL SOCIAL SERVICES

The health authority through which the sample was drawn crossed the boundaries of three local authorities. This chapter discusses the support given by the local authority social services departments to the single carers and their parents in the study.

Broadly there are two ways in which a social services department can give support. One is by providing practical support services such as Meals on Wheels or home help and the second is by social work support. The first section of the chapter focuses on the practical services and the second on the reality and the potentiality of social work support.

The Practical Services

Local authorities at the time of the study had both powers and duties to provide a wide range of practical services for the elderly in their own homes. Under the Health Services and Public Health Act of 1968, it was their duty to provide a home help service. The same Act also gave them a power for the first time specifically to promote the welfare of the elderly. Two years later the Chronically Sick and Disabled Persons Act required them if satisfied that there was a need, to provide meals, telephone aids and house adaptations for the disabled. As 60% of impaired people have been estimated to be above retirement age, this act has particular relevance for the elderly population.⁽¹⁾

In terms of simple numerical criteria the post-Seebohm era, that is, 1968 until approximately 1977, was one of unprecedented expansion for practical support services. For example, between 1968 and 1977, the number of meals for the elderly served by local authorities in England more than doubled; and between 1970 and 1977 the home help service expanded from assisting 62.4 to 88.0 per 1,000 elderly population.⁽²⁾

The actual need for these services is clearly hard to gauge. However, it is safe to say that, by the late 1970s, the level of provision in most local authority areas was still well below D.H.S.S. guide lines. The 1976 consultative document on priorities for the health and personal social services demonstrated the gap in provision.⁽³⁾ Although the guide line was 12 full-time equivalent home helps per 1,000 elderly, the actual level was 6.⁽⁴⁾ The meals guide line was 200 per 1,000 elderly but the actual level was 100.⁽⁵⁾ Day centre guide lines were 3-4 per 1,000 elderly compared with an actual level of 2.⁽⁶⁾

The period of expansion for these practical services came to an end by the financial year 1976-77.⁽⁷⁾ The late 1970s and early 1980s have been characterised by public expenditure cuts in the personal social services. The concluding chapter discusses the implications of these cuts for the community care policies for the infirm elderly.

Meals on Wheels

One in four of the parents with a working daughter or son had Meals on Wheels. There was virtually no difference between the use of the service by parents living with daughters and by those living with sons. Rather more parents had used the service in the past.

Meals on Wheels had been discontinued either because they were found to be unpalatable or because the parent was no longer able to cope with them. In some cases, physical problems made it impossible for the parent to re-heat a meal which was delivered long before lunch time. Severe arthritis, or a tendency to fall when bending down could make using an oven an impossibility. Another problem which had occurred for some carers in the past and was currently being experienced by three carers was the parent becoming too senile to cope with a meal after it had been delivered by a meals service. The carers' response to such situations was either to give up working altogether or to make some arrangement to ensure the parent was given a lunch. One woman was enabled to continue working because a retired friend was prepared to travel a considerable distance each day to give a cooked lunch to a mother whose sense of balance had become too disturbed to cope with bending to re-heat a meal in the oven. In another case, a man travelled home each lunch time just to heat up a meal which the service had delivered to his very senile mother;

'Well, she can't cope with it now. I just have time to heat the meal up for her and make us both a drink. I have biscuits with mine and then its back to work fast'.

But, often, the carer worked too far away to get back at lunch time.

One woman solved the problem by involving the home help service:

'Mother is too forgetful now to eat a meal by herself. She takes a spoonful of food and then forgets to put it in her mouth. She has to be reminded each time to eat it. It got so Meals on Wheels were no good because the whole meal was still there when I got home in the evening. I went to see the Home Help organiser and I had to make an awful fuss. But, in the end, they arranged for a home help to come for an hour each lunch time. She spends the time helping Mum to eat the meal which the council has delivered'.

Usually the carers were enthusiastic about the Meals on Wheels service. Not only was a lunch delivered, but the service ensured that

at least one person called at the house during the day to check that the parent had not fallen. Indeed, the person delivering the meal could easily assume considerable social significance for the parent relieving what would otherwise be the loneliness of a day without human contact.

'The lady who delivers the meals never actually comes into the house apparently. She just hands the meal over to Mum at the door. But Mum always comments on who delivered it. She is always pleased when it's this short lady with a nice smile'.

Home Help

Unlike Meals on Wheels, there was a significant difference between households with a son and those with a daughter whether or not support was obtained from the home help service. As discussed in chapter five, home helps assisted 55% of the households with sons and only 22% of the households with daughters. The difference was not so great if households with working carers were compared; although numbers are small 53% of households with a working son had a home help compared with 35% of those with a working daughter. It was suggested in chapter five that a contributory factor to the sex bias was that daughters were less likely than sons to apply for a home help; but it was also true that if they did apply they were more likely than sons to be refused assistance by the home help organiser. Four daughters had been refused a home help at some point in their careers; an experience not shared by any sons.

The amount of assistance given by the home help service varied widely among and within the local authorities. Often, there was no obvious reason why some people received a great deal of help and others relatively little. For example, the one male carer who had given up his job to look after his mother was supported by a home help coming in daily for three hours. The man had some difficulties in coping

with his mother. However, he was given far more support than a woman in the same local authority who, herself severely disabled by multiple sclerosis, looked after a very frail mother and had a home help for only one morning a week.

Several people complained about the inadequacy of the home help service. It was not unusual for a home help to fail to turn up. One carer, herself severely disabled but with a job outside the home, was very upset by the situation;

'I worry because mother is blind and by herself. A home help is supposed to come in twice a week. If only she would come that often. We have whole weeks passing with nobody turning up'.

One of the single men commented,

'Don't mention home helps to me. It's always somebody different coming anyway. Often nobody turns up at all. It's supposed to be once every week but, at the most, it's once a fortnight'.

On the other hand, there was also evidence of consistent reliable support. A man, whose mother had become very senile, said,

'They have been very good to us. A home help comes in twice a week. And on the other days she always calls into the house on her way past to other jobs just to check that mother is all right. It stops me worrying so much at work'.

Another man, also at work, commented,

'The home help makes all the difference to mother. She is stuck in the flat all day and every day. The home help comes round three mornings in the week and apparently she is a very pleasant person who really cheers mother up'.

Over half the respondents being helped by the service would have welcomed an increase in the amount of help given. This echoed the findings of the 1968 government survey of local authority services for the elderly in 13 areas.⁽⁸⁾ A high proportion of the recipients then said they would have liked more time allotted.

Aids and adaptations

Most of the parents in the study used at least one aid for the disabled. The most common one was a commode which had been supplied either by the health authority or by the local authority. In just over half the households some form of adaptation had been made to the accommodation to assist the parent usually by the social services department. A stair rail which was relatively inexpensive, was the most common adaptation. One exception to the pattern of minor adaptations only in this study was a council flat where indoor and outdoor ramps had been built, doorways widened and a bathroom entirely altered for a wheelchair user.

Although there is an obligation under the Chronically Sick and Disabled Persons Act of 1970 on local authorities to provide aids and adaptations 'when they are satisfied that it is necessary in order to meet the needs of a disabled person', these particular forms of help have been a target in the public expenditure cuts in the late 1970s.⁽¹⁰⁾ As Keeble pointed out, in a study of the different policies in respect of the provision of aids and adaptations pursued by the London boroughs, one effect of these cuts has been the adoption of more rigid criteria.⁽¹¹⁾ Whereas in 1974-75, the majority of the boroughs issued a great many aids to people with comparatively minor handicaps, by 1976, aids were often issued only to people strictly defined as 'at risk'.⁽¹²⁾

An example of a relatively expensive adaptation which would have benefitted many carers and parents in the current study was a toilet on the ground floor. About a third of the parents had to use a commode because they were unable to climb the stairs to reach the only toilet in the house situated on the first floor. They had all

made a bedroom out of a room on the ground floor. The use of a commode was unpleasant both for the parent and for the carer who had to empty it. Installing a downstairs toilet would have been one possible solution, but a relatively expensive one, and there were no instances in the study of any of the three local authorities doing this. There were, however, two cases where a toilet had been specially built on the ground floor. One had been paid for out of a daughter's life savings and the other by a brother living abroad.

Incontinence laundry service

As was discussed in chapter three, more than a third of the parents were described by their children as occasionally or frequently incontinent. Although all three local authorities had an incontinence laundry service, it was used by only five carers. A further three carers had also used the service in the past. The reasons given for discontinuing included embarrassment at the thought of neighbours seeing bags of soiled linen collected from the house and dissatisfaction with bedding being lost or spoilt. Most of the carers, then, coped with the problem by using disposable pads, obtained through the district nursing service, and by daily washing.

Short stay places in residential Homes

Short stay places for infirm old people in local authority residential Homes or in geriatric hospitals can give invaluable temporary relief to the supporting family; but, as Davies pointed out, residential Homes continue to be used almost entirely as a long term facility.⁽¹³⁾ Although in 1978, one entrant in two was 'short stay', according to D.H.S.S. statistics, only 2½% of those in care had been admitted on that basis.⁽¹⁴⁾ As discussed in chapter four, all three local authorities and the health authority provided a limited number

of short stay places. Altogether one in four of the parents had used a short stay place in a Home or hospital at least once. In several instances, short term care provided by the statutory authorities would have been inappropriate because relatives were willing and able to look after the parent while the carer had a holiday. In other cases neither the parent nor the carer were unwilling to consider short term care. However, it was not unusual for the carer to appear to be unaware that such facilities existed. It was reported that neither the district nurse, nor the general practitioner, nor the social worker, in the cases where there had been contact with the social services department, had mentioned short stay places.

Day care

Under the Health Services and Public Health Act 1968, local authorities were given the power to provide day care centres for the elderly and those in need of psycho-geriatric care.⁽¹⁵⁾ Between 1975 and 1979 the number of places in local authority day centres run solely for elderly people increased by almost 80%.⁽¹⁶⁾ As D.H.S.S. returns do not include data on the number of hospital units offering day care for elderly people, there are no precise statistics on day hospital places.⁽¹⁷⁾ However, in a 1981 study on community care, the D.H.S.S. suggested that the current provision was about 1 place per 1,000 elderly people; although the departmental guideline was 2 places per 1,000 elderly people.⁽¹⁸⁾

As far as the current study is concerned, very few parents experienced day care of any kind. Only three parents attended a local authority day centre and none went to a day hospital. The day centre appeared to have a significant impact on the lives of both carer and parent. One of the daughters, in her thirties and unable to work because of her mother, commented,

'At least, I do get one day off a week. Mother goes to the day centre and she benefits because she needs a break from the same surroundings and I can go out and get to the library or the hairdressers' or do something away from home'.

