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FOREWORD

by the Prime Minister, The Rt. Hon. Tony Blair, MP



When I talk about the importance to Britain of strong communities and of people having responsibilities towards each other, I'm not speaking of abstract ideas, but of real people and real events: the things many people do to make things better for those around them.

The extraordinary work which carers do may well be the best example of what I mean. Extraordinary not in ways which make headlines, but in ways which really matter and which really make a difference to those they are caring for.

Carers devote large parts of their own lives to the lives of others – not as part of a job, but voluntarily. And often in addition to working themselves. For the sick, the frail, the vulnerable and the elderly, carers provide help and support in ways which might otherwise not be available. By their effort, their patience, their knowledge, their understanding, their companionship, their determination and their compassion, carers very often transform the lives of the people they're caring for – even if the difficulties they're grappling with still remain. Carers are among the unsung heroes of British life.

We all may need care, or to provide care. When I was a boy, I watched my own mother care for my father after he had a stroke. Like her, there are now many people – daughters, sons, parents, relatives, friends and neighbours – who give help and support in many, many ways to those they're caring for.

Caring is personal. It is individual. But it is social too; and the Government can help in its own way. The very first group of people I invited in to Downing Street when I became Prime Minister were carers. We have already taken action which will help carers, including the New Deal for the disabled and tax help for mothers with dependent children and disabled spouses. But we want to do more.

The national strategy for carers – the first ever by a Government in Britain – sets out what we have been doing, and what we are going to do. It offers practical help in ways which are needed, and which will work. Carers will have better information. They will be better supported. They will be cared for better themselves.

This makes a decisive change from what has gone before. While we will continue to make sure that help goes directly to people who need it, we will now ensure that help is offered to carers themselves as well – because helping carers is often a good way of helping those they're caring for. Caring for carers is a vital element in caring for those who need care.

What carers do should be properly recognised, and properly supported – and the Government should play its part. Carers should be able to take pride in what they do. And in turn, we should take pride in carers. I am determined to see that they do – and that we all do.



EXECUTIVE SUMMARY

We are giving new support to carers – because we value what they do.
Carers care for those in need of care.
We now need to care about carers.

So the Government is bringing forward for the first time a **new substantial policy package** about carers.

- Caring may affect **every one** of us.
- We may all **need care**, or need to provide care.
- Caring forms a vital part of the **fabric and character** of Britain.
- One in eight people in Britain is now a carer – close to **6 million people**.
- **Women** are more likely to be carers than men.
- Three-fifths of carers are looking after someone with a **disability**.
- 855,000 carers provide care for more than **50 hours a week**.
- Three-fifths of all carers receive **no regular visitor support services** at all.
- Carers' needs are currently only being **met patchily**.

What carers want

- wellbeing of the person being cared for
- freedom to have a life of their own
- maintaining their own health
- confidence in services
- a say in service provision

- Two thirds of working-age carers are in paid **employment**.
- **Flexibility** is central to their employment.
- Clear **business case** for carer-friendly employment policies:
 - **cost:** reduced turnover of staff, absenteeism
 - **flexibility:** labour availability, matching of work
 - **motivation:** improved morale
 - **performance:** business success

The Government is taking action on family-friendly employment by offering **unpaid leave for family emergencies** for employees.

Helping carers is one of the **best ways of helping** people they are caring for.

All organisations involved with caring must now focus not just on the client, patient or user – but must **include the carer**.

The Government believes caring should become something that people can **do with pride**. Our new approach to carers has **three strategic elements**:

- Information:**
 - **new charter** on what people can expect from long-term care services: setting new standards
 - consider how to **improve the consistency of charging** for services
 - carers need good **health information**
 - NHS Direct **helpline** for carer information
 - Government information on the **internet**
- Support:**
 - carers need to be involved in **planning and providing** services
 - local caring organisations should be **consulted**
 - Comment cards, advice surgeries, carers' weeks are good ways to **involve carers**
- Care:**
 - carers' right to have their **own health needs** met
 - **new powers** for local authorities to provide services for carers, as well as for those being cared for
 - first focus of the new powers should be on helping carers **take a break**
 - **new special grant** to help carers take a break

- on top of the £750 million for prevention and rehabilitation, there will be **£140 million** over the next three years to help carers take a break, to be used in a targeted way
- **financial support** for working carers to be kept under review.

There are special measures for carers in employment and young carers. The Government's **carers' package** also includes:

- **new legislation** to allow authorities to address carers' needs
- time spent caring will entitle carers to a **second pension**
- Government **consulting** on proposals, but by 2050, carers could receive an **extra £50 a week** in today's terms
- **reducing council tax** for more disabled people being cared for
- support for neighbourhood services, including **carers' centres**
- considering scope for extending help to carers to **return to work**
- new **census** question to tackle incomplete information about carers
- support for **young carers**, including help at school
- special funding for **breaks for carers**.

CHAPTER 1

Introduction: Caring about carers

1. Carers play a vital role – looking after those who are sick, disabled, vulnerable or frail. The Government believes that caring should be something which people do with pride. We value the work that carers do. So we are giving new support to carers. Carers care for those in need of care. We now need to care about carers.

2. We may all need to provide or arrange care for a loved one. Most carers choose to care – for reasons of love, loyalty, friendship or support for others. Many at least initially do not realise that, in the help they are offering, especially during periods of crisis, they are becoming carers. The people for whom they are caring usually value the help and support, often on a very intimate level which they receive, and they usually want the caring relationship to continue. The main aim of carers is to ensure that the person they care for is all right and is getting the best support. Caring can bring – as many carers will know – sleepless nights, physical effort and a feeling of being an intruder in someone else’s most intimate business. But at the same time, most carers will recognise how close a caring relationship can be, and how rewarding.

3. Everyone feels the effect of caring. One in eight people in Britain is now a carer – looking after someone who is ill, frail, disabled or unable to cope. Without this extensive caring, many more elderly, frail, sick or disabled people would need the support of the statutory services, and might need to enter a residential or nursing home or go into hospital. This might be a detriment to the quality of life for some people needing care, and would be at considerable cost to the taxpayer. In communities, the networks of giving, of caring, and of supporting relatives, friends and neighbours are part of the glue that helps join society together.

4. The need for care can arise in different ways. Sometimes a person’s need for care increases gradually, perhaps as they grow older and frailer, or perhaps because they are suffering from dementia or a similar progressive condition. Carers of people in these circumstances may find

themselves gradually giving more and more help as the days go by. They may not even notice that the stresses and strains of caring for almost 24 hours a day are beginning to affect their health.

5. Other carers, such as parents, may begin a relationship with their son or daughter knowing, from well before the birth takes place, that their child's needs and disability will mean there will be a need for care, far exceeding that needed by most children, until the child becomes an adult and sometimes for even longer. For other people, caring is something which suddenly impacts upon their lives – because their relative or friend suffers a road accident, a stroke, or perhaps a broken hip. In these circumstances the need for adjustment to the caring role is intense and rapid.

6. People who provide care for others are a very diverse group, with diverse needs. A man of 70, caring for his wife with Alzheimer's Disease during all her waking hours, may have very different needs from the 30 year old parent of a severely disabled child, from the 40 year old wife of someone who has suffered a head injury in a road accident, or from a child of 14 whose single parent has mental health problems.

7. The Government values carers and will support them in their caring role. Too often in the past, bureaucratic restrictions have made it difficult to target help at carers themselves. But helping carers is one of the best ways of helping the people they are caring for. Help for carers cannot be seen in isolation from help for the person for whom they are caring. Providers of the range of services and benefits which exist to meet the needs of sick, disabled or frail elderly people must recognise that the patient or user of services and their carer are closely linked, and must not neglect the carer's existence and needs when they are looking at and meeting the needs of the patient or user.

8. We know that almost all carers need some help and support to enable them to continue to care. We have already introduced policies which will help carers. In June 1998, the Prime Minister announced that there would be a National Strategy for Carers. Whilst we recognise that no single straightforward measure can meet the needs of all groups of carers, this National Strategy for Carers builds on the work we have already done and sets the direction for the years ahead. To care for those needing care must be added caring about the carers.

A national strategy

9. The terms of reference of the National Strategy for Carers were:

“To draw together existing work within Government that impacts on carers; to take account of the emerging findings of the Royal Commission on Long-Term Care; to gather examples of best practice in providing help for carers at local level, to assess whether any key needs of carers have been overlooked; to clarify the Government’s objectives for carers; to set out an integrated strategy for future action by Government; and to report to the Prime Minister by January 1999.”

We have worked with a wide range of individuals and organisations to take this strategy forward. We are grateful to all those who took part in the work, and especially to those who contributed to a consultative conference held on 19 November 1998. The report of the conference is being published in association with this document.

10. We recognise that caring is founded on close relationships. The caring role grows out of the relationship and is one which most carers undertake from choice. Our objective is, therefore, focused on enabling those who choose to care, and whose care is wanted by another person, to do so without detriment to the carer’s inclusion in society and to their health. Our aim is to support people who choose to be carers.

11. The Government’s strategy for carers has three key approaches:

Information for carers, so that they become real partners in the provision of the care to the person they are looking after, with the means to provide that care as well as they all wish to, and with wider and better sources of information about the help and services which are available to them.

Support for carers, from the communities in which they live, in the planning and provision of the services that they and the person they are caring for use, and in the development of policies in the workplace which will help them to combine employment with caring.

Care for carers, so that they can make real choices about the way they run their lives, so that they can maintain their health, exercise independence, and so that their role can be recognised by policymakers and the statutory services.

This strategy also deals with two particular groups: carers in employment and the special needs of young carers.

12. Helping carers is a good way to help those they are caring for. But there is another side to this – the risk that the lives of people in a caring relationship might become so inextricably entwined that one individual can have no independence of the other. Most human beings need some time to themselves, and the ability, time and energy to pursue their own interests, or see their own friends. Independence of two people in a caring relationship can immensely strengthen that relationship. Too often, building an effective partnership with carers in providing care for the most vulnerable members of our communities fails to recognise that the carer is an individual in their own right. We will address this, by empowering carers to make more choices for themselves and to have more control over their lives.

13. We want to strike the right balance. By empowering carers we are not taking away any of the rights of the people who need care, nor recognising their needs any the less. We are already introducing a range of initiatives to support people with disabilities, including legislation to set up a “Disability Rights Commission”. Our policies and procedures should ensure that **both** people in the caring relationship are valued. We must not subordinate the needs and wishes of one party to those of the other. Achieving this balance is never easy. But it remains our aim.

14. Caring must become something people can do with pride. It is one of the most valuable roles anyone can fulfil. Just as this Government recognises that parenting is a valuable, worthwhile, difficult and rewarding role, for which parents need help and support, so equally we value caring and will value and support the carers who provide it.

15. In making caring a source of pride, we want to enable carers to discuss their role and responsibilities freely in a range of situations. Caring for a very old person, perhaps with dementia or incontinence, or for someone with a mental health problem, such as schizophrenia, can be something that many people are reluctant to discuss. Carers need to be able to tell others about their caring without the fear of stigma, and without any concern that this could place them in a difficult or detrimental position and, most particularly, in the work place, so that

employers can recognise their needs and the value they can bring to the organisation.

16. The Government wants all organisations involved in caring to recognise that they can no longer have a focus just on the client, patient or the user. They must see the person needing care and support within the whole environment of their family, their neighbourhood and their community. This must include their carer or carers. Statutory services must take an inclusive approach – one which the voluntary sector, in many respects, has been following for a long time.

17. There is a wealth of guidance on supporting carers, and numerous examples of good practice. But carers' main needs are not being met, in some parts of the country at least, as well as they should be. Carers are not sufficiently high on the agenda of some organisations and in some service areas. The Government's new approach to carers, set out in this national strategy, offers a new direction and a new emphasis which will place a new value on the vital and important work which carers do – for the people they care for, and for everyone in the United Kingdom.

CHAPTER 2

Carers

1. Britain¹ has an estimated 5.7 million carers and one in six households – 17 per cent – contains a carer. In Northern Ireland, there are an estimated 250,000 carers². Most caring is based on close personal relationships.

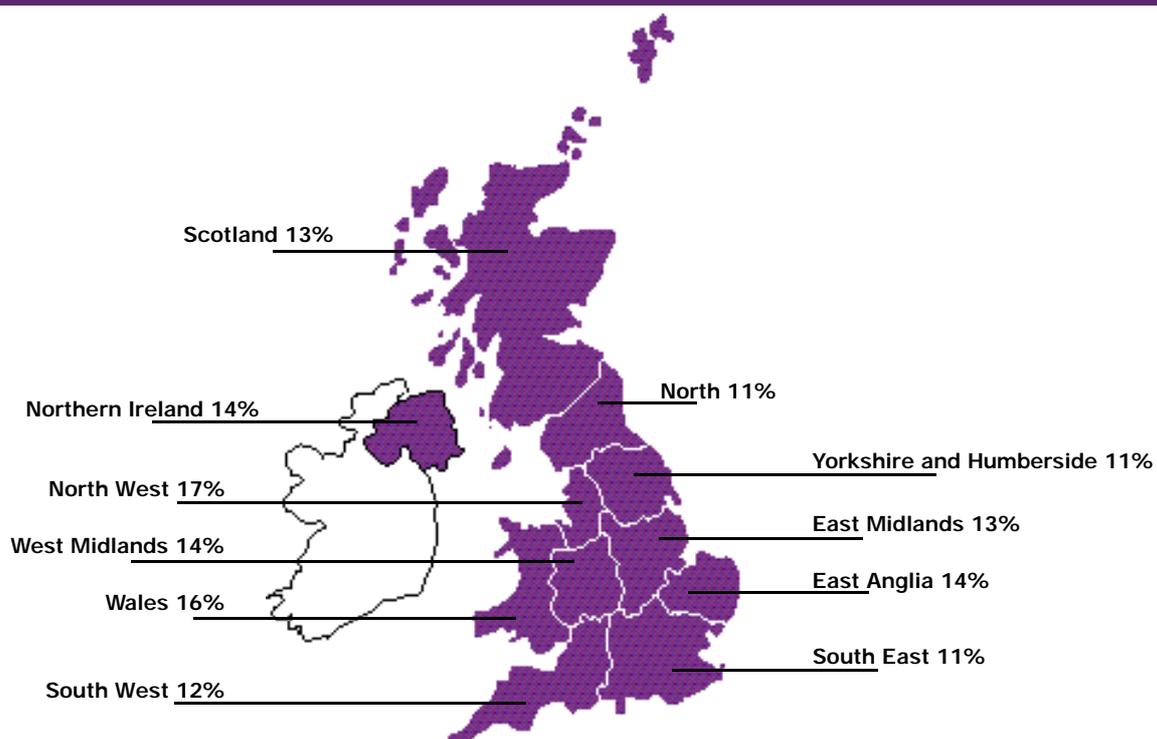
2. The proportion of adults who are carers varies between the countries and regions, and the map below illustrates this.

3. Women are more likely to be carers than men – 58 per cent of carers in Britain are women, compared with 42 per cent who are men. Women are also more likely than men to carry the main responsibility for caring, where there is more than one person with some responsibility.

Characteristics of carers

- 3.3 million women; 2.4 million men;
- Most likely to be aged 45-64;
- 9 out of 10 carers care for a relative:-
 - 2 out of 10 for partner or spouse
 - 4 out of 10 for parent(s)
- One half of all carers look after someone aged over 75
- 18% of carers look after more than one person.