Another daughter in her sixties was rather more emphatic;

'I would go mad if it wasn't for the day centre. She goes there three times a week. Really, I just could not have stuck it if she didn't go there....I know she can't help it, but she has just got so irritating since the stroke. She does everything wrong and so slowly'.

The third daughter was only able to continue working because her mother went daily to a psycho-geriatric unit:

'Well, obviously I could not work if mother did not go there. She can't be left alone in the house, she would just set fire to it. She does all sorts of crazy things even when I am in the house. She will get into the kitchen and put an empty saucepan on the cooker and just leave it there. She does like the day centre and tells everybody she works as a secretary there'.

Most of the carers had not heard of day centres or day hospitals even though all three local authorities ran such centres and the health authority provided day places in several hospitals. When the concept of day care was explained, one in four carers wanted it for, and thought it would be acceptable to, the parent. Their lack of knowledge about day care reflected a lack of information from professional sources such as the district nurse, the general practitioner and the social worker. This lack of information from professional workers may partly relate to the dearth of day care places in the study area. Priority tended to be given to the mentally infirm. Thus, one woman, who approached the general practitioner for a day care place for her mother who had become very depressed because of her loneliness while her daughter was at work, was told,

'It's no good you will have to wait until she gets really senile, as well as depressed, before she can have a place'.

However, some day centres only coped with certain kinds of mental infirmity as the following example shows;

'Mother went to the day centre for about two years. I took her in the car before I went to work and they brought her home at the end of the day. It worked very well because father could not cope with her at home any longer. Anyway, that had to come to an end because she didn't always get to the toilet on time. They said they could not cope with toileting problems'.

A lack of available places may not be the only explanation for the small number of parents in the study attending day centres. A research study by Bergmann et al in 1978 indicated that social workers were less likely to refer mentally infirm old people living with children for day care than those living alone or with spouses.⁽¹⁹⁾ A sample of eighty three patients with an organic mental disorder were evaluated on their first admission to a psychiatric day hospital assessment unit, after three months and again at twelve months or at death. Patients living with their children were less likely than those living alone or with spouses to have had social work support or to have been to day centres before admission. As a whole these patients were a particularly vulnerable group and, at the end of twelve months, 70% of them were either dead or permanently in institutional care. The most important factor affecting viability in the community was children's support. Nearly 46% of those living with children remained resident in the community at the end of twelve months.⁽²⁰⁾ Patients living with an elderly spouse were more vulnerable, while those who lived alone were the most vulnerable of all. Bergmann et al argued that the children looking after their elderly demented parents required help and advice from social workers and relief from their stress, especially by the use of day centres. 'Unfortunately this help was not readily forthcoming'.⁽²¹⁾ Because of the more favourable prognosis for patients living with their children, it was argued that social work support and day care facilities should be specifically directed at this group.

Social Work

Questions to members of the general public about social work are often greeted with some confusion. Few respondents have either a clear idea of the function of a social worker or of the potential services offered by a social services department. A National Institute for Social Work Research Unit's comparison of consumer and general public knowledge of the social services concluded;

'There does seem to be a certain amount of confused and blurred knowledge, particularly among the community respondents. Many of them would reach the social services by way of an initial request for help through an intermediary'.⁽²²⁾

The confusion is no less evident even when there is a vested interest, such as disablement, in knowledge of the functioning of social service departments. Blaxter, in a study of the career of patients with a long term disability after they had left hospital, concludes that few 'could distinguish between the 'social security', the social work department and an amorphous body called the 'city' by which they usually meant the housing department'.⁽²³⁾ The confusion is not confined to potential consumers as it evidenced by the 1981 D.H.S.S. initiative in setting up the Barclay Committee to inquire into 'the role and tasks of social workers in local authority social services departments and related voluntary agencies in England and Wales'.⁽²⁴⁾

Not surprisingly, many of the single carers were uncertain whether they had ever had visits from a local authority social worker. Three carers reported seeing a social worker as frequently as once every six months. Seven carers thought a social worker sometimes called to see their parents while they were at work. But, none of them had met the social worker, knew his or her name or how to establish contact. Almost half the carers recalled that there might have been a visit in the past from somebody from a social services depart-

ment. This had usually been in connection with an aid or house adaptation for the disabled. A few people said that they had been visited by a social worker many years earlier. As one woman said,

'Somebody used to come to see us regularly every month.
But all that stopped years ago. I don't know why'.

Approximately a third of the carers though they had never met anybody from a social services department.

The paucity of social workers' contribution towards the care of these infirm elderly parents in the community confirms the finding of other studies. For example, Parsloe and Stevenson's 1978 study of the work of field teams in eight different authorities concluded that the elderly were accorded low priority for social work as distinct from social service provision.⁽²⁵⁾ Similarly, Goldberg et al's 1978 analysis of the fate of a year's referrals to a long term area team found that although referrals of the disabled and/or elderly outnumbered child/family problems by 2 to 1, they made up only 20% of the cases allocated to social workers while child/family problems made up 35%.⁽¹⁶⁾

Furthermore, if an elderly person is visited by somebody from a social services department, it is unlikely to be by a trained social worker. As the 1978 D.H.S.S. consultative document on the elderly, 'A Happier Old Age', pointed out, 'most social work with elderly people is done by assistants or trainees supervised by trained staff'.⁽²⁷⁾ This not only applies to straightforward routine tasks. In the B.A.S.W. discussion document, 'The Social Work Task', social work assistants are described as, 'not being used to perform less complicated tasks in relation to social service clients overall but are being used primarily to perform all tasks in relation to the physically handicapped and elderly'.⁽²⁸⁾

Despite the apparent low priority given to the elderly client group, there is research evidence to show that trained social workers can be very effective in their interventions with this group. Goldberg's 1970 study of approximately a year's field experiment in social work, examining the outcome for a special group of old people assisted by trained caseworkers and a comparison group assisted by untrained local authority social workers, concluded,

'Both groups had significantly fewer practical needs on reassessment, but this was even more apparent among the clients in the special group. The clients in the special group had also improved significantly in their 'morale', more of them were attending clubs, had a holiday, felt satisfied with life, had a positive attitude to the world around them, had fewer worries and personal problems. They were significantly more active and less depressed than the old people in the comparison group'.(29)

The research evidence is that if social work support is offered, it is far more likely to be to the elderly living alone than to those living with relatives. Bergmann et al's findings, quoted earlier, that a sample of elderly demented patients living with their children were far less likely than those living alone or with spouses to have had social work support before admission to day hospital, were corroborated by Hunt's 1978 government survey of the elderly living at home.⁽³⁰⁾ This showed that the elderly living alone were twice as likely as those living with relatives to be visited by social workers.⁽³¹⁾

Two factors in particular have contributed to the low priority given to social work with the elderly in the 1970s. One has been the preoccupation of the social services departments with child and family problems. This has been accentuated by mounting public indignation over non-accidental injury to children and the criticisms made of the social services departments involved in several public inquiries into specific cases of child abuse.⁽³²⁾ The likely response to these

pressures was demonstrated in Hill's 1979 study of resource allocation issues in eight social services departments.⁽³³⁾ By a variety of directives within departments designed to prevent child abuse scandals arising in each authority, the social workers in the area teams studied were left in no doubt that this type of case should have the highest priority.⁽³⁴⁾

The second factor has been the sheer volume of referrals to social services departments. One response to this pressure has been to restrict contact between social worker and the client. Goldberg et al's 1977 study of one year's referrals to an area office demonstrated the brevity of most social worker and client relationships.⁽³⁵⁾ As many as 49% of cases were closed within one week of referral, 64% within a month and 81% by three months. Five months after the end of the study year only 6% of the 2,000 cases referred were still receiving continuous social work help.⁽³⁶⁾ These findings were remarkably similar to those in Hall's study of rationing behaviour in four childrens' departments just prior to the reorganisation of local authority personal social services in 1971.⁽³⁷⁾ In one of the inner London boroughs studied, 81% of 650 new applications received over a six month period were closed within three months of the initial inquiry.⁽³⁸⁾ Only 12% were still considered current cases six months after the original application. Contact between social worker and client was generally very limited, four out of five involving only one or two meetings.

A second response to the sheer volume of referrals appears to have been a tendency to initiate interventions at a crisis point. From a study of the priority ranking in social services departments, Algie concluded that social workers' 'preventive endeavours only involved intervention at one or two stages earlier than complete breakdown. No tertiary intervention was contemplated'.⁽³⁹⁾ A similar conclusion

was drawn in Goldberg et al's study of one year's referrals to an area team; 'early and containable manifestations of family stress of various kinds, and non-material problems of the elderly, were rarely taken on'.⁽⁴⁰⁾

Attitude to social workers

Most of the carers in the present study who had met a social worker on at least one occasion described the encounter as helpful. However, it is difficult to discern meaningful consumer opinion of the social services. As Shaw pointed out in a research review of consumer opinion and social policy, the problem is one of differentiating between the consumer's attitude to a department, the practical services received and the social worker involved.⁽⁴¹⁾

The most likely occasion for a carer in the study to meet a social worker had been when an aid or house adaptation for the disabled was being arranged for the parent. The carer's response to the social worker, or, more likely the social work assistant, was one of gratitude for such practical assistance. In response to a question about whether there was anything else the carer wished the social workers could have done to help, most respondents thought in terms of further aids or adaptations. Typical comments were,

'They came once about a stair rail for father. I suppose I could always ring up if I wanted any more adaptations'.

'Well, she could not have been more kind. She brought this lovely wheelchair for mother. I suppose we could always ask her to come again if we wanted anything else. Mind you, I can't think of anything else we would want'.

Several carers described the social worker as unhelpful. This usually stemmed from a failure to supply an aid or adaptation. An example was not providing a ramp promised for a mother confined to a wheelchair;

'Well, I could not say that the social worker was any help to us. He just came once after mother came out of hospital. I think the hospital got him to call. He did lots of measuring for a ramp out of the front door because I could not get the wheelchair outside without one. He said a ramp would be put in very soon but it never was. That was a year ago and we are still waiting'.

Only one carer, a woman who was herself disabled, was critical of social workers for other reasons;

'My mother remarried an elderly widower living two doors away and he sold his house and moved in to live with us. But, after about two years he suddenly became very aggressive. He attacked mother and knocked her down and she is blind. He punched me in the face several times. He had just suddenly become very senile. I did not know what to do. Mother was terrified of being left alone with him. I was at my wits' end and went to the social services department for help. I could not believe what happened. They said they were too busy for a social worker to see me but one would call round in ten days' time. They did offer to report my stepfather to the police. But what good was that? Even at the end of ten days no social worker turned up'.