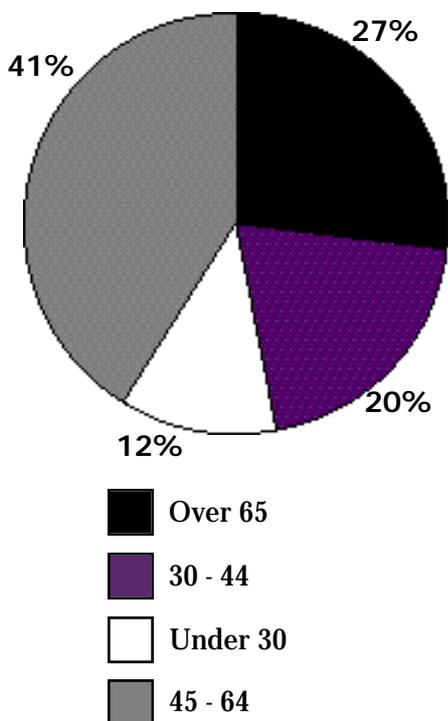
MAP SHOWING THE PERCENTAGE OF THE ADULT POPULATION WHO ARE CARERS



¹ *Informal Carers* Office for National Statistics, 1998

² Source of data on carers in Northern Ireland is the *Continuous Household Survey, 1995/96*

Diagram 2
Carers by age



Source: General Household Survey, 1995

4. A fifth of all adults aged 45-64 provide informal care. Diagram 2 shows how the total number of carers in Great Britain break down by age group.

5. Around 1.9 million of the carers in Great Britain are caring for someone in the same household. Just over half of these were caring for their spouse, just over one-fifth were caring for their parents or parents-in-law, and a further fifth were caring for disabled or sick children.

6. When asked to describe the reasons that they were providing care, the majority of carers – 60 per cent – said they were looking after someone with a physical disability, a further 15 per cent were looking after someone with both a mental and a physical disability, and 7 per cent looked after someone who was unable to care for him or herself because of a mental health problem. The remaining carers almost all said that the person they cared for needed help because of the results of ageing.

Time spent caring

7. Of the estimated total 5.7 million people who are carers in Great Britain, 1.7 million devote at least 20 hours a week to caring. Of those, 855,000 care for 50 hours a week or more. The amounts of time spent by men and women on caring were very similar. People who share a household with the person they are caring for tend to spend more of their time caring – 38 per cent of them spent at least 50 hours a week.

8. Nearly a quarter of carers had been looking after the person they had cared for at least ten years, and a further quarter had looked after him or her for between 5 and 9 years.

Economic status

9. 49 per cent of carers in Great Britain are working, either full or part-time. A further 26 per cent are retired. The remainder – 25 per cent – are either unemployed or economically inactive – which includes those unable to work, perhaps because of their own illness or disability or because of the nature of their caring responsibilities. In Northern Ireland, 42 per cent of carers are working, 4 per cent are unemployed and 54 per cent are economically inactive. Diagram 3 shows the proportion of carers who are economically active.

10. Of the carers who are working full-time, nearly 20 per cent provide care for more than 20 hours a week. Remarkably, 4 per cent of the carers in full time work *also* provide care for over 50 hours a week.

11. However, as might be expected, the proportion of carers who are not working – because they are unemployed, retired or otherwise economically inactive – and who are providing 20 or more hours a week of care, is considerably greater than among those who are working, as Diagram 4 illustrates.

Services and benefits

12. Very few of our current sources of information about receipt of services and benefits collect information about carers. Most of the information collected by social services departments, for example, concentrates on the person receiving community care services rather than on their carer.

13. The General Household Survey for 1995 shows the proportion of carers where the person for whom they were caring received regular visits from the health service, the social services (including private sector services) or

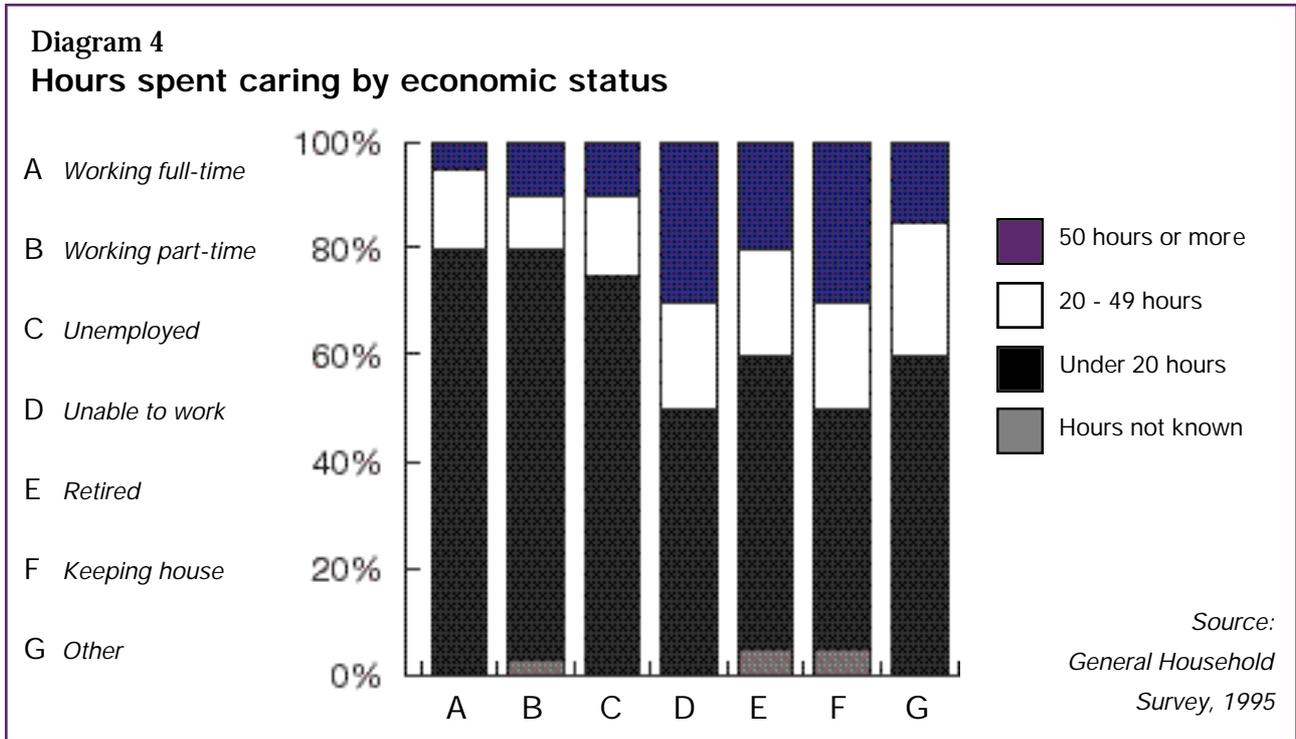
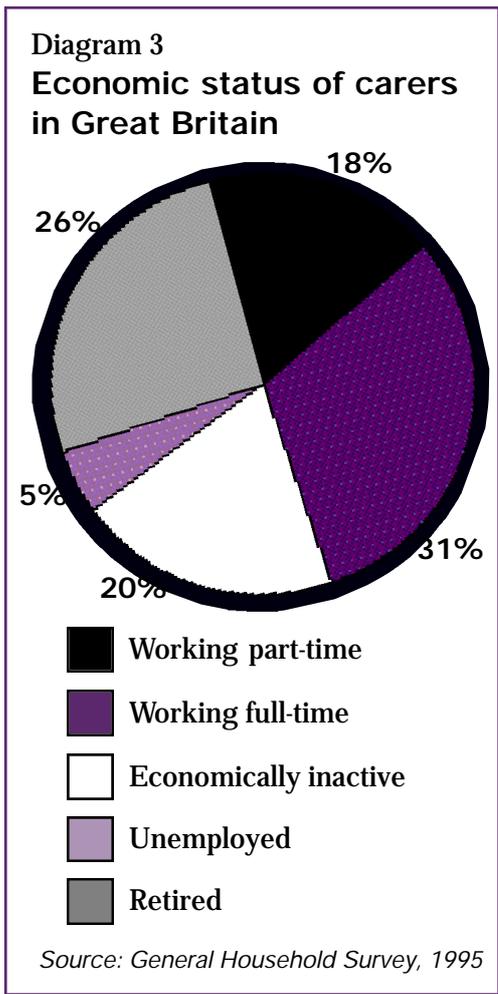


Diagram 5
Percentage of carers where the person being cared for is receiving services.
Visits from:-

Doctor	12%
Community or District Nurse	15%
Health Visitor	4%
Social Worker	7%
Home Help	22%
Meals on Wheels	8%
Voluntary Worker	3%
Other	3%
No Regular Visitor	59%

voluntary sector services. The information is set out in Diagram 5. This shows that nearly 60 per cent of carers had no regular visits from any of these service providers.

14. 33 per cent of all carers look after someone who is getting some form of social service, including respite care. Of people caring for more than 20 hours a week, 29 per cent are receiving some social services help, including help which they purchase privately. This proportion for those caring for over 50 hours a week is 31 per cent.

Trends in caring

15. The total number of carers in Britain is changing. According to the General Household Survey, which asked questions about carers in 1985, 1990 and 1995, over this 10-year period, the total number of carers has risen from 6 to 6.8 million, and then fallen back to 5.7 million.

16. Social trends may affect the supply of care. Increased participation of women in the labour market might be thought to result in a reduction in the supply of people able to care. In 1975, about half of married women aged 18-34 had some paid work; by 1995 this had increased to over 70 per cent. More women now work full-time. Across all age groups, women are less likely to be a carer if they are in paid work. On the other hand, a considerable proportion of carers are in paid employment and more people may find they are able, because of improved flexibilities in their working conditions, to combine employment with their caring responsibilities.

17. There are other social trends which could have an effect on the extent of caring in future. In particular, the growth in the number of lone parents, changes in patterns of marriage, the increase in the number of people living alone, and increased mobility among family members, may mean that people will be less likely in future to be part of the sort of relationships which can result in informal caring when someone becomes sick, disabled, vulnerable or frail.

18. In the past, older women were substantially more likely than older men to be living alone. But women who are now entering old age have a much greater chance than those in the past of still living with a spouse. Older people who need care, and who are married, are much more likely to receive that care from their partner than from anyone else.

19. But there may also be an increasing demand for care, caused by the growth in the numbers of old and frail people living in the community. The demand for informal care may be influenced by the proportion of older people who have care needs and the proportion of them who have those needs met in the form of long term care, whether in a residential or nursing home, a hospital, or by statutory services in the community. The estimated numbers of older people living in the community who were unable to wash themselves rose between 1991 and 1995, and the numbers unable to do their household shopping rose substantially between 1985 and 1991.

20. The work of the National Health Service may have an impact on the demand for care. Some of the reasons why people need care are preventable. Action to reduce the incidence of osteoporosis, for example, should reduce the number of older people with fragile bones who may need care after a fall which results in a hip fracture. The Government's initiative to improve the health of the whole nation as set out in our Green Paper *Our Healthier Nation*³ aims to reduce the numbers of people suffering from two of the main conditions which can lead to a need for care – strokes or the result of accidents. Better rehabilitation, following a period of time in hospital, will increase independence and may reduce the need for long term care. On the other hand, medical advance, such as the ability to save the lives of very premature babies, may increase the numbers of people with conditions which need care.

New information

21. The General Household Survey covers only a small proportion of carers in Great Britain and the figures given can only be approximate. There remain many areas where we have insufficient information. These include the numbers of carers from black and ethnic minorities and the number of young carers, aged less than 18. We also have no clear data about the distribution of carers in local authority areas, which would allow better estimates of the need for services to be produced by local service planners.

22. To improve the information we hold, the Government intends to trial a new question for use in the 2001 Census. We intend to target the question on provision of personal care, and to enquire about the number of hours per week for which care is provided.

If the trials are effective, the question will be included in the Census.

2001 census

- A new question on caring
- Completed by *everyone*
- Will give details on the numbers of carers *by area*
- Information on specific groups of carers *for the first time*
- Data on young carers and carers from black and ethnic minorities.

³ In Wales the Green Paper was called *Better Health – Better Wales*, and in Scotland *Working For a Healthier Scotland*

What helps carers to cope

23. Carers undoubtedly experience higher than average levels of stress. There is a growing body of research evidence⁴ which suggests what is significant in helping carers to cope and to continue to care, including:

- time off from caring
- relief from isolation, and satisfaction with the help they receive from their family and others
- receipt of reliable and satisfactory services
- information
- recognition of their role and contribution.

24. Time off from caring means different sorts of breaks, depending on the needs and circumstances of the carer and person they are caring for. Crucially, whether a day, evening or longer break, the aim should be to allow the carer to maintain aspects of their own life, including employment. Carers want to be involved in decisions on which services are best for them and the person they care for.

25. Emotional support may best be met by family and friends, or in more organised ways such as through support groups. Skilled help at particular times – for example near the start of caring or if the condition of the person being cared for changes – can be of considerable assistance to the carer. Recent research⁵ suggests that it may result in an increased ability to continue to care.

26. Information and advice about the health or condition of the person they are caring for, how to cope with it and about the services and benefits available is vital. Research continues to show that carers have difficulty in obtaining this information.

27. Recognition of their contribution to the care of someone else and to society more widely is important to many carers. They value involvement in discussions about the help provided to them and the person they are caring for, as well as practical help with the tasks of caring.

⁴ Twigg J. Ed (1992) *Caring Research and Practice*

⁵ In preparation. *Evaluating Community Care for Older People Personal Social Services Research*

28. Crucially, the research emphasises that caring takes place within an existing relationship which is characterised by bonds of obligation, affection and reciprocity. It may be unclear when the caring role begins in that relationship, especially for older carers. Support for carers should recognise both the pleasures and pains of caring.

What motivates carers to care

29. Individuals may provide informal care for a range of reasons, personal to them. These range from ties of kinship and affection to a lack of good quality alternatives⁶. Some carers report feeling trapped in a relationship or worried about how it would look if they refused to care for a relative⁷. Those in full time employment, or who live at a distance, may choose to support their relative by paying for care rather than providing informal care themselves. People who need care may prefer the independence of buying professional care for themselves rather than receiving informal care from family members.

When informal caring comes to an end

30. When a carer for whatever reason ceases to care it can often be a difficult time. The carer may be advised by health or social service professionals that he or she is unable to carry on caring. A breakdown in the caring relationship may result from the threat of loss of employment or social life, from behaviour problems on the part of the person being cared for, from stress, because of the carer's own health problems, from the impact of the caring role on the family, or from a range of other factors⁸. After a caring relationship comes to an end, the carer may remain a carer in an emotional sense. There is sometimes an important role for professionals in facilitating the ending of the caring relationship by easing the carer out of a role they can no longer sustain but may feel very guilty about ending. Equally, professionals need to recognise that many carers will wish to continue to provide some care for their relative – for example when that person has entered a residential or nursing home.

What carers want from services

31. For many carers, a key issue is that the services provided should benefit the person for whom they are caring. The welfare of their spouse, son, mother, father, other relative or friend is central to their concerns. Integrating this with a regard for the carer's own needs is central to delivering the right type of response.

⁶ Quereshi H and Walker A, *The Caring Relationship* (1989), Macmillan

⁷ Eg Twigg J and Atkin K, *Carers Perceived* (1994), Open University Press; Finch J and Mason J, *Negotiating Family Responsibilities* (1993), Tavistock/Routledge

⁸ Nolan M, Grant G and Keady J, *Understanding Family Care: a multi-dimensional model of caring*

32. When asked about what mattered most to them, carers identified the following:⁹

- freedom to have a life of their own – in particular the ability to spend time with family and friends, or with the person for whom they are caring, free of the usual caring responsibilities. Remaining in employment was of particular importance for some. Such activities reduce the likelihood of carers becoming socially isolated.
- maintaining their own health and well being.
- confidence in the standard and reliability of services. Carers want to feel assured of the quality of services provided to the person for whom they are caring – both at present and for the future, such as in the event of their illness or death – and to be empowered, in some instances, to make use of alternatives to their own care.
- feeling that they share responsibility with service providers – and especially that their knowledge about the person they are caring for is respected in discussions. Practical and emotional support contribute to their wellbeing, as well as knowing that assistance will be available in a crisis.
- a say in the way services are provided. Carers expect that professionals should listen to and respect their views.

Conclusion

33. Carers' needs are diverse. As individuals, they will have their own particular needs – their own reasons for providing informal care or for ending the caring role. But a number of common factors emerge from what carers themselves tell us: emotional support, relief from isolation, receipt of reliable and satisfactory services, information, and recognition of their role and contribution can all work well in supporting carers. The evidence on what helps carers to continue to care, and on what matters most to them, has been central to the work of the National Carers' Strategy. The Government's proposals show how we will better meet carers' main needs.

CHAPTER 3

Carers and employment

1. Many carers will be working when the need to care arises. Two thirds of working age carers are in paid employment of some sort, whether full or part time, or are self employed. This means that around 2.7 million people combine work with providing informal care.

2. Most carers wish to carry on working. Where the hours of care are low, the impact on work is usually minimal. But half of all working carers spend over five hours per week on informal care, with 20 per cent caring for more than 20 hours.

Paid work is important to carers for many reasons:

- financial independence
- covering the costs of caring
- giving an external focus and source of satisfaction
- maintaining social networks and friendships
- self esteem.

"I need to work ... for Neil (son) because I'm better for him if I've been away and come back than if I'm there all the time." Joseph Rowntree Foundation Report – Combining work and care: working parents of disabled children

3. If carers have to reduce the hours that they work significantly, or give up work altogether, the financial and emotional implications can be far-reaching. Carers who stop work face an immediate reduction in income and the loss of companionship at work. Social exclusion is a very real possibility. A period without pension contributions has, in the past, had a long-term effect which lasted throughout retirement. The impact on women may be disproportionately large, especially if they have already had a period out of paid employment whilst caring for young children.

4. Carers' needs can be very simple – the opportunity to leave work on time or to have access to a telephone during the day for a call home to reassure themselves that all is well. As the hours of care increase, greater flexibility is required to enable carers to continue in work. Employees may need time off for emergencies or time out of the workplace to attend hospital appointments. Working hours may need to be rearranged or reduced. Carers need family friendly employment policies to help them to combine their caring responsibilities with paid work.

5. Many employers – large and small – understand the business benefits of accommodating carers' needs. Where concern for employee welfare is an integral part of business management, a good line manager will always try to find a solution which satisfies both the needs of the business and those of the employee. This enables the employer to retain valuable staff, enhance employee motivation and loyalty and avoid heavy recruitment and retraining costs. Unfortunately, some employers continue to see the needs of the family as an external problem, which is the sole responsibility of the employee.

“We were expected to work overtime. When I said I couldn't they said I had no interest in the work.”

“Employers do not understand the need to leave work promptly, and I am sure that I was once chosen for redundancy because of my lack of flexibility.” Source: Carers in Employment – A report on the development of policies to support carers at work. Princess Royal Trust for Carers. 1995

“I gave up work because I felt it was my duty to do so – I didn't really think about the emotional or financial implications – I should have.” A carer in Wales.

6. Looking to the future, there will be higher levels of employment among middle aged women – the group which has traditionally taken on the major share of caring – whilst at the same time family structures are becoming less stereotypical and more complex. Many middle aged men will find themselves faced with the responsibility for providing care for elderly parents without necessarily having a non-working spouse to lend support. The number of employees who also have a caring responsibility will probably increase. More people may choose to buy or arrange care for their elderly relatives rather than provide it directly themselves, though they are still likely to be called upon to deal with unexpected crises.

Supporting working carers

7. The Government is committed to supporting families, both those with children and wider family networks. We have set out steps to help parents who choose to work to do so¹⁰. Our work on family friendly employment is relevant to the needs of carers as well as parents of young children. We are also concerned that carers get the support they need to help them to balance their family commitments with their working lives.

The Government's objectives for carers who are of working age are:

- to encourage and enable carers to remain in work
- to help those carers who are unable to, or do not want to, combine paid work with caring to return to work when their caring responsibilities cease.

Encouraging and enabling carers to remain in work

8. Nearly three million people already successfully combine paid work and caring. Flexibility is the single most important factor which enables them to do so:

- flexible employment policies adopted by employers
- flexible support services

"When I was caring for my elderly mother other staff could not have been more supportive, particularly my line manager, who sought ways to ease some of the burdens when things were most difficult. I was given compassionate leave for emergencies such as hospitalisation. Local flexible arrangements enabled me to leave work early. A course on Managing Stress was also helpful."

Source: Carers in Employment – A report on the development of policies to support carers at work. Princess Royal Trust for Carers. 1995

"My line manager knows that his kindness has bought my undying loyalty for the rest of my life." A carer in Wales.

"Long distance" carers

Carers who live some distance away from their elderly relatives may only provide personal care at weekends, but they may feel constant responsibility for arranging care. They may need:

- time off from work in a crisis
- use of a telephone to arrange care, or to check on their relative during the day
- help from the local carers' centre (e.g. support for their relative from volunteers, and information about local services)
- particular support from the statutory services in their relative's area (so they should be included when primary care teams and social services authorities identify patients or service users who have a carer)

¹⁰ *Supporting Families* – a consultation document. October 1998.

Flexible employment policies

9. The Government attaches great importance to developing a modern approach to employee relations which allows individuals to meet both their work and family responsibilities. But one of the issues which we face in seeking to help carers is that people do not always identify themselves as being or likely to become a carer. Anyone can suddenly become a carer. In practice, caring is a very diverse activity which ranges from doing the shopping once a week or managing the finances of an elderly relative, to the full-time care which can be needed for a severely disabled child. We want to encourage a working environment where carers can feel free to discuss the work issues around their caring responsibilities.

10. We have already made sure that our work on family friendly policies includes carers and their needs. Our White Paper *Fairness at Work* sets out proposals to give all employees, including carers, the right to time off to deal with a family emergency. Surveys of carers have shown that this would be a great help to them. Parliament is debating legislation to give all employees this right by December 1999.

11. There is a clear business case for carer friendly employment policies. It has four key elements:

- | | |
|--------------------|--|
| cost issues | <ul style="list-style-type: none">• reduced staff turnover. Replacement and retraining costs can be as high as around 1 to 1½ times annual salary• lower absenteeism and sickness. Carers, like parents, may take days off sick to fulfil their caring duties• poor rates of return on investment if trained and experienced employees leave |
| labour flexibility | <ul style="list-style-type: none">• availability of a larger and more diverse labour pool• improved access to scarce skills• more flexible working patterns, which will enable better matching of peaks in work load |
| motivation | <ul style="list-style-type: none">• improved morale• greater staff loyalty• reduced levels of employee stress |
| performance | <ul style="list-style-type: none">• the way in which companies manage their people is crucial to business success. |

A research programme at Sheffield University has identified a clear link between an organisation's people management practices and its profitability.

This 10 year study is examining management practices in over 100 small and medium sized manufacturing companies in the UK. It has shown that human resource practice is significantly more influential than a number of other management policies such as use of competitive strategy, quality focus and investment in research and development.

A concern for employee welfare was shown to be the most significant predictor of a change in profitability¹¹.

12. For carers, a significant number of existing flexible employment policies and initiatives can easily be adapted to accommodate many of their needs. The existence of such provisions can enable carers to remain in paid work where otherwise they may have been forced to change employer or give up work altogether. The ‘work-life’ approach recognises that people have different interests and responsibilities they want to fulfil.

TYPE OF PROVISION	SPECIFIC RELEVANCE FOR CARERS
<p>Flexible Working Patterns:</p> <ul style="list-style-type: none"> • Part time working • Flexitime • Job-share • Annualized hours • Home/tele/flexi place working 	<p>Any of these can help carers remain at work. Many employers already offer these and find they also help the business to be more responsive to customers’ needs.</p>
<p>Leave Provisions</p> <ul style="list-style-type: none"> • Emergency family leave (paid or unpaid) • Employment breaks 	<p>Often targeted at parents, but in some cases these are being explicitly extended to encompass carers.</p>
<p>Other Provisions</p> <ul style="list-style-type: none"> • Information on caring for disabled children, elderly relatives or those with mental health problems • Help lines /Employee Assistance Programmes (which may include access to counselling) • Vouchers to cover the cost of child or elder care • Day Care Centres supported by employers • Support for informal networks of carers within the workplace 	<p>A key area for carers is access to information, particularly as the onset of caring can be sudden and unexpected.</p> <p>Technology can assist in the delivery of such information with screen based systems becoming increasingly available.</p>

13. The Government will review its own position as a major employer and ensure that carer friendly policies are in place. We will monitor the take up of such policies and measure their effectiveness. As a major employer we will join private sector organisations in participating in a project on flexible employment policies which is being developed by the Work-Life Research Centre, the independent European research centre which brings together researchers on employment, the family and community issues.

The table which follows shows the extent of “family friendly” policies in Government Departments and agencies.

"CARER-FRIENDLY" POLICIES IN GOVERNMENT DEPARTMENTS AND AGENCIES

	C&E	DETR	DFEE	DH	DSS	BA	DTI	HMT	HO	MOD	NIO	SO	WO	CO	PS
Flexible working hours	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Part-time working	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Job-sharing	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Career Break	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Home working	✓	✓	✓	✓	S	✓	✓	✓	✓	D		S	✓	D	✓
Term-time working	✓		✓	✓	✓	✓	✓	✓	S	D		✓		✓	S
Part year appointments	✓		✓	✓		✓	✓	✓		D					
Use of telephone	✓	✓	✓			✓	✓	✓		✓		✓	✓	D	
Costs covered when away from home for work/training	✓	✓	C	✓	✓	✓	✓	✓	C	C			✓		C
Unpaid leave for emergencies	✓	✓	✓	✓	✓	✓	D	D	D	D	D	✓	✓	D	D
Paid leave for emergencies	✓	✓	✓	✓	✓	✓	✓	D	D	✓	✓	✓	✓	D	D

Key

✓ - available

D - discretionary

S - in some areas of the Department only

C - only child care expenses specified

C&E Customs and Excise

DETR Department of the Environment, Transport and the Regions

DFEE Department for Education and Employment

DH Department of Health

DSS Department of Social Security

BA Benefits Agency

DTI Department of Trade and Industry

HMT The Treasury

HO Home Office

MoD Ministry of Defence

NIO Northern Ireland Office

SO Scottish Office

WO Welsh Office

CO Cabinet Office

PS Prison Service

14. The Government will encourage more employers to adopt carer-friendly policies. We recognise that employers face many different challenges and are undergoing a period of continuous and rapid change. But employers already have significant numbers of carers in their employment and this number will probably increase. The precise numbers will obviously depend on the individual profile of an employer's workforce, but at present around 11 per cent of all employees are carers.

15. Small and medium-sized businesses may be concerned that accommodating carers' needs would be difficult and costly. Often, however, they are more responsive in practice than many of the larger organisations which have a wide range of formal policies for parents and carers. Their smaller size enables them to be closer to their employees and to recognise and meet their needs more readily.

16. The Government will publicise the benefits of carer-friendly employment policies, working closely with employers and other organisations. We will promote the adoption of good practice in carer-friendly employment. This will be an integral part of an awareness and promotional campaign on family-friendly employment.

17. In our consultation document *Supporting Families*, we invited comments on the benefits of developing a family friendly award or accreditation scheme for family friendly employers. We will consider the merits of establishing such a scheme which could include carer-friendly employment.

18. To be most effective, policies to support carers need to be well targeted. This means that employers should find out more about the carers in their workforce and should involve them in determining what particular provisions would help them best. Even where policies are being introduced, deep rooted and traditional organisational cultures may undermine their effectiveness. Even in those organisations which say they are flexible and profess to be output driven, underlying cultures can be quite different. Employers will need to continue to address these issues.

19. Although much is known about working carers, there are still some gaps in our knowledge. In particular, there is very little research into the effectiveness of carer friendly employment policies. We will commission and fund one or more research projects in this area.

Flexible support services

20. Support services can and do operate in flexible ways for carers in employment. Carers at work may need someone to check on the person for whom they are caring in the middle of the day. Some make use of technological aids to alert them if anything is wrong. However, statutory services sometimes assume that carers are always available. Simple things, like checking that hospital appointment times are convenient can make a lot of difference, especially to working carers.

21. Concerns about reliability, standards, and having a say in the type of service provided are common to all carers. The Government's White Paper *Modernising Social Services* makes specific reference to enabling carers to remain in employment, and together with our White Paper *The New NHS*², emphasises prevention, independence and confidence in services. We will develop pilot schemes, in partnership with carers, employers and the statutory services, to find out more about the ways in which support services can help carers to remain in employment.

22. Another source of support that working carers need is accurate and reliable information to enable them to make decisions. When the onset of caring is sudden, carers may have to deal not only with the immediate needs of the person they are caring for, but also with a range of new concerns – details about the illness or medical condition, what services might be available, who to approach for help and so on. Many new carers will have had limited previous contact with the statutory and voluntary services and will not know who to turn to.

23. Minority groups may face discrimination or perceive that they are being discriminated against in the workplace. They may not be aware of, or have appropriate information about, any support their employer provides. Employers should ensure that information they provide about opportunities for support and access to flexible working arrangements is accessible to all of their employees.

24. Some employers have identified ways in which they can help by giving staff access to information which enables them to find out about many of these issues. This can range from handouts on the availability of local care facilities through to telephone help lines and sophisticated technology-based services. Employers may also provide counselling services. Internal publicity about the availability of such services can make carers and non-carers more aware of the issues which carers face. Employers can also facilitate the development of informal networks of working carers, for example by giving them

NatWest is one of several large employers to recognise the value of providing a confidential telephone help-line service.

- Employees can contact trained advisers who offer advice across a wide spectrum of needs, which includes caring. The service is provided by a private company which specialises in this area. Confidentiality is guaranteed.

- The service can point an employee in the right direction quickly and thus save significant time and worry.

- Benefits to the employer include fewer distractions during working hours, reduced levels of stress in the workplace and increased employee loyalty.

access to rooms for meetings. The Government will encourage more employers to develop such schemes. We will also review our own provision of information.

Helping carers to return to work when caring comes to an end

25. Carers who give up paid employment in order to meet their caring responsibilities can find it very difficult to return when caring comes to an end. They may have lost confidence and feel out of touch with the world of work and its changes. However, they may have learnt new skills through being a carer which could be of benefit to potential employers. Indeed, some employers are actively looking to recruit carers who gave up work but now wish to return.

26. The Government is reforming welfare so that people can become independent, rather than be locked into dependency. Welfare is about work for those who can, and security for those who cannot. Carers will benefit from the single gateway, which will bring together the Employment Service, Benefits Agency and other welfare providers at a single point of contact. All new benefit claimants will have access to a personal advisor to help plan a route back to independence, whilst also ensuring that they receive the benefits to which they are entitled. This will help carers to remain in touch with the world of work and will ease their transition back into employment. Some carers will wish or need to care full time, and such wishes should be respected.

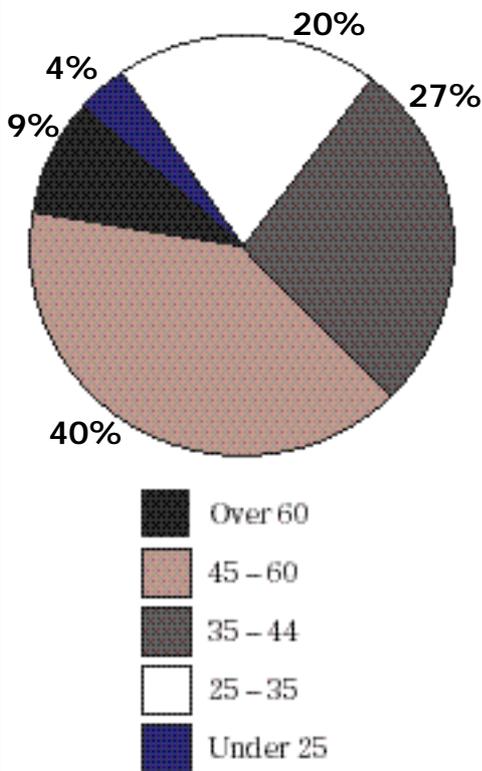
Surrey County Council and Devon County Council Social Services, in partnership with The Carers' National Association, are developing ways in which carers can be supported to take up training or retraining for employment, or to retain current employment, where that is their choice.