An expectation of social workers providing practical assistance was also reported by McKay et al in a 1973 study of client opinion in Southampton. Less than 10% of the sample of clients interviewed said they expected to discuss personal problems with social workers or to receive advice or sympathy. There was clearly a wide divergence between clients' and social workers' perceptions of the social work task. Most of the social workers thought clients wanted advice and sympathy. Most of the clients expected some kind of practical assistance.⁽⁴²⁾

Potential social work roles

There was considerable evidence in this study of needs generated by the caring situation which potentially social workers could have helped to meet. In the British Association of Social Workers' Working Party Report, 'The Social Work Task', no less than twenty social work roles were listed.⁽⁴³⁾ I would suggest that three of

these roles had particular relevance for the caring situations described in this study; counselling, advising and mobilising resources. Counselling was defined in the Report as involving 'the application of personal skills by the worker to assist a client in resolving problems of an emotional nature, often in connection with his personal relationships'.⁽⁴⁴⁾ Advising was described as 'the giving of factual information rather than counselling' and mobilising resources as involving 'the utilisation of any available resource (skills, facilities, manpower, services) in order to help the client'.⁽⁴⁵⁾

Some form of personal counselling would have been appropriate for many of the respondents in this study. There was considerable evidence in the interviews of the pent up feelings and frustrations that another's dependency could produce. Several women broke down and wept during the interview. Often these seemed to provide a long awaited opportunity actually to tell somebody else about the caring problems. As one woman said,

I've never been able to talk about it before. Nobody wants to know what it's like looking after Mum. You are just supposed to get on with it'.

In a discussion of the research problems and priorities in community care, Abrams identified the carer's need for care;

'A peculiar feature of social care in our sort of society is that it has itself now become a source of needs for care; and that characteristically these needs are felt by those who have them to be unreasonable, improper or shameful'.⁽⁴⁶⁾

Not only were there problems in expressing the needs generated by the caring situation, many of the respondents in the present study appeared to lack a suitable confidante. Often they were without friends, work colleagues or sympathetic siblings. When there were work colleagues, they were often spoken of as people from whom the reality of home life had to be hidden. It was felt that talking

about such topics as parental senility or incontinence would only invoke a hostile response. As one woman said,

'The people at work would hate to know anything about my life at home. I just have to pretend to lead the same sort of lives that they do.'

When there were siblings, they could be sympathetic and helpful but they could equally well be infrequent visitors who had little idea of the caring problems. As Miss Hook explained,

'We see my brother once a year on Mother's Day. He drives up to London with his wife and she spends the day with her mother and he comes here. It's funny my mother does not recognise me any longer. She thinks I am her sister or somebody else and she often does not seem to know my name. But she knows his name all right on Mother's Day and she knows enough to be able to ask about the grandchildren. She really is not half so bad on that day. If I ever tell him anything about what life is really like with her, I am sure he thinks that I make it up'.

A clear need emerging in this study was for advice about the relevant welfare services which potentially could provide support. Many of the respondents did not appear to know about services theoretically provided by the social services department. Two examples which have already been discussed in this chapter are short term places in residential Homes and day centres. In addition, there appeared to be inadequate knowledge of two highly relevant social security benefits, the attendance allowance and the invalid care allowance.⁽⁴⁷⁾ As was discussed in the previous chapter, 33% of the parents had an attendance allowance at either the full or part rate but a further 28% appeared to meet the criteria and had never made an application. In almost all cases, the failure to apply arose from the carer knowing nothing about the attendance allowance.

The third potential social work role of mobilising resources, particularly the care giving resources in the community, has been strongly and consistently advocated in official reports and by individual authors for more than a decade. For instance, a persistent

theme of the 1968 Seebohm Report on the reorganisation of the personal social services was that social workers had a responsibility for stimulating people in the community to perform 'mutual aid and caring functions'.⁽⁴⁸⁾ The report advocated that a clear responsibility 'should be placed upon the social service department for developing conditions favourable to community identity and activity'.⁽⁴⁹⁾ It was emphasised that 'the staff of the social service department will need to see themselves not as a self-contained unit but as part of a network of services within the community'.⁽⁵⁰⁾

The Aves Report of the following year, on voluntary workers in the social services, argued that social workers should make far greater use of volunteers. Volunteers were seen both as an important resource for narrowing the gap between social needs and social provisions and as representing community participation in the social services.⁽⁵¹⁾

The 1982 Barclay Report on the role and tasks of social workers expounded the community social work theme of the Seebohm Report.⁽⁵²⁾ While not decrying the traditional counselling activities, the report argued that promoting community self help was an undeveloped aspect of the social worker's role.⁽⁵³⁾ A main conclusion was that social work policy and practice must be directed more at the support and strengthening of informal networks and 'to caring for the carers and less to the rescue of casualties when networks fail'.⁽⁵⁴⁾ In a very similar vein to the Seebohm Report, it was argued that social workers must have an attitude of partnership with people living in the community; 'the function of social workers is to enable, empower, support and encourage, but not usually to take over from, social networks'.⁽⁵⁵⁾

Similar recommendations have emerged from individual studies. For example, a 1978 study of the work of a long term area team by Goldberg et al concluded,

'Work for the very frail elderly has brought into sharp focus the question of how to ensure continuous support and surveillance for them. It has become obvious that the occasional social work visit was not the most appropriate means of providing support or of anticipating approaching crises. It is almost universally accepted by now that the statutory social services need the underpinning of local care or neighbourhood support groups, if we are in earnest about improving the quality of life for the very old and frail'.⁽⁵⁶⁾

Similarly Bayley, from a study of a sample of families with a mentally handicapped member, argued that social workers should be 'helping and enabling the community to do better the caring it does already, with more help and less strain on individual members of it'.⁽⁵⁷⁾

As discussed in chapter seven, there appeared to be only two instances in the current study of single carers of social workers mobilising caring resources in the community by arranging for support from volunteers. There is also considerable evidence from other studies that social workers continue to make very little use of volunteers. For example, Goldberg et al's 1977 study, of a year's intake in an area office, found that only 3% of the elderly and physically handicapped referred to the office were put in contact with a volunteer.⁽⁵⁸⁾ Sainsbury and Nixon in a study of long term social work in a social services department commented on what little use was made of voluntary helpers to undertake befriending functions.⁽⁵⁹⁾ Similarly in a 1978 national study of social workers' use of volunteers, Holme and Maizels found that such use was on a very small scale.⁽⁶⁰⁾ At any one time less than three in five social workers were using the services of a volunteer and in most cases only one or two volunteers were being used for just one or two clients.⁽⁶¹⁾

In a 1980 preliminary report on the Kent Community Care project, Challis and Davies described a scheme whereby extra help was successfully generated in the community by social workers to meet the needs of a group of vulnerable elderly clients requiring residential accommodation.⁽⁶²⁾ Locally based helpers were recruited through advertisements in the local press and given relatively small payments for the tasks performed.⁽⁶³⁾ One of the conclusions drawn was that there had been definite benefits to the elderly clients in raising their level of well-being and in reducing the likelihood of admission to residential care.⁽⁶⁴⁾ An interesting point is that some of the elderly clients in the project were apparently assisted by the paid helpers in personal care tasks such as dressing and undressing.⁽⁶⁵⁾ However, one of the findings in the present study of single carers was that non-kin rarely gave assistance in personal care tasks. It was reported in chapter seven that the two most common tasks performed by neighbours were shopping and 'keeping an eye' on the parent by calling briefly at the house during the carer's absence. This clearly has implications for the type of support which a social worker could hope to mobilise in the community for this type of dependency situation. It suggests that a volunteer looking after an incontinent senile parent for an evening to allow the carer to leave the house would be likely to prove unacceptable, but that a volunteer helping with the garden or doing shopping would be acceptable. Challis and Davies' findings tend to suggest that possibly payment makes a difference to the acceptability of help with personal care tasks from non-kin.

CHAPTER 10 CONCLUSIONS

This chapter begins by summarising the main findings of the study. After considering the costs of caring borne by the single daughters and sons, it examines common needs arising from the caring situation. Using the Wolfenden Report's distinction between the four systems of social helping, the informal, the commercial, the statutory and the voluntary systems, the contribution of each one to meeting those needs will be discussed.⁽¹⁾ The primary health care team's role will be considered as part of the statutory system although its remit is wider than that of social helping. Finally, the chapter concludes with a discussion of some of the implications of the study for equality of opportunity in employment.

Summary

Although the study was based on a small sample of 58 carers of one particular type, there was a wide diversity of caring situations. Some carers were far more successful than others at coping with the frequently conflicting demands of a job and a disabled parent. Parents, at one extreme, could be confused and senile, unable to cope with even the basic necessities of life such as eating and going to the toilet; at the other extreme, they could have a zest for living and a determination to overcome the most formidable impairments.

Despite this diversity certain general similarities did emerge from the study. The majority of the parents were so disabled that, without the carers' support, they would have found it virtually impossible to continue living at home and would probably have been on a waiting list for urgent admission to a residential Home or geriatric hospital. Although so many parents were seriously disabled, the first hypothesis of the study, that there would be a relationship between parental dependency and the sex of the carer was sustained. Mothers living with sons tended to be far more active domestically than those living with daughters. Approximately half of them did general cleaning and prepared and cooked an evening meal compared with one in seventeen of those mothers living with a daughter. Although there was no difference between parents living with sons and those living with daughters with respect to incontinence or to needing help with bathing, significant differences were apparent for other personal care tasks. Parents living with daughters were approximately twice as likely to need help in going to bed ; approximately four times as likely to need help in dressing or undressing; and three times as likely to need help in using the toilet or commode.

The single carers, themselves middle-aged or elderly, often found their caring role difficult to maintain. A third of them had themselves a noticeable health problem. Frequent interruptions to their sleep by the parent was a difficulty for one in three of the carers. Many felt that their social lives had been appreciably affected because of the problems in having leisure activities outside the home, in taking a holiday or in making and maintaining friendships. Not surprisingly there were frequent signs of considerable strain. Four in ten carers showed evidence of emotional disturbance as measured by the malaise inventory.⁽²⁾ The women were far more likely than the men to have a

high malaise score.

There was also a significant sex difference in employment. With one exception, all the men below retirement age worked full-time but this was the situation for less than half the women of this age. A few women worked part-time and more than a third were not working at all. The second hypothesis, that caring for a parent would have far more effect on a daughter's employment than on a son's, was fully substantiated.

No simple comparison could be made between kin and neighbour support because the type of help given was usually quite different. The two most common neighbourly tasks were shopping and 'keeping an eye' on the more physically active parents by calling briefly at the house during the carer's absence. Neighbours rarely entered the house or gave the parents assistance with personal care of any kind. Kin, on the other hand, gave support of many kinds including assisting the parent with personal care during the carer's absence. Just over half those carers with a sibling living outside the household had received some form of practical support at some point in the caring process from one or more of them. Sisters were more likely than brothers to give practical support. Female carers were more likely than male carers to receive such support. Neighbours, however, were more likely to help male carers. Neither friends nor volunteers gave much support. Although the sons got more support than the daughters from neighbours, the third hypothesis that they would get more support from the community as a whole could not be substantiated.