27. We also want to help former carers, whose caring responsibility has come to an end, to return to work. The Government's New Deal programmes focus in particular on young unemployed people aged 18-24, older long-term unemployed, partners of unemployed people, lone parents and people with disabilities. But many carers have not been registered as unemployed for the two year qualifying period required for the long term unemployed within the New Deal. The Government will consider how best to meet the needs of the group of carers whose caring has ceased and who need to return to work.

North West New Deal Project

- Centrica plc, in partnership with the Carers' National Association, Employers Forum for Disability and others, has successfully introduced a project that guarantees 50 placements for disabled people and carers within Centrica's call centre and data processing operations in the North West of England.
- The project has received Government funding as an 'Innovative Project' within the New Deal for disabled people.
- Benefits to Centrica include access to a wider recruitment pool, increased awareness among Centrica line managers of carers' issues (customers can be carers too) and strong brand reinforcement during the introduction of gas competition in the North West.

Recipients of invalid care allowance by age group



DSS, September 1998

Financial support for working carers

28. Invalid Care Allowance is a taxable, non-contributory benefit for people of working age (16-65) caring for more than 35 hours a week for someone who is themselves getting Attendance Allowance, the middle or highest rate care component of Disability Living Allowance, or certain rates of Constant Attendance Allowance. There are 373,000 recipients of Invalid Care Allowance¹³. It costs £800 million a year. It helps people to maintain their income when they have to give up full-time work to provide care. Around 10 per cent of people receiving Invalid Care Allowance say they are employed or self-employed.

29. The largest group of recipients of Invalid Care Allowance are aged between 45 and 60, reflecting the peak age for caring.

30. Invalid Care Allowance amounts to £38.70 per week, plus additions for adult and child dependents where appropriate. Once earnings from employment reach £50 per week, after allowable expenses, the benefit ceases to be payable. The median length of time for which a carer receives Invalid Care Allowance is about 2 years.

31. We have also taken steps to improve financial support for carers by, for example, announcing the introduction of a tax allowance for all working mothers with dependent children and incapacitated husbands.

32. As the Government continues to reform welfare, we will keep under review how financial support for carers – including Invalid Care Allowance – can best meet their needs.

Protecting carers' pensions

33. Many carers at present lose the opportunity to make proper provision for their retirement because their working lives are interrupted by a period of caring. In the case of women this may be a second interruption of employment, following one they have already taken to bring up children.

34. In future, time spent caring will qualify carers to entitlement to a second pension. This is a major step forward, and will represent a significant improvement in the financial position of carers and former carers on reaching state pension age. The Government is consulting on the precise conditions, but our initial proposals are that carers will receive credits towards a second pension if they are not working or have insufficient earnings to cross the National Insurance Lower Earnings Limit (currently £3,328 a year), and if they are:

- receiving Invalid Care Allowance
- caring for someone receiving Attendance Allowance or Disability Living Allowance and they qualify for home responsibilities protection.

35. By 2050, thousands of carers, both those who care long-term and those who take a shorter break from paid employment in order to care, will benefit from these proposals. They could receive up to the equivalent of £50 a week in today's terms in extra pension, which will be payable in addition to the basic state retirement pension.

Conclusion

36. The Government believes that awareness of the needs of carers in paid work is growing and that policies are changing to meet those needs. We have already taken some steps to help carers to remain in employment and we intend to do more. We will also do more to help those carers who gave up paid work in order to care, to return to employment when their caring responsibility ends, and we will protect their pension entitlement. This is a new step forward for carers – and a clear underlining of the new value in which they are held.

CHAPTER 4

Information for carers

1. Good information is one of the main needs of carers. Information needs to be accessible, relevant, and comprehensible.

2. Carers are a diverse group of individuals. Information needs to be relevant to each individual carer. So it must take account of their particular circumstances and their main needs. Carers' needs can change over time. Information which is needed at the beginning of a period of caring may be quite different from that which is needed later. Providing information to carers is part of a two-way process. Statutory services need to collect information about carers and their needs, both individually and as a group, and to use it to respond with relevant and targeted information.

Good information on carers' needs

3. People who need care and the people caring for them know most about their own circumstances. Those working in the statutory services, and especially those carrying out assessments, should recognise the expertise, perspective and circumstances of both carers and those they are caring for. When informing carers about services appropriate to them, health and local authorities¹⁴ need to listen first to what carers have to say. We will establish a partnership between carers and the services they use, based on respect and recognition of carers in their own right.

4. Services must aim to understand carers' needs – individually and as a group. The Government believes that all services used by carers should involve them in service planning. Carers' organisations and representatives can help service providers by providing a forum in which consultation of carers about service provision can take place. Services which have one-to-one dealings with individual carers, and with the people for whom they care, need to make sure that the carer is involved and consulted about the services which he or she needs.

¹⁴ Health Boards in Scotland and Health and Social Services Boards in Northern Ireland

5. Individual assessment of carers' needs is intended to allow service providers to judge the state of their health, their needs and wishes, and their ability to continue to care if that is what they want to do, or to bring informal caring to an end if that seems right both for the carer and for the person being cared for. For social services, assessment is a formal process laid down in legislation. But health professionals locally should be aware of the carer's own health needs and how best they can help. Housing authorities may also need to assess the carer's circumstances, wishes, and needs in the provision of accommodation which is right for him or her and for the person needing care.

6. The Carers (Recognition and Services) Act 1995 gives people who provide "substantial care on a regular basis" the right to request an assessment from social services. But the implementation of this Act is patchy. Assessments are not always carried out. Some carers are offered very sensitive practical and emotional support. But others receive very little, or nothing. However, when assessments are undertaken, carers report satisfaction both with the process and with the results.^{15 16} Carers should be entitled to expect at least an annual discussion of what they need, what is available, the help they are receiving and the care provided.

New information on carers' assessments

- The "Referrals, Assessments and Packages of Care" data collection.
- First collection of data in 1999-2000.
- Count of people using services, who have had their own assessment and who are known to have a carer.
- Will also count numbers of **carers** who have an assessment, either separately or jointly with the service user.

7. Britain has some 855,000 carers who provide care for more than 50 hours a week. People who need care to this extent should generally be in touch with social services, and their carers should be receiving an assessment of their own needs. However, we do not have reliable information about the precise numbers of carers who are receiving assessments. The Government will collect more information so that local authority social services departments will be able to judge the extent to which they are carrying out assessments for those carers for whom they are most appropriate, and will be able to compare their level of activity with that of similar authorities around the country.

Information services for carers

8. Carers often find it difficult to get information about either the type of response or the quality and standard of service they can expect from local agencies. We will put in place a long term care charter which will describe what people needing care and carers can expect from housing, health and social services. We will be consulting on a draft charter within the next few months. In Scotland, these commitments are being taken forward by an "Action Plan to modernise Community Care", published on 26th October 1998. A key element of the plan is the provision of more home care and respite services for carers. £5 million will be made

available to local authorities in 1999/2000 to implement the recommendations from the Action Plan.

9. It is important that carers are informed about the basis on which decisions are made about who qualifies for social services. The White Paper *Modernising Social Services* describes proposals to develop guidance on fair access to care. This will set out the principles which local authorities should follow when devising and applying criteria on who is eligible for their help, taking full account of carers' circumstances. Carers will also need to know how they can make a complaint about a service and who this should be made to.

Information on cost of services

10. Charges for social care have caused confusion and concern to many carers. There must be greater transparency and fairness in what people are asked to pay towards their social care. At present there is a wide variation in what local authorities charge. Some make no charges for particular services. Each can develop their own rules for assessing income. As a result there is a great deal of inconsistency, and what happens is often not clear to the carer and the service user. The Government's White Paper *Modernising Social Services*¹⁷ makes it clear that the Government believes that the scale of variation in the discretionary charging system, including the difference in how income is assessed, is unacceptable. We will consider how to improve the system of charging for services in the light of the report of the Royal Commission on Long-Term Care for the Elderly and of the current survey by the Audit Commission.

Information on first contact with services

11. For many carers, the most important initial point of contact with services is with the NHS – with their General Practitioner, the community nurse, or another member of the primary care team. Others will begin to find out where to get information from initial contact with the social security benefits system. Carers also make contact with voluntary organisations concerned with carers, such as the Carers National Association. Carers who are looking after someone with a particular health problem may contact a voluntary organisation which specialises in helping people with that condition, such as those organisations specifically concerned with services for cancer patients or for those with mental health problems.

The Long Term Care Charter will:

- require local agencies to set standards in key areas
- tell local people the standards they can expect
- improve standards, by empowering people who need care and their carers, and through effective performance management
- improve transparency and accountability in long-term care services.

¹⁷ In Wales, a White Paper will be published shortly. In Northern Ireland a document *Improvement in Social Services: Discussion Paper* has been issued

The National Schizophrenia Fellowship produced, in May 1998, a binder of practical information for those caring for people with schizophrenia. Each of the 27 sections deals with a specific topic – ranging through information about schizophrenia and its causes, what the carer needs to know when a relative with schizophrenia is in hospital, how to get help and support in the community, including welfare benefits, and how to encourage the person with schizophrenia to be as independent as possible.

12. All these organisations need to see their own role as a part of a wider network of support for carers and to be able to refer them to services which can help them. Receptionists in doctors’ surgeries, community nurses, health visitors, care assistants, hospital staff, therapists, volunteers and people employed by voluntary organisations all have a crucial role in referring carers to other appropriate sources of help. In many areas, carers’ centres and carers’ support groups will be able to meet a range of carers’ needs for information about services, benefits, or about the process of caring.

Newcastle City Health NHS Trust have funded a three year corporate, trust wide post of a nurse specialist in carer support. The nurse concerned provides information, support and training to carers whilst also raising awareness to facilitate the development of more carer support activity and good “signposting”. The person appointed has fourteen years’ experience of being a ward sister in psychiatry. As part of her brief, she has to ensure that carers are involved in service planning and delivery; to work across agencies, both internal and external; to share good practice and offer information and advice; and to establish a volunteer carer network within the Trust.

13. Some local GPs provide a specific leaflet rack for carers or a waiting room notice setting out the main sources of help in the locality. Some GP practices, hospitals and social services authorities have also taken the initiative of issuing all the carers they identify with a “contact card” which lists the telephone numbers for the area of the main services which support carers. This would include, where they exist, the telephone numbers of the carers’ centre and for the carers’ support group.

GP carers’ project

More than ten GP practices in York and Selby have developed a range of initiatives to reach carers and provide them with the information and support they need. Initiatives include carer “messages” on prescriptions, putting up a notice asking carers to identify themselves at reception and carer-designated notice boards.

14. There are also a number of important initiatives being taken by social services departments to inform carers. Cambridgeshire, for example, has circulated 10,000 copies of a comprehensive handbook,

covering information on the role of the statutory agencies, how carers can access support, and sections on money, benefits, respite care and day care services. Cambridgeshire has also supported a newsletter as a joint initiative between the carers' centre, local carers' organisations and social services.

Rhondda Cynon Taff Social Services Department have had a Freephone Carers Line and Carers Pack available since 1 October 1998. Posters and leaflets, like other publications in English and Welsh, have been issued to advertise the Carers Line. The Carers Pack has sections of useful addresses and includes 12 other sections with general information for carers on such subjects as money matters and benefits, young carers, looking after yourself and your feelings, and caring for someone who is terminally ill. The pack can be made available on tape or in large print. If a caller to the Carers Line asks for information on particular subjects, such as benefits, they can be sent the appropriate section from the pack rather than the whole thing.

Information on health care

15. Carers need good information on the health needs and treatment of the person they are caring for – especially on medication: when to take it, and recognising any side effects arising from it. They need information to allow them to deal with the symptoms of some illnesses and to recognise when they should urgently ask for professional help and where to get such help, especially when they are caring for someone with a mental health problem.

16. The NHS has always sought to maintain the confidentiality of information which is given to clinicians in confidence. But in the majority of cases where a patient has a carer, the patient would be very happy for their carer to know as much as they do. The Government believes that general practitioners and other clinicians should proactively offer help and full information to their patients, and should **always** explicitly seek the patient's consent for information to be passed to their carer. If health professionals fail to ask for a patient's consent, then they cannot pass information about the person's illness or disability, or about their medication or symptoms to their carer. Health professionals must also recognise that patients have a right to change their mind on whether to give consent and they should review the decision regularly with the patient.

17. In a small number of cases, patients will refuse to consent to any information being given to their carer. While there are some circumstances where even without consent being given, the carer should be given information in the interests of maintaining their own safety or that of other members of the public, such decisions can only be taken on the basis of each individual case.

Carers' need for information from the NHS¹⁸

Of 1,346 carers in touch with a carers' centre who were caring for more than 8 hours per day:

- 94 per cent helped to ensure that the person cared for took medication;
- 23 per cent changed dressings;
- 13 per cent gave injections

But only 33 per cent had received any information, training or guidance.

Of those of working age:

- 71 per cent believed GPs were unaware of carers' needs;
- 70 per cent of those with experience of hospital discharge said no-one had asked whether they could cope before discharging someone from hospital into their care at home.

¹⁸ Warner, L and Wexler, S (1998) "Eight hours a day and Taken for Granted?" Princess Royal Trust for Carers

18. Carers from minority groups have some additional needs that health and local authorities need to pay particular attention to. They may need information about services in appropriate languages. Health and local authorities should consider employing support workers who understand the needs, cultural traditions and religious practices of carers from minority groups. People from ethnic minorities may also have particular health problems, such as sickle cell disease.

19. Many carers have expressed concern about lack of recognition of the role of the carer in hospital settings.¹⁹ At the time of hospital discharge, carers must be fully informed and involved in the planning of future care of the patient, so that assumptions are not made about their ability or willingness to care. Studies of carers' views of hospital discharge highlight particular difficulties about failure to involve them in the timing of discharge and to give them enough information about the future care of the patient.

Accessible information

20. Whilst almost all the information which carers need is already available somewhere, carers may not be aware of the existence of particular information to help them. Where facts and advice can change quickly, such as on social security benefits, there is a need to make sure that information is kept up to date. Information also needs to be accessible. Carers from ethnic minorities may not read English easily. For some groups of carers, such as older people, tapes may be a helpful way of conveying information. Services need to consider supplying information in a range of languages. The Government believes that telephone helplines and information technology can play an important role in providing carers with the information they need.

Helplines

21. The Government's new NHS Direct, a nurse-led telephone service on health and NHS services, is a major initiative towards ensuring that patients and members of the general public, including carers, can access the health information they need. NHS Direct aims to provide callers with the advice and reassurance they need to care for themselves or others at home or, where professional help is needed, to put them in touch with the right service at the right time. Where carers need more specialist information or help from other agencies, such as social services, NHS Direct will be able to refer callers onto other sources of help. Three pilot services have been operating since March 1998 and have been proving very popular with callers, including carers. By April 1999, 40% of people

in England will have access to the service. By December 1999, 60% of people will have access to the service and it will be available in all parts of the country by the end of 2000.

22. A number of organisations which support carers run helplines specifically for them. Some are targeted mainly at particular groups of carers – e.g., older carers, or those where the person they are caring for suffers from a particular health problem. We have collected the telephone numbers of some of the main organisations and, with their permission, these are listed as an Appendix 1 to this report.