Participation by the wider community in the caring process often seemed to be remarkably sparse. The carer's siblings were virtually the only kinsfolk likely to give any practical assistance. However, a substantial number of carers, just over a third, lacked the possibility of any support from this source either because they had been only children or because they had lost contact with their siblings years earlier. The minority of carers with a brother or sister living in the same household were undoubtedly the best off because somebody else was readily available

to share some of the everyday chores and to allow the carer to go out for an evening or at the weekend. There were only two instances of siblings living outside the household really trying to share the caring burden. The main forms of sibling help given to other carers included sitting with the parent for an occasional evening to allow the carer to go out, having the parent to stay for a week or two so that the carer could take a holiday, taking the parent out for a car drive on a summer Sunday afternoon and, on occasions, giving financial support. Minor examples of help included fixing up a night bell for the parent to ring for attention, sending £5 at Christmas, chopping wood for fires and doing some shopping. If the carer had to contend with problems such as parental senility or incontinence or demands for attention throughout the night, such sibling support could seem very minimal. The fourth hypothesis, that when kinsfolk and neighbours gave support it would generally be slight in relation to the total burden of care and that the overall caring burden would rest primarily on one person, the single carer, was substantiated.

Almost all the carers spoke highly of the district nursing service. None of the working carers, however, reported meeting a district nurse or having had an opportunity to discuss with her any difficulties in looking after the parent. Few referrals were described from either the district nurse or the general practitioner for local authority support services. Nor did many referrals for an attendance allowance appear to have been made. Nonetheless, half the parents who appeared to meet the criteria for an allowance had never made an application usually because the carer did not know of it. A wide variation was apparent in the support given by the general practitioner. At one extreme, a minority of the parents were regularly visited at home. At the other extreme, a similar minority reported a general practitioner refusal to make a home visit, even when requested to do so.

From the carer's point of view, social workers were the least evident of the professionals. Only three carers in the study were regularly visited by a social worker, although seven of them thought that a social worker visited their parents while they were at work, there being no contact between the social worker and the carer.

As far as the local authority practical services were concerned, Meals on Wheels and the home help service were the most widely used. One in four parents with a working son or daughter had meals delivered by the service. A sex bias was evident in the assistance given by the home helps. Over half the households with a son had a home help compared with one in five households with a daughter even though the daughters tended to have far more dependent parents. There were several complaints about the service's unreliability. The amount of help given was often considered inadequate and more than half of those being assisted would have welcomed more.

The parents' use of day care was virtually non-existent. Only three parents attended a day centre and none a day hospital. But the potential demand for day care was considerable. One in four carers both wanted some form of day care for the parent and thought that the parent would find it acceptable. Respite care in a local authority Home or a geriatric hospital had been used for one in four parents at least once in the caring process, usually to enable the carer to take a brief summer holiday. A substantial number of carers, however, had no knowledge of the availability of short term care.

There was a palpable absence of appropriate support for those women who had given up work because of their parents' needs for attention. The two local authority services most in evidence, Meals on Wheels and the home help service, were directed primarily at the working carer. With the exception of minor aids and adaptations, the majority of the carers, three out of every five, were not, and never had been, assisted by

local authority support services. The evidence in the study, therefore, supported the fifth hypothesis that the majority of the single carers would receive little or no support from social services departments.

The cost of caring

A major justification for the political emphasis during the past twenty five years on the desirability of community care has been its alleged cost effectiveness. Care in the community, if it is based on scant or no support from the health and local authority services, will clearly cost the government less than institutional care in a residential Home or geriatric hospital. However, community care can only be regarded as cheap if the public expenditure costs are calculated. As the 1981 D.H.S.S. Report on a study on community care admitted,

'The 'cost-effectiveness....often depends on not putting a financial value on the contribution of informal carers who may in fact shoulder considerable financial, social and emotional burdens'. (3)

Many carers in this study paid a high cost for supporting their parents. These costs frequently included giving up a job, deprivation of sleep, hard physical work in the home, poor health, emotional strain and a loss of personal freedom. Having to give up a job was a cost particularly likely to be paid by female carers. The figure given earlier of less than half the women below retirement age being in full-time work must underestimate the final impact of parental dependency. The interviews for the study represented a cross-section at one point in the caring process. If the whole of the caring period could have been studied, it can safely be assumed that more of those working at the time of the study would have given up their jobs or taken part-time work before reaching retirement age.

Giving up work or taking a part-time job had both short and long term financial consequences. In the short term both actions entailed a drop in income. As all those jobs which had been given up were of

professional or non-manual work status, the drop in income to supplementary benefit level was usually considerable. In most cases, giving up work was rarely done on a temporary basis. The women involved tended to be in their early fifties and the chance of being able to return to an equivalent job in the event of the parent dying before the carer reached retirement age must have been remote. In the long term, a single woman's income in old age would almost certainly be reduced through having given up work completely or taken part-time work at an earlier age. Any occupational pension would be affected, but the right to a basic State pension would be protected for those years in which the carer either received supplementary benefit because of staying at home to look after a sick relative or the parent received an attendance allowance.⁽⁴⁾ It is likely, however, that the additional State pension, payable to those people not in an approved occupational pension scheme, would be affected.⁽⁵⁾

Giving up work also had psychological and social consequences. Paid employment is an important source of self esteem for both men and women in an urban industrial society. For many middle-aged, single women in the caring situation, without the additional social relationships created by marrying and having children, employment must be an important source of social contact. The loss of a job could mean forfeiting more than social relationships in the work place. Several carers, who were no longer working, found that parents, used to their presence during the day, objected to being left alone for even a short period during the evening or at the weekend when previously there had been no problem.

Disturbance of their sleep by the parent was a cost to both male and female carers. One in three had this problem and, in most cases, it had persisted for several years; the average being four and a half years. Sleep was rarely interrupted just once a night, the norm being three times. Some carers had to get up for the parent as often as seven times every night of the week. A few people appeared to cope

extremely well with broken sleep; but the majority undoubtedly found it a strain, particularly as there was a tendency to sleep lightly through fear of not hearing the parent call out. To miss the parent calling for assistance might well mean a soiled bed or the parent falling in trying to reach a commode unaided.

Given the relationship between parental dependency and the sex of the carer, the daughters were more likely than the sons to find caring for the parent hard physical work. A few sons did have as heavy a caring burden as any of the daughters. Life for many of the women and a few of the men, who had both a job and a highly dependent parent, must have seemed like being on a treadmill. The day had to be started early because of the numerous chores to be done before going to work. At a minimum, these usually included helping the parent to get out of bed, to use the commode, to wash and to dress. In addition to preparing breakfast, food and drink often had to be prepared ready for the parent during the day. The evenings were usually hectic with the carer preparing an evening meal, doing housework and being sociable to a parent who had usually spent a very lonely day.

Part of the hard physical work for several carers; themselves middle-aged or elderly, was having to lift a parent crippled by arthritis out of bed and into a wheelchair or onto a commode. Several carers thought that such lifting had caused their permanent back trouble. Parental incontinence caused particular problems to both working and non-working carers. At the very least it usually entailed daily washing and drying of sheets and clothing.

The hard physical work of caring was exacerbated for a third of the carers by their own health problems. Not only could several of these problems be directly attributed to the mental or physical strain of caring for the parent; there were also instances of carers being unable to accept treatment for conditions such as arthritis because the parent could not be left alone for long enough periods. About a third

of those with health problems were so severely disabled that coping with housework and tending the parent was physically very demanding. As in other studies of dependency situations, a cost to a considerable proportion of the carers, four out of ten of them, was emotional strain. (6)

Above all, caring often imposed a loss of personal freedom. Many carers, both men and women, appeared to be very socially isolated people. They had few relationships with people outside the household. It was frequently out of the question to pursue leisure interests outside the home and, for many people, maintaining friendships was virtually impossible. The loss of freedom was not only in being unable to go outside the home; it was inside the home as well. Working carers, particularly the women, were often so busy with chores in the evening and at the weekend that there was no time for them to pursue leisure interests of their own. The loss of freedom was particularly acute in some cases where the parent had become senile. Several women were virtually persecuted by a senile parent when activities such as knitting or sewing were undertaken. The parent repetitively demanded to know what was being done, ignoring or not comprehending the answer. A common response was to give up activities which excited this reaction from the parent.

It was striking how few of the carers spoke of their parents with warmth and affection in the interviews. For many the costs of caring were so high that bitterness, resentment and frustration were the dominant emotions.. A social biologist might interpret these emotions in terms of disengagement theory.⁽⁷⁾ A basic premise of this theory is that as death is biologically inevitable then a preceding disengagement of an old person from society is also inevitable. Such a disengagement is mutual between the ageing person and others in the social system to which she or he belongs.⁽⁸⁾ The carer's antagonistic feelings could thus be interpreted as part of the process of an old person's disengag-

ement from life.

The costs could seem so high that the question arises of why the carer continued to look after the parent. It is likely that the strain drives some single carers in the population to abandon the parent, but there is no way of knowing how frequently this occurs. The current study, in selecting on-going caring situations through district nursing records, could not include carers who had taken this decision. Many of those interviewed appeared to have a strong sense of obligation, but the view was often expressed that there was a lack of choice about continuing to provide care. In choosing to live in the same household as the parent before the phase of dependency, their life choices had effectively been restricted years earlier. When the phase of dependency itself was reached, married siblings were, on the whole, unlikely to offer to take permanent responsibility for the parent. The female carers tended to think that there was little likelihood of their parent ever being offered a place in a local authority Home or a geriatric hospital because a female relative was available to take responsibility. As discussed in Chapter Six, this expectation had been confirmed for several of them by an experience of rejection when seeking the parent's temporary admission to care. A reason suggested in Chapter Three why daughters were more likely than sons to look after the most dependent parents was that really severely disabled parents would be more likely to be admitted to institutional care if they were living with a son than if they lived with a daughter.