23. Information about social security benefits is available for disabled people and their carers from the Benefits Enquiry Line²⁰. This is run by the Benefits Agency and provides a confidential advice service. More locally, some social services authorities also run helplines. These have the advantage of providing locally-based information, as well as that on national policies and services.

Hampshire Social Services run a confidential telephone helpline for carers, providing advice and information as well as a listening ear and practical help in an emergency. Their carers handbook is now in its 5th edition and has been developed in partnership with the local health authority and carers' associations. Carers have helped to develop an assessment proforma and guidance for adult and young carers.

Information technology

24. The Government intends to ensure that full use is made of information technology in providing information for carers which is up-to-date and easily accessible. We are following closely the development of a project called "StartHere", which is about to be piloted in North London and will be evaluated by April 2000. This system, which can be accessed by individual carers, might be situated in GPs' surgeries, libraries and other locations. The "StartHere" system will bring together information from a large number of different charities and other organisations. It will provide a carer with benefits information, the telephone numbers of helplines, leaflet information on particular issues, contact details for support groups, information about health problems and about specialist services. Carers may also be able to access specific information about medical conditions or other care needs.

25. We will also ensure that each Government department will provide, on the Internet, details of the services or benefits affecting carers for which it is responsible. People working in a carers' centre will be able to

²⁰ The number is 0800 882 200

access information on a particular issue when helping a carer with an enquiry.

Conclusion

26. The Government believes that information is central to meeting carers' needs. Without it, they do not have the means to make choices and to have control over their own lives.

27. Informing carers means statutory health and local authority services giving them general information about what is available and how to obtain particular services. Service providers must also ensure that, through the assessment process, carers are provided with individualised information on the help available to meet their particular needs, and must support them in their caring role by provision of information about the health of and services for the person for whom they are caring. Local staff must be knowledgeable about carers' issues and about other local services which can help them. The Government will ensure that more sources of information are available to help carers at a national level and that people working in statutory services provide them with the right information, in the right form, and at the right time.

CHAPTER 5

Support for carers

1. The Government's objective is to support carers in carrying out their caring responsibilities. This requires a different response from services providers than the one they have commonly followed in the past. Services providers must see carers as partners in the provision of help to the person needing care, and must involve them as partners. Carers need the help of the statutory services – working together – to provide the best possible care.

2. The Government believes that people who use services are in the best position to say how those services should be provided in order to meet their needs. Involving carers and their organisations, alongside patients and users of services, is a way to ensure that those services are responsive.

3. Carers can be involved in many ways – in discussions about the care of the person for whom they are caring, in planning processes, in commenting on particular services and on specific initiatives, for example, training programmes or drawing up new assessment criteria. Authorities and organisations should look for new ways of involving carers.

4. The cultural traditions of minority groups should be considered carefully and it should not, for example be assumed that minority groups have close knit families offering support.

What the Government has done so far

5. We have already introduced a number of important initiatives which will ensure that people, who need and use services and their carers, are more involved than in the past in the planning and provision of those services. In particular, we have:

- brought in health improvement programmes, where health and social services authorities will work together with partner organisations, including patients and carers, to develop a strategy to improve the health of the whole community

- required health and social services to plan jointly their investment to meet the needs of the most vulnerable people in the community, and to consult locally on their plans – including, within such consultation, patients, service users, and their carers;
- required those planning local rural regeneration projects to involve carers and their organisations in developing proposals, such as on community transport, village halls, village shops;
- introduced the NHS survey of patients' and carers' views to make the health service more responsive to the views of the public. Carers will be specifically included in this survey in future years;
- emphasised the need for local authorities to involve the public, including carers, in proposals to renew democratic local government, to improve leadership of local communities and to serve local people;
- set up the patient partnership strategy at national level, which involves patients and their carers in developing policy on the provision of health services;
- made clear in our consultation paper *Best Value in Housing Framework* that we expect local authorities to consult with and involve a wide range of people on the provision of housing services.

6. But involving carers in service planning or provision must be relevant to carers and aim to achieve something for them. Health authorities and local authorities should follow a series of key steps:

- identify carers in the area and their needs;
- establish which services are already available and the extent to which they are used;
- involve carers in assessments, or ask them to assess their own needs;
- ensure carers are fully briefed about meetings they are being invited to attend;
- communicate regularly and routinely with carers and their organisations;
- make sure that the times and locations of meetings suit carers. Working carers may find it difficult to attend meetings in the daytime, and some locations may be difficult to reach or unsafe for vulnerable people during the evenings.

A good practice checklist on involving carers forms Appendix 2 of this report.

7. Not all carers will wish to be involved in a formal way. Services should consider a range of different ways of involvement, including:

- comment cards – particularly for services that go into the home, such as home care and occupational therapy;
- meetings where services are based, such as in day centres and day hospitals;
- going to where carers are – for example, holding carers’ days in supermarkets;
- carers’ weeks – city events with the involvement of all council departments, health services and the voluntary sector, a major aim of which is to provide information and stimulate comment about services.

8. The carers’ centre, the local branch of Carers National Association, and the local respite care or sitting service, as well as other organisations, especially those working with young carers or with minority ethnic groups, should be involved in consultation exercises on carers’ needs and on services to help them. But these organisations do not necessarily have contact with all carers. Health and local authorities should aim to reach carers who are not in touch with any of these organisations – for example, by calling meetings within the health centre or surgery of carers identified by General Practitioners and primary care teams.

Oxfordshire Learning Disability NHS Trust work with the Oxfordshire Carers’ Forum and three Carers’ Centres. This helps to improve the support provided and the information given to carers. The Forum sends a representative to all Trust board meetings and once a year the board meets with a larger group from the Forum. Community Teams have links with Carers’ Centres and other local carers’ groups. The Trust has suggested to the health authority issues to include in the health improvement programme for people who have learning disabilities, including ways of supporting their carers.

Support for carers of disabled children

9. The Government is determined that the most vulnerable children in this country should get the best that society can offer as well as the care, safety and security that all children deserve. We will increase the help and support to parents who care for a disabled child. For example, we have already announced that the age limit of a disabled child for whom parents can claim help with childcare costs as part of the Working Families Tax Credit will be raised from 12 to 16 from October 1999.

Diana, Princess of Wales, Community Children's Nursing Teams

- Support for children with life-threatening health problems
- Ten teams will be established initially, at a total cost of £2 million a year
- Led by highly trained and qualified children's nurses
- Each team will support 150-200 families
- Will link together existing support services and voluntary organisations.

10. The caring responsibilities of parents with disabled children are made more arduous by the difficulty of accessing mainstream services, for example child care, including after school clubs and leisure activities. The Government's policy initiatives to increase the social inclusion of disabled children will reduce the extra responsibilities of care which fall on their parents.

11. Two reports from the Social Services Inspectorate²¹ revealed that:

- the demand for support services for families with disabled children, including day care and short term breaks, is high. Once families gain access to services they generally report that the services are good.
- services are not sufficiently tailored to the needs of families, and in places families have to adjust to fit into the services available
- there are sometimes problems in arranging short term breaks because of the medical needs of the child.

If services for disabled children are to meet their needs, their parents must be involved in discussions about the way services should be provided.

12. The Government has announced, for the first time, objectives for children's services, to provide a clear framework for developing local services. We want local and health authorities to set their own local objectives which are fully in line with the new Government objectives, one of which requires that the needs of disabled children should be adequately met and reviewed. Local and health authorities should arrive at a complete picture of the numbers and circumstances of disabled children in their area. The closer inter-agency planning and focus on the needs of disabled children will result in improvements in assistance for parent carers.

13. The Government has allocated £375 million for England over three years to help local authorities' social services departments achieve the objectives of this programme, called "Quality Protects". The Social Services Inspectorate will be monitoring closely to ensure that the dedicated additional funds are being properly used.

Supporting carers through technology

14. The Government believes that technology has an important role in developing better support for carers. We intend to look at the longer-term uses of technology and to develop ideas for the future. We will also encourage use of technology in current provision – not necessarily high-tech, but sometimes relatively simple devices, such as timer switches and automatic door opening systems. These devices are often low cost, and can be of considerable assistance to people in their own homes. Staff in statutory services need better training so that, when putting care packages together, they take account of the contribution that technology can make. Currently older people may not be used to using electronics or keyboards, but future generations will be, and many younger carers already know, and regularly use, such equipment. Local and health authorities need to start planning for the future.

15. Some examples of technology that may support carers are:

- telephone or community alarm links to opening doors
- movement sensors which switch on lights
- smoke, heat and gas detectors
- time clocks for domestic equipment
- community/intruder alarms
- home monitoring systems linked to a call centre
- dispensing boxes for medication which indicate clearly which tablets need to be taken at which time
- quick “vertical to horizontal” detectors, for falls
- remote door opening
- habit monitor pads (which monitor changes in routines)
- shopping from home
- internet/telephone chat groups and Email
- videophones/conferencing and interactive digital TV
- telephone befriending schemes
- pump mattresses to prevent bed sores
- tele-medicine e.g., to take blood pressure remotely.

16. The challenge is to make such technology “people-friendly” and to use it to complement other services. The Government will seek to stimulate thinking between industry, the health service, local authorities and carers themselves about a greater use of technology. Statutory agencies should place more emphasis on the value of devices as part of a care package, and evaluate the outcome.

Housing support

17. Living in the right sort of accommodation can make a considerable difference to the lives of carers. This might mean living near, or moving to live with, the person they care for. Or it may mean having a home which is in good repair and which has been adapted to suit the particular needs of the person being cared for. For example, a shower or a stair lift may have been installed. Carers need good information and advice about:

- the range of housing options available to them
- the effects on their tenancy rights of any possible move to different accommodation
- repairs and adaptations to their home.

18. Local authorities are required, under the Housing Act 1966, to provide housing advice in their areas. They are also required to have a housing register and to run a scheme on allocation of housing. Guidance issued by the Department for the Environment, Transport and the Regions and by the Scottish and Welsh Offices asks local authorities to be sympathetic to carers’ wishes to move, in order to be closer to a sick, disabled or elderly relative, and to grant joint tenancies where adults share accommodation because one party is caring for the other. The HOMES (Housing Organisations, Mobility and Exchange Services) schemes are one means of facilitating the move of local authority and housing tenants, including carers who need to be near to the person they are caring for, to another area. The Government will review the guidance it issues to local authorities on allocation of housing, in order to ensure that allocations meet the needs of carers and the people they care for. In particular, the Department for the Environment, Transport and the Regions will encourage local housing authorities to allocate accommodation to applicants who need care which includes bedroom space for a carer, even if the carer would not reside permanently with the applicant, where they are satisfied that this is necessary to enable the carer to fulfil his or her responsibilities.

19. People needing care can benefit from a range of services provided with their accommodation. These may include the services of a warden, a call system in case of emergencies, or other facilities. Funding for such services has in the past been provided separately and was not necessarily helping people in the greatest need. The Department of Social Security has issued a consultation paper called "Supporting People" which is intended to tackle the problems in the existing housing benefit structure by:

- bringing together housing benefit paid for support services, and certain other existing funding streams, into a single budget which will be distributed to local authorities to be applied at the local level on the basis of individual need;
- creating incentives for local housing, social services and probation services to work together to deliver cost-effective and high quality services to many thousands of vulnerable people.

20. The proposal will bring the funding of these services onto a secure legal footing for the benefit of vulnerable people, to allow them to remain independent in the community.

21. The proposals will benefit carers by:

- enabling the provision of more flexible support services that better match the needs of vulnerable people;
- removing restrictions in some current programmes that prevent the funding of support services for vulnerable people who live with their carers or are owner occupiers.

Repairs and adaptations

22. Adaptations to the homes of people who are disabled or too frail to continue to live there without them are available through a Disabled Facilities Grant if they live in rented or owner occupied private accommodation. In England, 60 per cent of the grant programme is funded by the Department for the Environment, Transport and the Regions and the amount allocated is rising from £60 million in 1998-99 to £75 million in 2001-2002. Local authorities make provision for adaptations to their properties in their Housing Investment Programme.

23. In some areas, carers can experience considerable delays in obtaining the necessary adaptations to their homes, or those of the person for whom they are caring. There are a number of ways in which carers can get help and information about adaptations, for example through Home Improvement Agencies, which provide assistance to elderly or disabled people on low incomes about disabled facilities grants, renovation grants and home repairs. Under the Government's proposals for best value, local authorities must account to local people – including carers and organisations representing them – about the provision of services. Local authorities should consult carers and work effectively with them to reduce the delays in providing disabled facilities grants, for example. Carers of disabled people in all parts of the country should be entitled to expect an efficient and high quality service for the adaptations they need to their homes.

Cutting council tax for people with disabilities

24. The Government intends to change the law to give reductions in council tax for some disabled people. There will be significant new help for people who need care and their carers.

25. Currently, council tax can be reduced for some people with disabilities, but restrictions limit how far it can be applied. The Government intends to lift these restrictions so that reductions can be obtained by more people.

26. At present, there is a scheme which reduces the amount of council tax payable by people with disabilities. Where someone with a disability has an extra room in their home which they need because of the disability, or has enough floor space to allow movement in a wheelchair, they received a reduction in their council tax. The reduction is achieved by charging the tax at a band below that which is shown on the valuation list, so a disabled person living in a house valued in Band D would in fact be charged at Band C. But people living in accommodation which is valued at Band A cannot get a reduction, because there is no band below Band A.

27. From 1 April 2000, the Government intends to amend the regulations governing the scheme. As a result, people with disabilities and their carers who live in Band A accommodation which has a qualifying extra room or enough floor space for wheelchair circulation should receive a reduction in council tax – equivalent to that currently given for the other bands.

Transport

28. Carers frequently express concern about the availability and accessibility of public transport and the provision of reliable specialised transport for them and the person for whom they care. The Government has taken a number of steps to improve transport services, and especially those for sick, elderly and disabled people and their carers. By the beginning of 1999, all new trains must be accessible by disabled people under the provisions of the Disability Discrimination Act 1995, similar requirements for new buses and taxis will be introduced over the next few years. The Government has increased its funding for services provided by local authorities – in particular, it has provided an additional £32 million for bus services and £5 million for rural buses. The Department of the Environment Transport and the Regions has sponsored a major national review of voluntary and community transport, the results of which will be available shortly, and a review of door to door transport for disabled people living in London has also recently been completed.

Conclusion

29. Giving strong support to carers over service planning and provision will help to ensure that they become partners with the statutory services in the provision of care. Better-supported carers will be better able to make better lives for the people for whom they are caring.

CHAPTER 6

Care for carers

1. The Government's aim is to enable carers to make more choices for themselves and to have more control over their own lives – for their own health and wellbeing. We want services to recognise carers as individuals in their own right.

Carers' health

2. Carers have a right to see their own health needs met. They need help to maintain their own health, both physical and emotional.

3. Maintaining health is not just a question of treating illness or disease. The Government will be bringing forward a White Paper on public health following the consultative Green Paper *Our Healthier Nation*. The White Paper will stress that everyone's health – including that of carers – is affected by a number of factors, including the environment, their housing conditions, whether or not they are in employment, their level of income, and their social and family networks.

4. Research suggests that carers have two main health problems. A study²² revealed that:

- 51 per cent of carers had suffered a physical injury such as a strained back since they began to care.
- 52 per cent had been treated for stress-related illness since becoming carers.

5. But the evidence on whether carers suffer proportionately more health problems than other people of the same age is not conclusive. Physical injuries in particular become more common as people get older, and a large proportion of carers are over 60. However, some studies have found significant effects, particularly on carers' mental health²³. Of 93 carers interviewed, 32 per cent felt their health was affected by caring – 63 per cent reported stress and 47 per cent depression.