The needs of the carers

Most of the men and women in the study had needs arising from the caring situation. About one in three of them desperately needed a decent night's sleep. Often these carers had to get up for their parents several times in the night and then face the demands of a job the following day. Other studies of comparable dependency situations have also identified broken sleep as a significant problem.⁽⁹⁾ There

is evidence that it can terminate a carer's willingness to continue the support of an aged disabled parent in the community. Sanford's 1975 study, of the home circumstances contributing to 50 people being admitted to a hospital geriatric unit because relatives and friends could no longer cope with them at home, reported that not only was broken sleep the most frequently re-occurring problem, but that it was also one of the least well tolerated.⁽¹⁰⁾

Many carers needed regular relief from the caring burden. Those who were not working would have found life far more tolerable if it had not been necessary to look after the parent all the time every day of the week. But, those with highly dependent and demanding parents needed relief for more than the odd day in the week. There was a need to be totally relieved of the caring burden for temporary regular periods throughout the year.

Working carers were often anxious when away from home because in the event of a fall the parent would be unable to get up again. This was a very real, not an imaginary, anxiety. One mother had fallen against a fire and had remained there, suffering agonising burns, for several hours until her son returned home. Several other parents had also fallen and remained lying on the floor until the carer returned. In addition, some parents who had become senile appeared to be too much of a danger to themselves to be left alone. Several parents with working offspring, then, undoubtedly needed to be under continual supervision and many others needed somebody to check that they had not fallen and were lying unattended.

Working daughters often needed far greater assistance in coping with the volume of domestic work in the home. As we have seen, daughters were more likely than sons to have dependent parents unable to cope with any housework or personal care tasks; yet they were less likely to be assisted by the home help service.

As social isolation was a common difficulty for many respondents, there was often a need for greater interaction with other people living in the community. Somebody else prepared to sit with the parent for an evening would, at least, have created an opportunity for the carer to go out.

The women in the study clearly felt far more pressurised than the men to give up their jobs. In part, this resulted from pressures in the home, but, pressures were also exerted by the work situation. Carers should have a real choice of maintaining employment outside the home in addition to caring for the parent. For such a choice to exist, flexibility of work hours is necessary particularly as so many parents need considerable help in the morning before the carer goes to work. There is also a need to be able to take leave from work if the parent requires extra attention for reasons such as 'flu' or 'bad turns'.

In addition, many carers with specific problems needed advice. Parental incontinence and senility posed particular problems but little advice was given on how to deal with them. Guidance was also needed about potentially supportive services such as day care, incontinence laundry services, aids and adaptations for the disabled and appropriate voluntary organisations. Information should have been given far more frequently about the attendance allowance which can make a financial contribution to coping with the problems of disablement.

To what extent were these needs being met by any of the four systems for social helping in our society?

The informal system

A basic tenet of current government policies is that society itself not the government has the prime responsibility for infirm elderly people. Asserting that the primary sources of support are informal and voluntary, the 1981 white paper 'Growing Older' averred

'Providing adequate support and care for elderly people in all their varying personal circumstances is a matter which concerns - and should involve - the whole community: not just politicians and officials, or charitable bodies. It is a responsibility which must be shared by everyone'.(11)

The evidence in this study is that the responsibility for support and care was rarely shared by the community ; it usually fell quite inequitably on the single daughters and sons. Potentially adequate support could have come from three sources in the community, kinsfolk, friends and neighbours.

As we have seen earlier in this chapter, siblings were virtually the only kinsfolk to give support. This source of support was not available to just over a third of the carers who were either only children or had lost contact with siblings years earlier. The examples of assistance which were given earlier showed that, even when siblings gave support, it was often minimal in relation to the total caring burden. A few carers with single siblings living in the same household were able to share some of the responsibility for the parent with them; but only two out of the 58 carers could really be described as having married siblings from outside the household share the responsibility with them. Why were the vast majority of married siblings failing to share responsibility for the parent? As none of the siblings were interviewed for this study, it is only possible to speculate on the possible reasons.

1. Reasons for inadequate support by kin

Geographical proximity undoubtedly makes it easier to contribute to caring for an infirm parent. Although about half the siblings lived some distance away, no less than two out of three sisters and one out of three brothers lived within three miles of the carer's home. Living so close enhanced the opportunity for giving considerable support

Sociologists have frequently suggested that the marriage bond reduces the feeling of obligation to the family of origin. A single person would be assumed to have prime responsibility for an elderly disabled parent because the first loyalty of married siblings lay with the family of marriage rather than the family of origin.(12) That most married siblings would be in their fifties and their children no longer dependent did not appear to affect the assumption that the single person had the greater obligation.

As Shanas et al pointed out in a study of old people in three industrial societies, when tending tasks were undertaken by relatives living outside the household, they were far more likely to be performed by daughters and daughters-in-law than by sons or sons-in-law.(13) Although a single carer's sister or sister-in-law would be unlikely to have dependent children at the point when support would have been welcomed, the expectation that many married women in Britain now have, of returning to work, is likely to affect their willingness to give substantial help. A measure of the significance of this social trend is that in 1961 only 32.6% of married women in the 45-59 age group were economically active but by 1979 this figure had increased to 61.0%.(14) Even though much of this increase is in part-time work, the point remains that women's economic activity in addition to their domestic responsibilities in their own families is likely to affect their willingness to be involved significantly in supporting infirm parents or parents-in-law in another household.(15)

From the perspective of offspring outside the household, the prospect of accepting responsibility for a highly dependent parent whether for an evening or a week must have appeared particularly daunting. Undertaking tending tasks for an immobile arthritic person can be extremely physically demanding. Parental senility appeared to make it

even more difficult to obtain assistance. Several carers referred to brothers and sisters refusing outright to be left alone with a senile parent.

It is likely that some siblings genuinely did not comprehend how dependent the parent had become. There were a number of rather exasperated anecdotes about the parent making a tremendous effort to appear less frail or confused when visited by other offspring. In this situation, any complaints by a carer about the difficulties of living with the parent could seem like an unjust exaggeration.

It was not uncommon for a parent to be very resistant to being looked after by other offspring, refusing to stay with them for even a short period of time. Various explanations for this resistance were offered by the carers involved such as the parent's dislike of a daughter-in-law or son-in-law, mistrust of an unknown house, a reluctance to reveal the true extent of disablement and a simple refusal to leave the familiar surroundings of home. On the other hand, some carers made it clear that they themselves were unwilling to involve siblings in caring for the parent. The reason given could be altruistic, 'Looking after mum has spoilt my life and I don't see why it should spoil anybody else's'. But there were other motives. One appeared to be acquiring status in the family as the parent's sole supporter.

2. Increasing kin support

Despite many married siblings either making no contribution to parental care or giving support which was minimal in relation to the caring burden, kinship, as Abrams pointed out in a summary of research on community care, remains the strongest basis of attachment and the most reliable basis of care that we have.⁽¹⁶⁾ Siblings are generally acceptable as a substitute for the carer in assisting a dependent parent with personal care tasks in a way that, on the whole, non-kin simply are not. If married siblings accepted far more responsibility for dependent parents

by actions such as regularly undertaking night sitting, regularly spending an evening or a day with the parent to enable the carer to go out, providing holiday care or actively seeking alternatives to a female carer giving up employment as the parent becomes too frail to be left alone, then the cost of caring to the single daughter or son would be considerably less. A small number of families do appear to share responsibility in this way. More research is needed into the attitudes and behaviour of middle-aged adult offspring towards their elderly parents to understand why some families behave in this way and others do not.

3. Support from friends and neighbours

Compared with kin or neighbours, friends rarely gave any practical support to the carers in this study. Other studies of dependency situations have had similar findings.⁽¹⁷⁾ Given the apparent social isolation of many of the carers and the difficulties which were frequently encountered in sustaining relationships at all with friends, it seems rather unlikely that more support could be mobilised from this source.

As we have seen, neighbours were second to kin in giving support. However, because they rarely entered the house and tended to restrict their support to two relatively impersonal tasks, shopping and 'keeping an eye' on the parent, they were unlikely to be involved in supporting the very dependent parents. Although Townsend, in a study of the family life of old people, found evidence of neighbours and friends substituting for relatives, the data in the present study did not substantiate a theory of compensation.⁽¹⁸⁾

Because the dynamics of neighbourliness are insufficiently understood, a satisfactory explanation cannot be offered for the restricted forms of help given by the neighbours. It seems likely that there is a taboo on non-kin giving the most intimate types of necessary bodily care. In any case, neighbours may be cautious about offering

even slight assistance when the need for support is so great. An offer of help in one sphere could reveal needs in other spheres which the neighbour would feel unable or unwilling to meet. Female rather than male neighbours are likely to be involved in supporting infirm people and, as in the case of female kin, it is likely that the expectation that many women now have of resuming employment when their own children are no longer dependent affects their availability for neighbourly support.

The informal system frequently failed to meet the carers' needs for support. In Abrams words,

'the world of private, informal care is something of a disaster. Quite simply, the private sector persistently fails to provide enough care for enough people. However much one may value its emotional depth and qualitative standards that at its best it sets, it quite plainly cannot be relied on to provide care where it is needed or in the forms it is needed for vast numbers of people'.(19)

The commercial system

Theoretically it is possible to purchase a whole range of different forms of social care on the open market. Those carers needing relief from the constant care of a highly dependent parent could have employed people to give the parent appropriate attention at night, during the day or during the evening. Periodic relief for a week or more could have been purchased by paying for a private nursing home for the parent. Very few carers, however, had sufficient income to do this. At the present time, as the Wolfenden Report pointed out, only the very wealthiest members of society can afford to purchase social services on the open market.(20) A State contribution towards the purchase of services or goods to relieve high dependency situations is the attendance allowance.(21) In relation to other social security benefits, the allowance, at either the full or the part rate, is not an insignificant amount of money.(22) / But it does not, as its name implies it should, pay the cost of a full-time attendant.

A few carers were either currently buying, or had previously bought, some form of relief from the caring burden. In almost all cases, the attendance allowance gave them some or all of the necessary purchasing power. To avoid having to give up their jobs, two women had employed full-time attendants for their mothers. In one case, the carer was assisted in paying the attendant's wages by the attendance allowance and contributions from two sisters living outside the household. It was apparent that, in the other case, not only did the attendance allowance make a substantial contribution to the attendant's wages but the attendant, a foreigner illegally working in the country without a work permit, was prepared to accept a very low rate of pay. Two other women, who had been refused a home help, employed private domestic help for a few hours each week. In another instance, a woman who had been refused respite care for a senile mother despite being very ill herself, had her two sisters living abroad pay for two weeks' private nursing home fees for her mother.

One way in which the commercial system could potentially benefit greater numbers of carers is if all the people eligible for an attendance allowance actually received it. A significant finding in the study, discussed in Chapter Eight, is that only about half of those parents apparently meeting the criteria for a full or part allowance actually received it. The attendance allowance would, however, have to be substantially increased to meet the commercial costs of full-time attention. There is no possibility in the foreseeable future that more than a tiny minority of carers will be able to meet their needs for relief on the open market.

The statutory system

The health and personal social services are the parts of the statutory system able theoretically to play a major role in supporting the carer.