²² Henwood, Melanie (1998): *Ignored and Invisible? Carers' Experience of the NHS* (Carers' National Association).

²³ Tiston R, Mann I & Bannerjee (1995) *Stress in Informal Carers of Hospitalised Elderly Patients* *Journal of*

6. Physical injuries are more common among women carers than men. Stress-related health problems are most acute among people caring for someone with very serious disabilities, with dementia or with a chronic mental health condition such as schizophrenia. An American study²⁴ has shown that 80 per cent of carers of people suffering from dementia were themselves suffering from chronic fatigue, depression, or other psychological problems. Carers can also suffer from stress because of a lack of information about how they can best help the person they are caring for.

Meeting carers' health needs

7. Carers have a right to expect that the NHS and social services should help them to maintain their health. Both of the health problems commonly suffered by carers are preventable. The first step for the health and social services is to identify patients or service users who have a carer, or those who are themselves carers. The Government's new National Priorities Guidance for the health and social services in England²⁵, issued in September 1998, asks general practitioners, members of primary care teams and social services staff to identify carers by April 2000. Identification of carers is the first step towards helping them. We will continue to use the National Priorities Guidance to ensure that the NHS and social services work together to meet carers' wider health needs.

8. Many of the physical injuries from which carers suffer could be prevented if they were helped through proper training to learn how to move the person they are caring for in a safe and effective way. Sometimes carers will need special equipment installed in their home to help them to do this. But even straightforward actions, such as helping someone to sit up in bed, can cause injury. The NHS must help carers to learn the necessary skills so that they can care without risk of injury to themselves. This can be particularly important at the start of caring and so we will, for example, emphasise the training of carers in our revised guidance on hospital discharge which will be issued later this year.

9. Social support and assistance from their family and friends plays an important role in maintaining the mental wellbeing of carers²⁶. Emotional support may just mean having someone to listen to problems. It may mean help and advice from someone else who is or who has been a carer. Mental and emotional wellbeing can also result from feeling in control of the situation – which means, for carers, having the information to help them to

²⁴ Robins, P., Mace N., and Lucas, M., (1982): *The impact of dementia on the family* Journal of the American Medical Association, 248 pp 333-335.

²⁵ Modernising Health and Social Services: National Priorities Guidance 1999/00 – 2001/02 Department of Health.

²⁶ Mittelman, M., Ferris, S., Shulman, E., Steinberg, G., Ambinder, A., Mackell, J., Cohen, J (1995): *A comprehensive support programme: Effect on Depression in Spouse-Caregivers of*

care. Not all carers will want to join a support group or will find it helpful, but research suggests that carers who have links with a support group are better able to continue to provide care²⁷.

10. Carers are regularly in touch with the NHS. The survey of carers' experience of the NHS²⁸ showed that 88 per cent of carers had seen their General Practitioner in the previous 12 months. Fifty-one per cent of the carers had seen the district nurse, and 28 per cent, the community nurse. During these regular contacts with carers and the people for whom they are caring, GPs, community and district nurses and therapists should review the carer's health and particularly consider the carer's ability to undertake tasks which require physical strength or stamina. A discussion around their willingness to act as a carer may reveal emotional or mental health needs.

Services for carers

11. Local authorities and others can do a great deal within existing community care legislation to increase flexibility and choice for carers. But there are also legislative obstacles preventing authorities from making provision which would be of great benefit to carers directly, or from putting packages of measures together – including those designed to allow carers to take a break – which would be both more cost-effective and in line with carers' wishes and needs.

12. The way current legislation is cast prevents carers receiving help in their own right. It undervalues their role and needs, and their ability to have a proper say in the kind of provision which best suits them.

13. For example, where a person who needs care has been offered but has refused a community care assessment, it is currently not possible for a local authority to assess the carer's needs, even if that is what the carer themselves wanted, and to make life easier for the carer, and also for the person being cared for, by giving help directly to them. Local authorities in these circumstances are prevented from providing equipment for the home, such as a mobile phone, which could ease the carer's burden and reduce the risk of injury. Or when putting a package together which would allow a carer to take a break from caring for a while, a local authority cannot include, in a package, help intended directly for the carer, such as paying for a taxi, even though the alternative – such as providing several hours of a sitting service – could well be both more expensive and less preferable for the person being cared for.

Checklist for GPs and Primary Care Teams to help carers

- Have you identified those of your patients who are carers, and patients who have a carer?
- Do you check carers' physical and emotional health whenever a suitable opportunity arises, and at least once a year?
- Do you routinely tell carers that they can ask social services for an assessment of their own needs?
- Do you *always* ask patients who have carers whether they are happy for health information about them to be told to their carer?
- Do you know whether there is a carers' support group or carers' centre in your area, and do you tell carers about them?

²⁷ Mittelman, M., and others (1993): *An intervention that delays institutionalisation of Alzheimer's Disease Patients: Treatment of Spouse Caregivers* The Gerontologist Vol 33, no 6 730-740.

²⁸ Henwood, Melanie. Op. cit.

Types of breaks for carers

- A short stay for the person being cared for in a residential care home
- Time for the person being cared for in a day centre
- Nightsitting service, to allow the carer to get a full night's sleep
- Someone to take the person being cared for on outings, to give the carer time to him or herself at home
- Sunday sitting service, to allow the carer to go to church or visit family and friends
- Evening sitting service, to allow carers to go to evening classes, to the cinema or have a meal out
- Day-time sitting, for shopping and other activities
- Holidays for both the carer and the person being cared for, together.

14. Individual carers could have greater flexibility and choice if they were able to receive direct payments or credit scheme arrangements to enable them – with the consent of the person needing care – to arrange for services to be given to them in a way that was useful and at a time and a form that was appropriate. For example, a credit scheme could operate on the basis of providing time-based credit which could be exchanged during the year for sitting services or other short-term break support at a time appropriate to the carer.

15. These changes require legislation. In looking at legislation, we need to retain the balance between both respecting the views and meeting the needs of the person being cared for, and giving greater control to carers over services they need to carry out their caring more effectively and to maintain their own health, emotional wellbeing and independence.

16. While bearing this in mind, the Government will legislate when Parliamentary time allows to ensure that authorities are able to address carers' wishes and needs more directly.

Helping carers take a break

17. Supporting the independence of carers means allowing them to have some time on their own, or for themselves. This means time to pursue their own interests, see their own friends, take care of their own needs or just catch up with jobs around the house. A break from caring is invaluable in reducing the psychological and emotional stress faced by many carers. Access to support services and breaks can also help carers to continue providing the support they give to a sick, disabled or elderly person.

18. Some local authorities provide a wide range of services to give carers a break. But in many areas there is no choice. All too often, the only service available to allow the carer a break in their area is a place for the person being cared for in a residential care or nursing home. This may not provide what either the carer or the person needing care wants. A number of local authorities also provide day centres to give a break to the carer. But there can be difficulties, particularly where the transport to the day centre is unreliable or does not arrive at a fixed time to allow the carer to plan his or her day and carry out other activities. A range of services is more likely to meet the diverse needs of carers.

19. The most common form of break for carers is support from friends or relatives, which is used by 2.3 per cent of all carers²⁹. Only 1.3 per cent of carers used time in a nursing or residential home for the person for whom they were caring to enable their last break. Among carers who spend at least 20 hours a week caring – nearly half of them had been caring for more than five years – 49 per cent had not had a break since they began to care. Six out of 10 carers, who lived with the person they cared for, felt unable to leave that person unattended for as little as 2 hours. Of those, 14 per cent had, in the past, made use of a sitting service.

20. Some carers do not use services to allow them to take a break – for a number of reasons, including:

- a lack of information about the availability of services and how to access them;
- little choice about the timing or type of service;
- the quality of services is not always good and can deter carers and the person for whom they are caring.

21. But when services are provided they are usually found to be helpful. One of the most comprehensive studies of services providing a break for carers was *Better for the Break*³⁰ which considered services for carers of elderly people with Alzheimer's Disease or related disorders. The study found that:

- ninety per cent of the carers in the study who used day care said that it had made their lives better, and 80 per cent thought it benefited the elderly person.
- a third of those who had used relief care at least once felt the elderly person benefited, and 80 per cent of them said relief care had made their own life better. The most frequently reported benefit was increased patience and feeling more able to carry on;
- sixty per cent of those who had used a sitting service said the visits helped the person they cared for. Nearly all the carers said the service had improved things.

22. We are publishing, alongside this report, a separate document called *A Real Break*, which provides useful details about schemes to allow carers a break which meet their particular needs and circumstances as well as those of the people they care for.

The Winged Fellowship Holiday Centres

The Winged Fellowship provides holidays and respite care for people with severe physical disabilities at five centres in the UK. Each year, over 6,000 volunteers help the organisation to provide care and companionship to guests at these centres, for example:

- The Skylarks centre, near Nottingham, has state of the art facilities.
- The centre provides accommodation for individuals or couples, so that carers can take a break *with* the person they are caring for.
- It is staffed by a mixture of professional full-time nurses and care assistants who oversee teams of volunteers.
- There is an extensive range of facilities, including a swimming pool and shop on site and a wide range of activities/visits are arranged to suit the needs of guests.

²⁹ General Household Survey, 1995.

³⁰ <http://www.betterforthebreak.org.uk/>

23. For many people, local authorities will have the lead responsibility for arranging and funding services to allow carers to take a break from caring. The NHS also has a crucial role, especially when specialist medical or nursing help is required for the person needing care in order to allow the carer to have a break. Planning and provision of services to give carers a break must involve both the local authority and the health authority. They should agree on who will be eligible for services, and describe their proposals in Joint Investment Plans. Carers and organisations which represent them should be consulted on those plans.

New funding for taking a break

24. The Government has already announced the allocation of £750 million over the next three years to promote independence through prevention of illness, disability or disease, and through rehabilitation, and carers and the people they care for will benefit from this. On top of that we are making available a new special grant – ringfenced funding – to local authorities for the enhancement of services to allow carers to take a break from caring. The grant will total £140 million for England over the next 3 years – £20 million in 1999/00, £50 million in 2000/01, £70 million in 2001/02. Local authorities will need to assess the needs of carers in their area for services of particular types. These services may be many and varied, including domiciliary and sitting services that give the carer a short-break, or longer breaks or holidays. Local authorities could use a checklist of questions in making their assessment.

Checklist to establish a range of services to give carers a break

- do carers in your area want services in the evening to allow them to leave the house for leisure or educational activities?
- are such evening services available?
- do carers and the people for whom they care want the means to go out together in the evenings for leisure activities?
- are services available to help them do this?
- do carers in your area want the means to have a break on Sundays for family or social reasons?
- are services available to allow them to do this?
- do young carers in your area want support projects outside the family home which can give them a break?
- are projects available for this?

25. The Government will make it a condition of receipt of the new special grant for carers that local authorities review, with other agencies and especially the health service, their provision of services to give carers a break from caring. They will be required in the first year of the grant explicitly to involve and consult carers and their organisations on the appropriateness of current provision and the possibility of greater diversity. Where evidence shows that existing services meet the needs of carers, these should be enhanced. Where more diversity is needed, and especially a wider variety of services at different times of the week and at weekends, authorities must plan how to stimulate provision of such services.

Good practice by statutory agencies in provision of breaks for carers

- A culture shift away from labelling services as “respite”, and towards recognising a range of provision of breaks.
- Transparent and equitable charging system within a national framework.
- Publicising services available, and making them accessible – e.g., through models like a “short-term breaks bureau”.
- Breaks must be positive and fulfilling for the person needing care and the carer. Being able to go to the dentist should not be regarded as “a break” for the carer.
- Statutory agencies should pro-actively identify the likely needs of carers in their community as part of needs assessment generally. They should have a good understanding of likely demand.
- All local and health authorities should review the provision currently being made for short-term breaks, and the information on which they base their funding decisions, to determine what carers want. People needing care and carers themselves must be involved in the review.
- Short-term breaks should not be provided in long-stay residential units unless in a separate part of the unit.
- In planning a short-term break, it is important to prepare the ground with the person needing care and the carer, and to learn from them about the needs and habits of the person being cared for.
- It should be routine practice to encourage an assessment by the person needing care and the carer of how successful a break has been. It could be a contractual requirement of providers to do this.

26. In providing or developing the provision of short breaks for carers, the empowerment of the carer should be a key aim. What carers want most of all during a break from caring is that their relative is well cared for and secure. But the carers' voice is often not heard, and their own needs can be overlooked. Carers' needs should be considered on an individual basis and they should have choice about the type of services designed to give them a break which they would like, and about the timing of the break.

Training

27. Training can empower carers – by giving them new confidence, allowing them to make new contacts and equipping them with skills which will enrich their lives and, perhaps, help them with plans to return to work when their caring responsibilities end. Research shows that training is an important way of providing direct support to carers – and training courses are often run by carers' projects or carers' centres. Participants in a course on "Looking after yourself" reported decreasing levels of stress and valued the contacts and friendships that they made³¹.

Lancashire College are running an adult education carers project. This enables carers to acquire skills and knowledge that could assist them in understanding, managing and enriching their lives. To help develop the collaborative approach in partnership with carers, carers' organisations and statutory agencies, a part-time carers project worker was appointed in 1997. Two more were appointed this year when a successful bid was made for joint funding by local health authorities. 24-hour re-charge events are run, featuring such subjects as reflexology and wine appreciation, which enable carers to relax and meet other carers.

Conclusion

28. Caring for carers means giving them more control over their lives and over the range, nature and timing of the services which they need. It will offer real choices about the extent to which they provide care, remain in employment, receive information, and are involved in the life of their community.

CHAPTER 7

Local care for carers

1. People in every community need a range of support services and networks. Supporting networks may include those which people build at work, a range of friends with similar interests, and friends and relatives who may not live near by, but with whom there is regular contact. In the neighbourhoods where people live, they rely on local services, such as the General Practitioner, local shops, local transport, the availability of appropriate housing in the locality, the library, delivery services such as the postman and other door to door services such as refuse collection.

2. Carers' needs may be heightened by their caring role, by their isolation and, often, by their inability to leave the house for very long because of the needs of the person they are caring for. Carers may be in particular need of support from sources of practical local help and from networks with a range of individuals, organisations and groups in their area – encompassing voluntary organisations, their family, friends and neighbours, other carers and perhaps networks formed around the local church or other religious organisation.

3. Research evidence strongly suggests that carers benefit from contact with other carers in a similar situation to their own. Such contact provides information about the services they need, about how to cope with caring, and the reassurance that they are not alone in feeling the strains and stresses of caring.

Carers' support services and carers' centres

4. Carers' centres, or other forms of community support for carers based within localities, may provide:

- information and advice about all issues, including local services, affecting carers;
- emotional support and befriending schemes – a listening ear and/or individual counselling;
- training for carers – for example in managing stress;

Benefits of a carers' centre

Percentages of carers perceiving the benefits of a carers centre to be:

- being able to speak to someone who listens (59%)
- links with other carers (35%)
- help with Social Security benefits (33%)
- help in dealing with officials (29%)

- practical locally-based support, such as help with daily tasks – shopping, gardening or providing transport;
- the means for carers to learn from others in the same position, by running or facilitating carers' support groups;
- social and recreational activities;
- help to give carers a break from their caring responsibilities;
- advocacy – helping carers to access benefits and services;
- a means of involving carers in the community – by providing a focus for their involvement in local decision-making.

5. A report by the Social Services Inspectorate³² highlighted the important factors in establishing and sustaining carers' support services and carers' centres:

- projects must be developed in consultation with carers.
- they should support the independence that many carers value.
- they should act as “one-stop” shops, providing advice as well as emotional support.

6. Carers' centres or other local support services can take a range of different forms. Often they have a central base within the locality, perhaps using rooms in a hospital or space provided by a voluntary organisation. Some have high street premises for easier face-to-face contact with carers. The services of the carers' centre can be made more accessible to carers who may have limited opportunities to leave their home, and the person for whom they are caring. Outreach workers can visit carers in their own home, provide help at advice surgeries – perhaps in health centres or in General Practitioners' surgeries, run coffee mornings or support groups for carers, or provide newsletters and a local telephone service allowing carers to find out about how to get practical help or further information.

7. Carers' centres may employ very few permanent members of staff, but often obtain a considerable amount of help and assistance from a range of volunteers.

VOLUNTEERS IN OXFORDSHIRE

The Carers' Centre in North and West Oxfordshire recruited and trained 32 volunteers with the help of funding from the National Lottery Charities Board. Many of the volunteers act as Carer Contacts in villages. They publicise the work of the Carers' Centre by giving talks, taking displays to local events and putting up posters. Volunteers have also:

- organised outings and social events for carers;
- developed fundraising activities;
- provided a "befriending" service to carers;
- provided a short-term intervention service for carers in crisis

8. The Princess Royal Trust for Carers, established in October 1991 on the initiative of Her Royal Highness the Princess Royal, has developed a network of 79 carers' centres across the UK. The Trust provides help and advice to these centres and a system of ensuring that they can continue to provide a high quality service to carers. The Trust may also assist voluntary organisations, which would like to establish a carers' centre, to do so.

9. Carers' centres can be the focus for carers' self-help groups. These do not exist in all parts of the country. But even where they do, research has shown that only one-third of carers are in touch with the groups. A further third did not want to have such contact and the remaining third did not know about the existence of the group. Many carers are known only to contact their local carers' centre at times of crisis.

10. The Government believes that local support services for carers are best run and managed by the voluntary sector, and particularly when carers themselves are involved in the management arrangements. In a number of local authority areas, there is no support service available (see Appendix 3). In other areas the service may be embryonic, or on a very shaky financial footing. Some areas have, in contrast, well developed carer support services, providing a range of services including those to employees of local organisations, to young carers, to carers from minority ethnic groups, and the centres have clear and close links with General Practitioners, local hospital services, and other voluntary organisations.

11. We believe that all carers should have access to a support service. We will make sure that carers can have confidence in the quality of these services. We will also ensure that health and social services authorities identify carer support services in their area in their joint investment plans and give priority to funding these services.

12. Existing carer support services may draw funding from a number of different sources, including local social services authorities, health authorities, local employers or local charitable organisations, “project” funding for particular specific short-term purposes, funding from the National Lottery Charities Board or through the distribution of money received at national level by major charities or charitable trusts.

13. Voluntary organisations wanting to establish a carers’ support service or carers’ centre in their area can apply to the National Lottery Charities Board for a grant. The Charities Board runs a number of grant programmes. Its two main continuous grants programmes, *Community Involvement* and *Poverty & Disadvantage* have policies and criteria which may fit the objectives of a new carers’ support service. Applications have to be well focused and costed and to fall within the Board’s policies. All applications are assessed on merit and in competition with other applications. Decisions on grants are made independently by the Board’s country and regional grant making Committees.

14. The Government will require health authorities and local authorities, acting jointly, to bring together the organisations in their locality which assist carers to assess exactly what the needs of carers in their area are, and how local support services should best be provided. This process will inform and assist applications by voluntary organisations for National Lottery funding to establish services in areas where they do not exist at present.

15. It is essential that carers using any form of service – whether provided by the statutory or voluntary sector – should have confidence in the quality of that service. We know that the carer support services which currently exist are variable in quality. Carers should be entitled to expect, for example, reasonably easy access to support – both for face-to-face discussions and by telephone – so that any information about themselves, or the people for whom they care, which is given to people working in the support service, is held securely and in confidence. They should have direct involvement in the way the service is planned and provided.

16. With the aim of helping and protecting individual carers and those for whom they care, the Government has asked the three major national organisations working with all carers which have branches around the country – the Carers’ National Association, the Princess Royal Trust for Carers and Crossroads “Caring for Carers” – to work together with the Government on developing a quality assurance scheme for local carer support services. The three organisations have been asked to involve all other relevant organisations – including all members of the Carers’ Alliance³³ – in the work, which will involve:

- agreement on the standards which should apply to all carer support services to ensure quality for individual carers.
- defining precisely which services should be covered by the standards.
- commenting on the suggestion that quality standards would be best monitored through contracting rather than independent inspection.

17. Health and social services authorities are the main statutory services supporting carers in any locality. GPs and NHS professionals need to be able to refer individual carers to the support service in the knowledge that it can help to meet their emotional, practical and other needs. Carers' support services can work in partnership with social services authorities by assisting to support the most vulnerable members of communities.

Carer support services

Possible Outcome Measures

- Carers' satisfaction with services (measured by independent survey)
- Number of carers on the mailing list or contact list (to show that the support service is in touch with an increasing proportion of carers in the area)
- Number of new carers in contact with the service (should increase year on year)
- Number of referrals from the statutory services (health, social services, DSS) (to indicate their confidence in the carers' support service and that all agencies are acting in partnership)
- Number of referrals from other organisations (e.g., employers and voluntary organisations)
- Number of volunteer hours used to help carers through and with the support service.
- Amount of funding from non-statutory sources (to allow the service to increase its activities beyond its core activities)
- Value of in-kind support from local employers and other organisations (this is needed for voluntary organisations' accounts, and indicates the existence of good local partnerships)

18. The statutory services, in their contracts for providing funding to carer support services, will need to ensure that the service provides an acceptable quality and quantity of help to carers in the area. Health and social services authorities will wish to have regard to whether their local carers' support service meets the quality standards which will be devised as a result of the Government's work with the three major national organisations. In addition, health and social services authorities may wish to measure a number of the above outcomes before renewing their annual financial support.

Local partnerships

19. Support for carers in the area where they live works best when a range of local organisations work in partnership to develop and support a community service for carers. Local organisations must include the local social services department, the other local authority services such as transport, housing and education, the health authority, General Practitioners and their primary care teams, local employers, volunteer bureaux, the Citizens Advice Bureau, the local office of the Department of Social Security, voluntary groups representing carers themselves, and local hospitals. In some parts of the country, such local partnerships are already in existence.

PARTNERSHIPS FOR CARERS IN SUFFOLK

- Involves Suffolk Carers, a number of local authorities' social services and education departments, the health authority, Association of Voluntary Organisations, NHS Trusts, primary care groups.
- Charter for Carers in Suffolk will be implemented by an action plan from each partner.
- The Charter emphasises that carers should have recognition, choice, information, appropriate practical help, assistance to meet the financial costs of caring and co-ordinated services.
- Carers should be involved in planning and monitoring the services they receive.

20. In some areas, local agencies working in partnership have developed innovative schemes to support carers in their area. In Gloucestershire, the carers' centre, working with the British Red Cross, the Social Services department and the "Health for All" Joint Strategy Group have developed an emergency card, which can be carried by local carers concerned about what would happen if they were out alone and had an accident or suddenly fell ill. The emergency card was developed to provide carers with something that offered them, and the people they cared for, maximum security and peace of mind.

GLOUCESTERSHIRE EMERGENCY CARD

- Carers enrol via the Carers' Centre with the local branch of British Red Cross, giving information about who to contact and what action to take in an emergency.
- Carers carry a card containing a reference number, but no personal details of the carer or person being cared for.
- In emergency, the Red Cross will carry out instructions, including contacting other family members or providing a trained person to stay with the person needing care until other arrangements can be made.
- Service is free to the carer, confidential and operates 24 hours a day, 365 days a year.

Partnerships with local employers

21. Partnership arrangements with local employers can give mutual benefit to carer support services and to the employers concerned. Help provided to employees who are carers can be extended to other carers in the area at very little extra cost. A confidential telephone service provided by the carers' centre, for example, can be advertised within a company to allow carers who work there to obtain locally based support, information and advice about their caring responsibilities and about local services and might be partly funded by the employer. Employers might consider that there were benefits in providing such personnel services through an outside agency, such as the local carer support service, because of its particular expertise.

22. Local employers' support to carers may also take a variety of forms. Through their local networks and representative organisations, employers can raise awareness of the needs of working carers and promote solutions which they have found to be effective. Employers can also help by making some of the time of their staff available to voluntary organisations. In many cases they have a considerable reservoir of business skills, including financial expertise, specific technical and information technology skills, project management skills and the ability to act as trustees. People working for local companies may also form part of a pool of potential volunteers who could assist carers and the carer support service, through, for example, participation in fundraising activity or the provision of transport. Some sorts of assistance, provided by employers to local voluntary groups, can be relatively inexpensive for the employer to provide, but invaluable to the local voluntary organisation. Examples may include access to photocopying facilities, use of meeting rooms or places on training courses.

Contact-a-Family's area volunteer representatives

Contact-a-Family has recruited area volunteer representatives to signpost parent carers to the best sources of local help. All of the volunteers are themselves parent carers or grandparents. They are provided with telephones, supplies of information, travelling expenses and back-up support, all of which costs approximately £1,500 for each area per year. The volunteers link parent carers to local and national parent support groups, answer enquiries from parents and professionals, liaise with the statutory services and increase professionals' awareness of parent carers' needs through information events.

SUNDERLAND CENTRE'S LINKS WITH LOCAL EMPLOYERS

The Sunderland Carers' Centre established a network of local contacts (employers, the Training and Enterprise Council, the Industrial Chaplain and local carers) to raise awareness of the needs of working carers. As a result:

- Local employers have begun to introduce "carer friendly" employment policies.
- The Carers' Centre now offers a monthly on site drop-in service to the Sunderland City Hospitals Trust for their employees who are also carers to get advice and support.
- A Carers' Charter has been developed which is awarded to employers who meet agreed standards for the support which they offer to working carers.
- The close relationship which has developed between the Carers' Centre and local employers means that the Centre can encourage employees to raise issues directly with their employers where the Centre is aware that these employers want to support working carers.

Volunteers supporting carers

23. Britain has more than 20 million volunteers, involved in a range of activities, predominantly within their local area. A number of organisations helping carers, including those providing help to people with particular health problems, carers' centres and other organisations supporting carers, make considerable use of volunteers. The Government has launched policies to ensure that the general public is engaged in a range of issues in their communities. Under the umbrella of "The Giving Age", the Government is promoting volunteering by older people, volunteers working in hospitals, volunteering by employees of companies, and youth volunteering through the "Millennium Volunteers".

24. Volunteers can be used to support carers by providing:

- information and independent advice;
- help within a carers' centre, including with administrative tasks;
- telephone support;
- a "listening ear";
- practical help, such as with shopping, laundry and gardening.

25. Many volunteers form very close relationships with the families they support. In these circumstances they can often fill the role normally filled by the carer and can provide night sitting services, supervision of the person needing care, company during outings, and home sitting.

26. There are some long established projects involving volunteers in support of carers. At London Lighthouse, for example, volunteers involved with the organisation befriend people with HIV/AIDS and their carers, carry out practical tasks such as shopping or taking the person needing care to hospital, providing night sitting and peer support.

27. Involving volunteers requires investment in their recruitment, training, support and management. Organisations need to match volunteers to the family they are supporting. Organisations supplying volunteers need to have carried out proper interviews and checks of volunteers, to give the carer confidence that the person who is coming into their home is trustworthy. The organisation recruiting the volunteers should have appropriate insurance and should also pay attention to:

- health and safety issues;
- support and supervision;
- back-up in case an emergency arises for the volunteer during his or her activity on behalf of the organisation;
- clear lines of accountability.

28. Some carers fear that volunteers may not be suitable to work with vulnerable people and that some of them may even pose a threat to the person for whom they care. Organisations recruiting volunteers need to be aware of the risks, and of the probability of encountering a cautious approach from carers. They need to ensure they adopt a set of principles which will help them to shape effective, high quality practices among their volunteers.

Neighbourhood shops

29. Local shops are an important service for many carers who often cannot be away from home for very long and so need easy access to retail and financial services such as shops and banks. In some parts of the country, including in particularly deprived neighbourhoods within cities, many basic public and private services which others take for granted have practically disappeared. While the reasons for this vary from one neighbourhood to the next, the result is often that the poorest, and those least able to travel outside their neighbourhood for whatever reason, face the highest prices. One study showed that the cost of the cheapest food in small independent stores can be 60 per cent higher than supermarkets.

30. Improving shopping access in poor neighbourhoods is vital to health, not only in terms of ensuring ready access to foods which make up a healthy and balanced diet, but also to improve people's overall state of wellbeing. The Social Exclusion Unit's report *Bringing Britain Together: a national strategy for neighbourhood renewal*, launched by the Prime Minister in September 1998, represents an ambitious Government programme to bridge the gap between the worst off and the rest of Britain. It aims to develop integrated and sustainable approaches to the problems of the poorest neighbourhoods, including crime, drugs, unemployment, community breakdown, and bad schools. The Department of Health is leading work on a strategy to improve shopping access for people in deprived areas by April 1999.

Carers in rural areas

31. About one-fifth of the population lives in the countryside. Carers who live in rural areas can find it even more difficult to obtain advice, help and assistance than carers in urban areas. The amount of help available to them, from both the statutory services and voluntary organisations, is generally lower than in urban areas and services may be difficult to access, involving long journeys to day centres or hospitals. Geography and social change in rural communities may mean that carers there are particularly isolated. Small centres of population do not provide a cost-effective base for many services.

32. Some innovative projects have been developed in rural areas. The "Home from Home" scheme, developed in West Oxfordshire with initial funding from the Department of Health, provides day-care support to older people in a rural area, and a break for their carers. Host families, who are volunteers, take a group of four or five elderly people with mild to moderate mental health, mobility or sensory problems into their family home for a day, providing them with lunch and with social interaction and stimulation. Evaluation of the scheme, carried out during 1998³⁴, showed that 28 per cent of the "visitors" had a carer. The hosts receive a small payment per "visitor" for their expenses. This project has a number of advantages – transport for the people needing care was very local and took no more than ten minutes from their home to the host's home, and the scheme was well received by the carers, who valued it as a means of giving them a break and time to themselves. The scheme is now managed by Age Concern Oxfordshire and funded through joint finance from the health and local authorities (two-thirds) and by charitable support (one-third).

33. Local organisations have experience of helping support people in rural areas. Meeting the needs of people in rural communities requires a number of steps, including:

- effective assessment of their needs, such as through specific research, consultation with local groups such as parish councils or village appraisals;
- specific consideration on whether the needs of people in rural areas can be met in the same way as those in urban settings, and whether people living in the countryside are receiving a fair share of time and resources;
- paying attention to basic services, such as health, community care and transport;
- introduction of effective rural projects, which can take longer to develop, must be tailored to the specific needs of each area, and must take account of existing infrastructure, services, networks, and sources of information.

Conclusion

34. The Government will play its part in developing support for carers in the communities in which they live. We believe that all carers should have access to a local carer support service, and we aim to ensure that such services are established, funded and of high quality. We also believe that the voluntary sector, working with local employers and others, has a key role and we will support volunteering to help carers.

CHAPTER 8

Young carers

1. Children and young people represent the future of the country. The Government is taking extensive action to offer new help, from higher standards in education to the New Deal welfare to work programme. We are placing particular emphasis on supporting the most disadvantaged children and their families. Young carers are potentially a group of the most disadvantaged. Although young carers will benefit from many of the Government's proposals set out here, they have particular needs.

2. The experience of growing up in a family where either a parent, a brother or a sister is ill or disabled can bring both rewards and difficulties. Many young carers are part of particularly strong, loving and closely-knit families. There may be only a narrow dividing line between "helping around the house" which many children do, and providing personal care for a relative. But, in the worst cases, young carers can be harmed by the responsibilities and expectations placed upon them. Many children will provide help and support in these situations; some will take on, perhaps gradually, significant responsibilities for care and, like all carers, they need recognition and support.