1. The district nurse

In the pursuit of successful community care policies, the primary health care team has a key responsibility. As an important member of that team, a district nurse has far wider duties than simply providing nursing care. In the words of the 1981 white paper 'Growing Older',

'In addition to her responsibility for nursing procedures the district nurse gives general advice to patients on how to take care of themselves, and advises on health problems including those associated with incontinence'. (23)

She is professionally accountable for assessing the needs of the patient and of the family and for monitoring the quality of care.

'It is her responsibility to ensure that help, including financial and social, is made available as appropriate'. (24)

It was apparent that the actual role played by the district nurses in this study was frequently far removed from these descriptions. All the parents were in contact with the district nursing service. A minority of the parents, who were either bedbound or needed assistance to get out of bed and dressed, were visited daily and, undoubtedly, the actual nursing care contributed a great deal to the viability of their care in the community. A major weakness of the district nursing service, however, was its lack of contact with the working carers. As was mentioned earlier, none of the working carers reported either having met a district nurse or having had an opportunity to discuss with her the difficulties they were having in caring for their parent. That the carer continued to work could not be taken to mean the absence of serious caring problems, such as those involved in coping with senile behaviour, parental incontinence and frequent disturbance of sleep. If she did not actually meet the working carer, the district nurse could not carry out her responsibilities to assess the needs of the patient and of the family and could not ensure that the appropriate financial and social help was received. There was evidence in the study of both working and non-working carers needing to be made aware of potentially supportive services such

as respite care, day care centres and day hospital places. In addition, as so many parents apparently meeting the criteria for an attendance allowance did not receive it, a far more active referral policy by the district nurse is needed. The district nursing service particularly needs to consider ways of ensuring that working carers receive adequate support. This would probably involve a service whose personnel were prepared to visit in the evening after normal work hours.

2. The general practitioner

As leader of the primary health care team, a general practitioner is in a strategically important position to assist old people to continue living in their own homes. Not only does the general practitioner have a therapeutic role to diagnose and treat ill health; she/he also has a potentially significant referral role to approach and mobilise appropriate health and welfare services. As in other studies, few instances of referrals for local authority practical services or social work support were reported.⁽²⁵⁾ Although general practitioners were reported as making rather more referrals than district nurses for an attendance allowance, a far more active referral policy could have been pursued.

It was apparent that the carers had widely different experiences of general practitioner behaviour. At one extreme, a small number of doctors appeared to be very supportive, making helpful suggestions for coping with the practical problems of care and either making regular home visits or responding swiftly when called in. At the other extreme, a small number of doctors appeared virtually to have rejected the parent and the carer by refusing to make home visits on any occasion. Most doctors appeared to occupy a middle position and merely to respond to specific episodes of parental illness. On the whole, few general practitioners appeared to be doing very much to alleviate the problems which contributed to the intolerable caring burdens of many carers. Disturbed sleep, for example, was all too common but doctors were not reported as assisting carers to deal with it. This particular caring problem requires a very

positive response from the doctor who needs to consider how to give the carer the possibility of an uninterrupted night's sleep. The best way to achieve this may be through the provision of a night nursing service, a facility which an increasing number of health authorities now offer.⁽²⁶⁾ A doctor may need to use his influence to persuade the authorities to set up such a scheme locally.

It is also important for the general practitioner to be aware of the need that most carers have for relief from the continual caring burden. Such relief is theoretically available on a daily basis in day centres and day hospitals and, for longer periods, in residential Homes and geriatric hospitals. In addition to the issue of adequacy of the existing provisions which will be discussed later in the chapter, there is also the issue of access to the existing services. As mentioned earlier, many carers had no idea that there were day care and respite care facilities in the study area. A general practitioner needs to ensure that not only do carers have access to the existing facilities but there is also pressure on the authorities to expand them.

Many of the carers' needs, however, were social rather than medical and, thus, were in the province of the social services department.

3. Local authority support services

Government statements about the role of local authority support services in sustaining community care lack substance in the light of this study's findings. The 1981 white paper 'Growing Older', for example, commented,

'Community care services play a vital role in enabling elderly people to remain in their own homes and in preventing or deferring the need for long term care in a residential home or hospital. They also make a very important contribution to the support of families caring for elderly people'.⁽²⁷⁾

Referring to day care, the same white paper contained the comment,

'The Government regards such provision as an important means of relieving families caring for elderly relatives, especially those who are disabled or mentally infirm'.⁽²⁸⁾

However, as we have seen earlier in the chapter, in reality the contr-

tribution of the social services departments to the support of the carer was often either non-existent or insignificant in relation to the actual caring burden. Only a minority of the carers, two out of every five, had actually ever been helped by a local authority practical service.

Day care was scarcely in evidence in the study. Short term care had been used at some point by a small proportion of the parents. As far as the domiciliary services were concerned, although Meals on Wheels were appreciated by the working carers concerned, they were inappropriate if the parent became too senile to eat unsupervised or physically unable to cope with re-heating a meal. The home help service was undoubtedly appreciated by most of the recipients, but there were complaints about unreliability and the amount of help given. As mentioned earlier, a sex bias was evident, in that the likelihood of having a home help appeared to be related less to the degree of parental dependency than to the sex of the carer.

An inverse relationship was apparent between parental dependency and local authority support services. The more infirm the parent became, the less likely there was to be any appropriate support. The carers least likely to be helped were those women who had given up their jobs to look after a very dependent parent.

Nevertheless, there is no denying that there has been an enormous expansion of domiciliary service for old people, particularly the very old, since the 1960s. In a comparison of Townsend and Wedderburn's national survey of the elderly living in the community in 1962 and Hunt's national survey of the elderly in 1976, Bebbington concluded that by 1976 about twice the proportion of elderly people received home help and Meals on Wheels as in 1962.⁽²⁹⁾ The extra services had gone to the very elderly, 30% of the over 80s receiving a home help in 1976 compared with 22% in 1962.⁽³⁰⁾

Day care, on the other hand, whether in local authority

centres or hospitals, remained poorly developed at the time of this study. Although the number of places in local authority day centres had increased by 80% between 1975 and 1980 and the number of geriatric day hospital places by 50% between 1975 and 1978, this expansion had been from a very small base. (31)

Cuts in public expenditure since the late 1970s have had an impact on these local authority services. Social services departments have been instructed by central government to reduce their expenditure. Central government has maintained that services for vulnerable groups, such as the infirm elderly, should not be affected: to quote from government expenditure plans for the financial year 1980-81;

'The Government expects that savings will, as far as possible, be made by further increases in efficiency, by reducing or eliminating low priority provision, by developing policies designed to help people to help themselves and others, and by promoting collaboration with the voluntary sector. Where reductions in standards of provision prove necessary, authorities will be relied upon to implement these in ways which protect the most vulnerable'. (32)

In reality, many local authorities have responded by making economies in services used by the elderly. A survey, undertaken by the Association of Directors of Social Services, showed that in 1979/80 two thirds of responding authorities had reduced their budget for residential care for the elderly and half had reduced their home help services. (33) A further survey showed that in both 1979/80 and 1980/81 both day care and aids and adaptations for the disabled, who would mainly be elderly clients, were also cut by a substantial proportion of local authorities. (34)

Such cuts in services are taking place at a point when the need of the elderly population for support is clearly increasing. The anticipated substantial increase, of about 60% in the number of old people aged 85 and over by the end of the century, has profound social policy consequences because a higher proportion of this age group than of younger age groups are consumers of local authority support services. (35) Hunt's 1978 government survey of the elderly, for example, showed

that 27.3% of those aged 85 and over had been visited by a home help in the preceding six months compared with 8.9% of all pensioners; and 11.3% of them had received Meals on Wheels compared with 2.6% of all pensioners.⁽³⁶⁾ In addition, there is evidence of increasing social and physical need among the very elderly. On the basis of the comparison between Townsend and Wedderburn's national survey of 1962 and Hunt's national survey of 1976, Bebbington calculated that 58% of those aged 80+ were moderately or severely incapacitated in 1976 compared with 46% in 1962.⁽³⁷⁾ A substantial increase was also found in the proportion of people in this age group living alone, 41% in 1976 compared with 25% in 1962.

4. The need to expand local authority support services

The D.H.S.S. acknowledgement that even the basic support services 'home help and meals on wheels may not keep pace with the growing number of very elderly people' does not augur well for an adequate development of services which will share the care of the parent and relieve the frequently intolerable burden on the carer.⁽³⁸⁾ Working carers, in particular, need the support of a reliable home help service giving sufficient assistance to lighten the load of domestic work. Daughters need this support as much as sons, if not more, because they are likely to have such dependent parents. A woman who is both working and caring for a parent should not be refused a home help on the grounds that as a woman she should either be able to cope or ought to feel obliged to give up her work. Such a refusal constitutes considerable moral pressure on individuals already prone to internalise these feelings.

Working carers with very dependent parents need an extension of the traditional Meals on Wheels service. Several women in the study had given up working when their parents could no longer cope with a meal unaided. Local authorities should consider ways of supporting these carers by ensuring some kind of lunch time supervision through the home

help service or a voluntary organisation.

Considerable expansion is still needed in day care facilities. As the government pointed out in 'Growing Older', such provision is an important means of relieving families caring for elderly relatives.⁽³⁹⁾ A break from looking after a parent for just one or two days of the week would make a difference to a non-working carer's ability to continue coping. A working daughter with a highly dependent parent would have felt less pressurised to give up work if day care had been readily available. The potential demand for day care, mentioned earlier in the chapter, of one in four carers both wanting it and thinking that it would be acceptable to the parent, would have been even greater if so many carers had not felt that their parents had become too infirm to cope with day care of any kind.

Expansion is also needed in the number of short term places for the infirm elderly in residential Homes to give carers regular relief from the caring burden. Although such places existed in the area studied for holiday relief, in practice, access was very restricted. A substantial proportion of the carers appeared to know nothing about the scheme. In any case, an annual break of one or two weeks was unlikely to be sufficient to meet the carer's need for relief if the parent were senile or highly dependent. Frequent breaks throughout the year might have given more appropriate relief.

A further service should be developed to meet a common need among carers. A 'sitter' service, providing somebody to look after the parent regularly for one or more evenings in the week, would have created an opportunity for the carer to have some form of leisure activity away from home. Such a 'sitter' might be a paid employee or a voluntary worker. These sitters would need some basic training to cope with eventualities such as behavioural problems arising from senil-

ility or having to assist the parent in using a commode.

5. The problems of joint planning for community care services

Apart from the basic issue of financial restrictions on the development of adequate support services in the community, there are administrative barriers to comprehensive planning. The health authority and the local authority social services department have a joint responsibility for the community care of infirm old people. Yet, they are separately funded and are accountable to different constituencies, the former directly to the Secretary of State and the latter to the local government council. Effective collaboration between the two authorities is crucial, but, as the Report of the Royal Commission on the National Health Service pointed out, the relations between them range from indifferent to excellent.⁽⁴⁰⁾

With the reorganisation of the National Health Service in 1974, joint consultative committees were established for each health authority and associated local authority to be served by a joint care planning team. Joint financing arrangements at the local level were introduced in 1976. These enabled health authorities to use National Health Service funds for both capital and revenue expenditure on local authority projects designed to reduce the need for long term hospital care. By 1981, 40% of the money available under the joint finance scheme had been spent on the elderly.⁽⁴¹⁾ Having been subjected to public expenditure cuts, local authorities have been somewhat cautious about joint funding as, under existing rules, they have to take full financial responsibility after seven years.⁽⁴²⁾

Joint planning and funding are likely to be made more difficult by the further reorganisation of the National Health Service in April 1982. The three tier administrative structure, set up in 1974, of 14 regional health authorities, 90 area health authorities and 199 district health authorities, was replaced by a two tier structure of unchanged regional health authorities and 193 district health authorities.

Some of the new district health authorities cover territory which is not coterminous with local government boundaries. Each local authority now has to deal with several district health authorities for joint planning and finance arrangements.

6. Social workers

As we have seen in Chapter Nine, social workers were conspicuous by their absence in meeting the social needs of the carers. In this respect, the social services departments in this study were not exceptional. Several studies confirm that not only do social workers accord low priority to the elderly client group but also that, when support is given, it is far more likely to be to those living alone than to those living with relatives.⁽⁴³⁾ When there is social work intervention, research shows that it is far more likely to be at a point of crisis rather than at an earlier stage in an attempt to prevent the occurrence of that crisis.⁽⁴⁴⁾ It was argued in Chapter Nine, that social work support should be offered to the carers in society through counselling, advising and mobilising the care-giving resources in the community. This latter role has been advocated by individual researchers examining current social practice and in no less than four major reports, the Seeborn Report of 1968, the Aves Report of 1969 examining the role of the voluntary worker in the social services, the 1978 Wolfenden Report on the future of voluntary organisations and the 1982 Barclay Report on the role and tasks of social workers.⁽⁴⁵⁾ It is to the voluntary system and its relationship with the statutory and informal systems that we now turn.

The voluntary system

There were only three instances of long term voluntary help in the study. In one case, a carer found voluntary help herself through a local church; in the other two cases, social workers had arranged for several volunteers to be involved in supportive action such as garden maintenance and transporting the parent to a club. That social workers make such little use of volunteers has been confirmed by other studies.

(46) An indication of social services departments reluctance to support voluntary action is that most commit less than 3% of their budgets to the support of voluntary organisations.⁽⁴⁷⁾ Nevertheless, as indicated in the previous chapter, a central recommendation of the Barclay Report is for a closer partnership between the statutory, the informal and the voluntary sectors. A community social work approach, it is argued, is required so that 'clients, relations, neighbours and volunteers become partners with the social worker in developing and providing social care networks'.⁽⁴⁸⁾

There is now an increasing body of literature describing schemes successfully extending voluntary involvement in support work within the community. Hadley and McGrath, for example, recently studied seven individual 'patch' teams covering local neighbourhoods, in which social services staff worked closely with informal helping networks and voluntary organisations to maximise the provision of care.⁽⁴⁹⁾ The 'patch' system they described had three main components: the support of voluntary care, the direct provision of statutory care, which often involved maximising the number of ancilliary staff such as home helps and social work assistants and widening the scope of the tasks which they could perform, and measures to optimise the mix of the two.⁽⁵⁰⁾ The 'patch' teams had a strong community orientation, working with local voluntary and statutory organisations and recruiting local volunteers.

Although systematic evidence on the results achieved was not available, an assessment was made from the impressionistic evidence. All the team organisers claimed that 'patch' organisation had enhanced their capacity to identify people needing help earlier than in conventional systems.⁽⁵¹⁾ They had been able to tap more resources both by developing the role of ancilliary workers and by developing volunteer support. As a result, the organisers claimed to deal with fewer emergencies and to support more people in the community than conventional social work teams. It was also claimed that fewer people were admitted

to residential care.

Preliminary reports on the Kent Community Care project indicate a similar success in increasing the amount of voluntary support in the community.⁽⁵²⁾ As mentioned in the previous chapter, the essence of the project lay in attempting to mobilise extra help in the community to meet the needs of vulnerable elderly clients requiring residential care.⁽⁵³⁾ The aim was to improve services to elderly clients by providing more flexible, individually tailored services in conjunction with those currently available.⁽⁵⁴⁾ To ensure that the project was cost effective, no more than two thirds of the marginal cost of a residential place could normally be spent on any one client.⁽⁵⁵⁾ Volunteers were recruited locally, either through advertisements or by word of mouth, most receiving small payments for undertaking a range of housework and personal care tasks.⁽⁵⁶⁾ Challis and Davies made the point that the helpers recruited represented a new source of care for the fragile elderly, drawing neither from potential home helps nor from existing voluntary agencies.⁽⁵⁷⁾

Both the 'patch' systems and the Kent Community Care project demonstrate that additional sources of support can be generated in the community. Other recent research, however, does suggest limitations to voluntary support for infirm elderly people living in the same household as their offspring. In a quasi-experiment in Weston-super-Mare, Power examined how far local volunteers could work in effective partnership with the health and social services. He reported that out of 20 cases of very frail elderly clients living with their children to whom volunteers were introduced, only five materialised into ongoing relationships.⁽⁵⁸⁾ It was suggested that the fraught family situations arising when an elderly person lived with offspring were too complex for 'good neighbours' to cope with. Levin's, as yet unpublished, study of the supporters of 150 demented elderly people in the community corroborates Power's conclusion about the unacceptability of volunteers to this type

of household.⁽⁵⁹⁾ One of the findings in the present study, that non-kin rarely gave assistance with personal care tasks, has implications for the type of voluntary assistance which a social worker might be able to mobilise in the community. It suggests that the idea of a voluntary worker looking after a parent with toileting problems to allow the carer to go out for the evening would be likely to prove unacceptable.

The voluntary system does potentially offer a way of meeting certain of the carers' needs. Locally based volunteers, whether paid or unpaid, able to call on the parent regularly each day could have relieved a working carer's anxiety about whether the parent had fallen over while alone. Undoubtedly many of those parents with working offspring got very lonely during the day and would probably have welcomed a friendly visit. A volunteer able to assist a parent for half an hour at lunch time might have solved the working carer's dilemma if the parent became unable to cope unaided with a meal delivered by the Meals on Wheels service. It is possible that the voluntary sector could meet two common needs apparent in the study for a 'sitter' to enable the carer to go out for an evening and for a night attendant to enable the carer to get an unbroken night's sleep. But, given Power and Levin's evidence, about the unacceptability of volunteers for households containing offspring, and elderly infirm parents, and the present study's findings that non-kin rarely performed personal care tasks for the parent, research is needed to find in what circumstances such assistance would prove acceptable.

Equality of opportunity in employment

It has been a major social policy objective for many years to foster and develop community care for the elderly infirm, the mentally ill, the mentally handicapped and the disabled. On the other hand, there is a commitment to sex equality of opportunity in employment enacted in the Sex Discrimination Act of 1975. A conflict exists between these two policy objectives because community care policies have far more

impact on women's employment than on men's. The evidence in the present study that a daughter's job is at far greater risk than a son's when an infirm parent is cared for at home finds confirmation in other studies of dependency situations. These show that, when a handicapped adult or child lives at home, there is a noticeable effect on the ability of the nearest female relative to undertake paid work outside the home.⁽⁶⁰⁾

Is it possible to envisage a community care policy for infirm parents which does not gravely disadvantage their daughters' employment? Such a policy would need to ensure that the daughters did not feel under continual pressure to give up work. In this study, the heavy domestic burden that many had in addition to their work outside the home, contributed to this pressure. Increased support from the home help service, already discussed in this chapter, would have helped to relieve the situation. By failing to offer appropriate support for the highly dependent parents, such as day care, regular respite care, a night nursing service and social worker mobilisation of voluntary support in the community, the statutory system itself contributed to sex inequality of opportunity in employment because the daughters were far more likely than the sons to have these highly dependent parents.

A tension exists between a work role and a caring role because of a highly dependent person's need for attention during normal work hours. Working carers, whether daughters or sons, need consideration from their employers. Flexibility of hours, making it possible to give the parent adequate attention before going to work, and the acceptance of the carer's need to take leave from work, if the parent becomes too ill to be left alone, would contribute to the carer's ability to maintain the two roles of worker and carer successfully.

In conclusion

Despite all the rhetoric about community care in various gov-

ernment papers for at least the past quarter of a century, the conclusion is inescapable that, as far as the single carers in this study were concerned, community care remained an empty, unrealised ideal. Care in the community was very far removed from the care by the community talked about in the 1981 government white paper on the elderly.⁽⁶¹⁾ On the whole, the daughters and sons in the study received insufficient support from the informal system; they could rarely afford to purchase care through the commercial system; the statutory syestem generally failed to provide appropriate services for the highly dependent parents and the voluntary system was scarcely in evidence. Many of these carers suffered a great deal in continuing to look after their parents at home.

It is unjust that the burden of care for the very dependent elderly should fall so unevenly on one person simply because that individual is unmarried. Care should far more equitably be shared with other family members, with other people in the community and with the State. This raises issues at several different levels. At one level, far more consciousness is required in society as a whole of the problems posed by infirmity and dependency in the very old. Such consciousness should be raised amongst the young by education in school about modern social issues. Sympathetic and informed discussion in the media would contribute to a wider understanding. At a more specific level, doctors, district nurses and social workers need to receive more training in understanding the needs of supporting family members as well as the elderly infirm. Their training should give them a knowledge of the potentially supportive statutory and voluntary social services and an appreciation of their own significance in making referrals. They have a responsibility not only to empathise with the carers but to become agents for change by positively advocating improvements in supportive services.

Infirm elderly parents often need to be far more sensitive to the needs of their single offspring to have relief from the constant burden of care. They should be willing to comply with arrangements

such as respite care, holidays with other offspring and the company of somebody other than the single carer for some evenings. It is impossible to ignore the evidence that some carers problems were compounded by their parents' selfishness. Such parents also need their consciousness to be raised about the needs of their own children to enjoy some form of independent existence.

At the local level, social services departments should be prepared to explore methods of forming partnerships in social care with the informal carers and the voluntary sector. At the same time, it is essential that both central government and local authorities be prepared to ensure that there is an adequate investment in support services such as day care and respite care for very dependent parents to relieve the strain experienced by both working and non-working single carers.

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APPENDICES

* Please delete whichever does not apply.

Appendix 2 The Interview Schedule

Background data

1. The district health authority.
2. The local authority.
3. Respondent's name and address.
4. Respondent's sex.
5. Respondent's age.
6. Household composition.
7. Is the respondent caring for mother, father or both parents?
8. Respondent's age.
9. Parent's (or parents') age(s).
10. Respondent's educational qualifications.
11. Age at which respondent left school.
12. Housing tenure.
13. Type of house.
14. Car ownership.

Parental impairments and disabilities

15. What is your mother's (father's) main disability?
16. How long has that been for?
17. Is she/he ill in any other way?
18. Has she/he been admitted to hospital in the past five years?

If yes

19. How long was she/he there?
20. Why was she/he admitted?
21. Is she/he able to do heavy housework?
22. Is she/he able to do any shopping?
23. Can she/he prepare and cook a hot meal?
24. Can she/he go up and down stairs?
25. Can she/he cut her/his own toenails?
26. Is she/he able to hang out washing?
27. Can she/he tie a good knot in string?
28. Is she/he able to wash herself/himself down or bath?

If mother/father needs help in bathing

29. Who helps?
30. Does she/he need help in getting in and out of bed?
31. Does she/he need help in dressing?
32. Does your mother/father use a commode or bedpan?
33. Does your mother/father have any difficulty in getting to the toilet
34. Does your mother/father need help in going to the toilet?
35. Is the toilet inside or outside the house?
36. Are there steps to the toilet?

If parent needs help in going to the toilet at night

37. How many times do you usually have to get up?

38. Does your mother/father need attention at night for any other reason?

If yes

39. How many times do you usually get up?
40. How long ago did you start getting up during the night?
41. How do you feel about that?
42. Does your mother/father ever lose control of the bladder?

If yes

43. Does it happen often?
44. How do you feel about coping with this?
45. Does she/he ever lose control of the bowels?

If yes

46. Does it happen often?
47. How do you feel about coping with this?
48. How do you cope with any soiled linen?
49. Do you use disposable pads or sheets?

If yes

50. Who pays for them?
51. What do you find the most difficult thing in looking after your mother/father?
52. Is your parent at all deaf?
53. Does your parent have good sight?
54. Does your parent get depressed?
55. Is your parent forgetful?

If yes

56. How bad is her/his memory?
57. Does your parent get confused?

If yes

58. In what way?
59. Is your parent able to get out of the house at all?

If yes

60. How often?

Respondent's Health

- 61. Do you have any health problems?
- 62. Have you had any health problems in the past five years?

If yes

- 63. Has this affected caring for your mother/father in any way?
- 64. Have you been admitted to hospital in the past five years?

If yes

- 65. How long were you there?
- 66. What happened to your parent at that time?

Amenities

- 67. Is the house/flat convenient for you and your mother/father?

If not

- 68. What is the difficulty?
- 69. What means of heating do you have?
- 70. Are you satisfied with this?
- 71. Do you have running hot water?
- 72. Do you have a telephone?

If yes

- 73. Who paid for it to be installed?

Household management

- 74. Does your mother/father do any housework?
- 75. Do you have any help with housework?

If no home help

- 76. Have you ever applied for a home help?

If home help

- 77. How many times a week does she come?
- 78. Is that about right or do you wish she would come more often?
- 79. What has your experience of the home help service been?
- 80. Who first suggested having a home help or was it your idea?
- 81. Do you have any help with cooking?
- 82. Do you have any help with shopping?
- 83. Do you have any difficulty with the shopping?

District nurse

- 84. How often does the district nurse call?
- 85. What are the main things she does for your mother/father?
- 86. Do you feel that you would like her to come more often?
- 87. Are there any other things that you wish she could do for your mother/father?
- 88. Do you feel satisfied with what the nurse does for your mother/father or is there anything you feel dissatisfied with?

General Practitioner

- 89. Does the doctor call to see your mother/father at home?

If yes

- 90. Does he call regularly or when sent for?

If no to question 89

- 91. Do you want her/him to call to see your mother/father?
- 92. Does your mother/father ever manage to go to the surgery?
- 93. Do you usually go along to the surgery for your mother/father?

If yes

- 94. Do you usually see the doctor or do you usually collect a prescription from the receptionist?
- 95. Has your mother's/father's doctor been a help to you?

Social Worker

- 96. Has a social worker called to see you or your parent?

If yes

- 97. How many times has a social worker called?
- 98. Has any social worker called in the last year?

If social worker called more than once

- 99. Has it always been the same one?
- 100. Would you have preferred her/him to call more often or was that about right?
- 101. How did you first come into contact with the social worker?
- 102. Would you say that the social worker has been a help to you?
- 103. Is there anything else that you wish the social worker could have done to help?

Support Services

104. Does your parent go to a day centre or day hospital?

If yes

105. How often?

106. What does she/he think of it?

If no to 104

107. If there was an opportunity for your parent to go to a day centre would she/he want to go?

108. Would you wish her/him to go?

109. Has your parent ever had Meals on Wheels?

If yes

110. What does your parent think of them?

111. What is your opinion?

112. Who first suggested Meals on Wheels?

113. Has your parent ever been to a chiropodist or had one visit?

If yes

114. Can you remember who suggested it?

115. Have any adaptations been made to the house for the parent?

If yes

116. Who did it?

117. Who paid for it to be done?

118. Does your parent use any aids for the handicapped?

If yes

119. Where did it come from?

Employment

120. What is (or was) your job?

121. How long have you (did you) work(ed) there for?

122. What about before that?

123. Do you (did you) like your job?

For those employed currently

124. How long are you away from home?

125. Do you normally come home for lunch?

126. Do you have to take time off work because of your parent?

If yes

127. What is your employer's attitude?

128. Is there any part of the day when you are worried about your parent?

For those working part-time

129. Why are you working part-time?
130. Have you ever worked full-time?

If yes

131. What happened?

For those not working

132. Have you ever had a paid job?

If no

133. Why is that?

If yes

134. What was it?
135. Why did you stop working?

If because of the parent

136. What was the main difficulty which made you feel unable to continue?
137. How did you feel about stopping work at the time?
138. Do you feel any differently now?

Leisure

139. Do you go on holiday usually?
140. Is it difficult to get away?
141. When did you last go on holiday?
142. What arrangements were made last time for your parent?
143. What arrangements have been made in the last five years?
144. When did your parent last go on holiday?
145. Has your parent ever gone into a Home or a hospital for you to go on holiday or to have a break?
146. Do you go out regularly in the evening?

If yes

147. Where do you usually go?
148. Do you get out at all at the week-end for relaxation?

Singleness

149. Have you ever lived away from home?
150. What are the advantages of being single?
151. What are the disadvantages of being single?

- 152. Do you ever wish you had got married?
- 153. Why?
- 154. Has there ever been an occasion on which you wanted to get married?

Relatives

- 155. Do you have any brothers or sisters?

If yes ask for each one

- 156. Is she/he married?
- 157. Does she/he have a family?
- 158. Is she/he working? if so what does she/he do?
- 159. Where does she/he live?
- 160. How often does she/he visit?
- 161. Does she/he help in any way at all?
- 162. Do you have any other relatives living in the area?

If yes

- 163. Do they call round to see you and your parent at all?
- 164. Is there anything in particular that they help you or your parent with?

Neighbours

- 165. Are there any neighbours you feel able to call in on?
- 166. Are there any neighbours who call in to see you or your mother/father?
- 167. Does any neighbour help you or your mother/father in any way?
- 168. Is there anything you wish neighbours could help with?

Friends

- 169. Do you have any friends that you are able to see regularly?

If yes

- 170. Where do you usually meet?
- 171. Is there any way in which your friend(s) is/are able to help you and your parent?

Voluntary Organisations

- 172. Do you go to church?
- 173. Are you or your parent visited by anybody from a church?
- 174. Are you or your parent visited by anybody from a voluntary organisation or a volunteer?

If yes

- 175. How did that happen?
- 176. Are you helped in any practical way?

Finances

If not working and not retired

- 177. How have you managed financially since stopping work?
- 178. Have you continued to pay the National Insurance contribution?
- 179. Have you ever applied for supplementary benefit?

If yes

- 180. Can you tell me what happened?
- 181. Has your parent ever applied for an attendance allowance?

If yes

- 182. Did anyone else suggest applying for it or was it your own idea?
- 183. What was the result?
- 184. How many times was an application made for the attendance allowance?

If parent has the attendance allowance

- 185. What difference has the allowance made?
- 186. Can you give me a general idea of what the allowance is used for?
- 187. How long has your parent had the allowance for?
- 188. Have you ever applied for an invalid care allowance?

If yes

- 189. What happened?

If has the I.C.A.

- 190. What difference has it made to you?
- 191. What was the situation before you received it?
- 192. What is your opinion of it?

Appendix 3 The Malaise Inventory

PLEASE RING CORRECT ANSWER

- | | | | |
|-----|--|-----|----|
| 1. | Do you often have back-ache? | Yes | No |
| 2. | Do you feel tired most of the time? | Yes | No |
| 3. | Do you often feel miserable or depressed? | Yes | No |
| 4. | Do you often have bad headaches? | Yes | No |
| 5. | Do you often get worried about things? | Yes | No |
| 6. | Do you usually have great difficulty in falling asleep or staying awake? | Yes | No |
| 7. | Do you usually wake unnecessarily early in the morning? | Yes | No |
| 8. | Do you usually wear yourself out worrying about your health? | Yes | No |
| 9. | Do you often get into a violent rage? | Yes | No |
| 10. | Do people often annoy and irritate you? | Yes | No |
| 11. | Have you, at times, had a twitching of the face, head or shoulders? | Yes | No |
| 12. | Do you often suddenly become scared for no reason? | Yes | No |
| 13. | Are you scared to be alone when there are no friends near you? | Yes | No |
| 14. | Are you easily upset or irritated? | Yes | No |
| 15. | Are you frightened of going out alone or meeting people? | Yes | No |
| 16. | Are you constantly keyed up and jittery? | Yes | No |
| 17. | Do you suffer from indigestion | Yes | No |
| 18. | Do you suffer from an upset stomach? | Yes | No |
| 19. | Is your appetite poor? | Yes | No |
| 20. | Does every little thing get on your nerves and wear you out? | Yes | No |

- | | | |
|---|-----|----|
| 21. Does your heart often race like mad? | Yes | No |
| 22. Do you often have bad pains in your eyes? | Yes | No |
| 23. Are you troubled with rheumatism or fibrositis? | Yes | No |
| 24. Have you ever had a nervous breakdown? | Yes | No |

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