Young carers' needs

3. Young carers generally care for members of their immediate family who may be:

- a parent with a physical illness, disability, mental health problem or dependency on alcohol or drugs;
- an elderly grandparent who is frail, or who has a health problem or disability;
- a brother or a sister with a health problem or disability.

4. Children in single parent families with the parent in need of support are especially likely to spend a large part of their time providing care and to take full responsibility for doing so.

5. Children in families where a parent suffers from mental illness can be at risk of developing mental health problems. Around 10,000 children across the country are in this position. Department of Health work shows that 30 per cent of mentally ill adults have dependent children. Between a third and two-thirds of children who have a mentally ill parent will develop problems themselves. In families where alcohol or drug abuse is a problem, children can be faced with a caring role which can create great anxiety or worse.

6. Research estimates suggest that there are between 20,000 and 50,000 young carers. Many of these children receive no support at all from statutory or voluntary services. Some young carers or their parents may fear that, if they draw attention to their situation, they will be taken into care. The report "Something to Think About"³⁵ summarised the findings of research about the experience of young carers. It reveals some serious disadvantages.

Frequent effects for children and young people of providing care

- Problems at school, with completing homework and in getting qualifications;
- Isolation from other children of the same age and from other family members;
- Lack of time for play, sport or leisure activities;
- Conflict between the needs of the person they are helping and their own needs, leading to feelings of guilt and resentment;
- Feeling that there is nobody there for them, that professionals do not listen to them and are working only with the adult;
- Lack of recognition, praise, or respect for their contribution;
- Feeling that they are different from other children and unable to be part of a group;
- Feeling that no one else understands their experience;
- Problems moving into adulthood, especially with finding work, their own home, and establishing relationships.

7. In some parts of the country there are special local initiatives to support young carers. *The National Handbook of Young Carers Projects (1998)* and *Young Carers in UK – Profile (1998)* provide information about over 2000 young carers and describe the services available to them. Young carers need:

- recognition of their role;
- support with caring tasks. This is especially important so that they can attend school and do their homework;
- information about the support available to them;
- emotional support, and especially someone who they can talk to about their feelings.

8. Under current legislation – the Children Act 1989³⁶, the Children (Scotland) Act 1995 and the Carers (Recognition and Services) Act 1995 – young carers can receive support from local and health authorities. Using Section 17 of the Children Act social services departments can help young carers, by considering whether their welfare or development might suffer if support is not provided.

9. Under the Carers (Recognition and Services) Act 1995, young carers can ask for an assessment of their needs. But many are not aware that this is possible. Some local authorities are reluctant to advertise this fact because of their concern about raising expectations. With the help of the voluntary sector, the statutory services should ensure that young carers are not expected to carry inappropriate levels of caring responsibility. To achieve this, disabled or ill parents need support to maintain their independence and to carry out their parenting responsibilities. Services must consider the needs of all family members including children with caring responsibilities. Sometimes there is a delicate balance to be struck between the rights of a child to have support to reduce the caring burden, and the reluctance of some families to accept intervention or support from social services.

10. Britain has about 110 young carers projects across the country. They are usually provided by the voluntary sector but are sometimes funded by the statutory sector. These projects can provide relief from the isolation faced by children who are carers. They are places where the young can go for advice, information and support or leisure activities and can share experiences with other young carers. Many young carers using these projects have no other support from statutory services. They can offer support for young carers from others in a similar position to their own.

³⁶ In Northern Ireland the equivalent is Article 18 of the Children (Northern Ireland) Order 1995.

Young carers in Northamptonshire have support provided from a project run by Northamptonshire Carers Association. Young carers and their families can have home visits providing opportunities for one-to-one discussion about their caring roles and the support they may need. They also have access to individual and group activities which include trips to the cinema, bowling or laser games. The project has also benefited from an “Arts for All” lottery grant which has provided trips to the theatre, music workshops and residential drama weekends. Young carers have the opportunity to have some fun, away from the caring situation and for leisure with other young carers. Four part-time young carer workers cover the whole of the county.

Young carers from minority groups

11. As well as sharing the specific experiences of all young carers, those from ethnic minority groups face other issues:

- minority families may be less likely to contact social services departments for fear that their children will be taken away;
- children from ethnic groups are more likely to be excluded from school. The Government is already taking action through initiatives to reduce school exclusion and through behaviour support plans to combat such problems. Increased awareness training of teachers will also help;
- children from minority groups are often expected to take responsibility for interpreting for the person they are caring for, regardless of whether or not they understand the issue or it is appropriate to their age.

Schools

12. A number of agencies, other than social services, will have greater, and probably earlier contact with young carers and their families. In particular General Practitioners and other primary care staff – who will already be in regular contact with the person needing care – can provide valuable, sensitive support to young carers and their families. All teachers already have duties to promote the general progress and wellbeing of children, and to provide guidance as well as advice to them on educational and social matters. This is done by teachers playing their part in implementing the school’s pastoral care policy. These contexts will allow the health and education services to address the needs of children who are carers.

13. The Government will draw schools' attention to effective practice in meeting the needs of pupils who are young carers, for example, through link arrangements with young carers' projects. The Green Paper on teaching "*Teachers – Meeting the Challenge of Change!*" suggests that many of the tasks which need to be carried out in schools could be allocated to dedicated staff who do not need to be teachers, but who have the right skills and time to develop special expertise. Schools might find it helpful to have one member of staff to act as a link between young carers, the education welfare service, social services and young carers' projects. Their role would be one of liaison with the relevant services. The person could benefit from getting to know others who can help young carers and what services are available in the area to meet their needs. This would be a proactive way of recognising the difficulties faced by young carers and getting help to them, both within and outside the school. Young carers may need the opportunity to talk to someone at school (perhaps their teacher or someone else with the right skills) in a way which is confidential and sensitive.

14. Punctuality and attendance at school are important. Arriving late or missing school can disrupt a child's education. However, schools need to be sensitive to the individual problems faced by young carers. We have already alerted head teachers and local education authority staff, such as education welfare officers, to the particular needs of young carers in our integrated guidance on school attendance and behaviour, which was issued for consultation in January.

Improving support for young carers

15. To support young carers better, the Government has already indicated that we will:

- aim to ensure that children whose parents or other relatives have specific needs arising out of disability or health conditions, enjoy the same life chances as all other children in the locality. This requires local authorities to identify children with additional family burdens and to provide services that are geared to ensure these children's education and general development do not suffer.
- do more to make health, education and social services work together on children's services plans, as set out in our White Paper *Modernising Social Services*.
- continue to emphasise the need for co-operation between adults' and children's services within social services departments. This means, for example, that the community care assessment of a disabled parent must pay attention to that disabled person's role as a parent.

16. We will also:

- improve awareness training about young carers for General Practitioners, primary health care teams, social workers and teachers at the time of their initial training and subsequently, through providing opportunities for young carers to share their experience with professionals;
- promote awareness of young carers in schools through ensuring that teaching on Personal, Social and Health Education includes references to young carers;
- encourage schools to designate someone to act as a link, for young people who are carers, with social services, the health service and any young carers' project;
- ensure that local authorities recognise, within a general objective to increase community support for carers, the need to sustain and enhance the number of young carers' projects, and especially to ensure that young carers have access to leisure and recreational activities;
- enhance counselling services and promote the independence of young carers. Older teenagers who have been caring for some time can find it difficult to move on and gain their independence. Emotional ties, a sense of duty and a lack of accessible housing can be very restricting. Under-achievement in education and lack of confidence can mean that financial independence is difficult. In some ways there are parallels with children leaving care, and local authorities need to ensure that their counselling and housing services are responsive to the needs of young carers.

17. The Government believes that cross-agency work to support young carers is very important. We are already introducing much greater co-ordination between health, social services and education for children in need, including children with disabilities. It is right that links between services to help young carers should be a priority.

Young carers in Norfolk have the benefit of three inter-agency support projects led by Norfolk County Council Social Services. The needs and profile of young carers are being raised by a “Young carers development officer” project jointly financed by health and social services, and delivered and managed by Crossroads. The development worker is helping the 10 Crossroads schemes in the area to be more accessible to young carers and is also providing individual support to young carers, as well as arranging group activities such as a weekend visit to Butlins. Young carers are also benefiting from the “School Workers – Carers Forum” which has been funded by the National Lottery. The schools workers are raising awareness of the needs of young carers with teachers and helping to develop the support available through schools’ pastoral care systems. As a result more young carers are self identifying in schools because they are more confident that they will get support from teachers and referrals to other services as necessary.

Conclusion

18. The Government wants to ensure that young carers, like all children, should be able to have an education, to enjoy good health and to have leisure time. The proposals we have set out in this chapter will improve the recognition and support that young carers can receive, and will reduce the chances that they will be denied such opportunities.

CHAPTER 9

Conclusion: Caring for carers

1. Carers need caring. Most of them need high quality, reliable and responsive support from statutory or voluntary services. Many need help from their employer. Carers have many of the same needs as the rest of the population – such as the need to maintain their own health and wellbeing – but, especially for those who care for a large number of hours each week, carers have less opportunity to get what they need.

2. We want to enhance the quality of life for all carers. This means finding ways to give them:

- the freedom to have a life of their own
- time for themselves
- the opportunity to continue to work, if that is what they want to do
- control over their life and over the support they need in it
- better health and wellbeing
- integration into the community
- perhaps most importantly, peace of mind.

3. The Government is setting out here measures which will allow us to move towards giving carers the quality of life we believe they deserve. Achieving this vision cannot happen overnight. Nor is the solution simply a question of increased resources.

4. We need to achieve a cultural change in the way society as a whole – employers, statutory services, members of the public, the media, the educational system, and friends, colleagues and neighbours – perceive caring. Carers should not be pitied, but respected and admired.

5. We intend to make progress so that more carers – and eventually *all* carers – feel prepared and equipped to care if that is what they choose to do, feel cared for themselves and feel that their needs are understood. The Government is giving support to carers because we value what they do. Carers care for those in need of care. We need now to care about carers.

6. This report explains what the Government has done to date but it is only a start. We are taking account of carers' needs in all our policies and introducing major new initiatives to help them. We will follow through with action to implement these new initiatives.

APPENDIX 1

HELPLINES FOR CARERS

Help/Advice for:	Organisation providing the service:	Telephone number:	Opening Times:	Area Covered:	Number of Calls per year
Carers	Carers' National Association	0345 573369	Mon-Fri 10.00 am-12.00 noon & 2.00 pm-4.00 pm	UK	15,000
Carers	Princess Royal Trust, Carers Centres	See directory under "carers"	Varied	Local	-
Parent carers	Contact-a-Family	0171 383 3555	Mon-Fri 9 00 am-5.30 pm	UK	10,000
Older people	Counsel and Care	0990 300 7585	Mon-Fri 10.30 am-4.00 pm	UK	20,000
Older people	Age Concern	0800 009966	7 days, 7.00 am -7.00 pm	UK	
People whose lives are affected by cancer	CancerBACUP	0171 631 2121 or 0808 800 1234	Mon-Fri 9.00 am -7.00 pm	UK	
People affected by Parkinson's Disease	Parkinson's Disease	0171 233 5373	Mon-Fri 10.00 am-4.00 pm	UK	6,000
Those with cerebral palsy, or disability	SCOPE	0800 626 216	Weekdays 9.00 am-9.00 pm & Weekends 2.00 pm-6.00 pm	UK	
People with severe mental illness and their carers	National Schizophrenia Fellowship Advice Service	0181 974 6814	Mon-Fri 10.00 am-3.00 pm	UK	17,000

People affected by Motor Neurone Disease	Motor Neurone Disease Association	08457 626262	Mon-Fri 9.00 am-5.30 pm & 7.00 pm-10.30 pm	UK	5,000
People affected by mental health problems	Mind	0345 660 163 (outside London) or 0181 522 1728 (Greater London)	Mon-Fri 9.15 am-4.45 pm	UK	16,000
Families and friends of drug users	Adfam National	0171 928 8900	Mon-Fri 10.00 am-5.00 pm (ansafone outside working hours)	UK	6,300
Employers, and employees with caring responsibilities	Carers in Employment	01222 664854	Mon-Fri 9.00 am-1.00 pm (ansafone at other times)	Wales	
People with craniofacial conditions	Craniofacial Support Group	01926 334629	24 hours	UK	300
People affected by autism and asperger syndrome	National Autistic Society	0171 903 3555	Mon-Fri 10.00 am-12 noon & 1.30 pm-3.30 pm	UK	9,000
People with dementia and their carers	Alzheimer Scotland Action on Dementia	0800 317 817	24 hours	Scotland	3,000
People affected by Multiple Sclerosis	Multiple Sclerosis Society of Great Britain and Northern Ireland	0808 800 8000	Mon-Fri 10.00 am-4.00 pm (from April 1999) 9.00 am – 9.00 pm	UK	17,000

Support to people in crisis including carers	Samaritans	0345 909090	24 hours a day 365 days a year	UK	4.4 million
People with mental health problems and their carers	SANELINE	03456 78000	2.00 pm - midnight (365 days a year)	UK	40,000

APPENDIX 2

INVOLVING INDIVIDUAL CARERS: GOOD PRACTICE FOR SERVICE PROVIDERS

- **Carers' time is valuable** – the effort they make to contribute is greater than the effort you make. Be sure to use their time *and* good will wisely.
- **Alternative care** – you must offer to provide/pay for alternative support for the person the carer normally cares for. Make sure that *both* people are given every opportunity and encouraged to discuss and choose between a range of services so they both feel valued.
- **Expenses** – you must offer to pay fares and any other costs that a carer will incur in helping you. For example, for a woman who looks after her elderly mother and has a family of her own, child care for children coming home from school.
- **Payment systems** – in all cases you must have systems in place to allow you to order train tickets, etc, in advance or pay substitute care providers directly. Where carers are living on benefits they will not have the income to meet costs prior to you reimbursing them. If you pay expenses in advance you should avoid giving cash. (If carers are on benefits this may affect payments.) Vouchers, train tickets, etc, are preferable.
- **Treat carers with respect** – remember that carers, who already give a great deal, are being asked to give more to help not only themselves but others. A little respect and recognition of their generosity in giving more on a wider stage goes a long way.
- **Feedback** – is very important. You know when, realistically, you will be in a position to provide feedback. Be honest and prepared to disappoint expectations of speedy and large-scale changes coming from the consultation process. Explain how and when you will be in a position to provide feedback, what changes you expect to see coming from the consultation exercise they have been involved in and give that feedback when you say you will.

APPENDIX 3

SUPPORT FOR CARERS BY LOCAL AUTHORITY AREA

A) England

Local Authority	Sitting/ respite service	CNA Branch	Carers Centre/ Drop in centre/ Carers project	Carers worker/ development officer	Other LOCAL groups specifically for carers
Barking & Dagenham	C		PRT	✓Y	
Barnet	✓	✓	✓	EM✓	
Barnsley	C		P		
Bath & NE Somerset	C			✓	✓
Bedfordshire	C			✓	✓
Bexley	C✓			✓	✓
Birmingham	C✓	✓	PRT		
Blackburn & Darwen	C✓			✓	✓
Blackpool	✓LA	✓			
Bolton	C✓		LA	✓	
Bournemouth			✓	✓	
Bracknell Forest	C	✓			
Bradford	C	✓			
Brent	C✓		PRT	✓Y EM	✓
Brighton & Hove	C		✓		✓
Bristol	C	✓	PRT	✓EM	✓
Bromley	✓			Y✓	
Buckinghamshire	C✓		PRT P	✓ EM	
Bury	C✓			✓	
Calderdale	✓	✓	P		
Cambridgeshire	C	✓	PRT	✓	✓
Camden	C		PRT	Y EM✓	
Cheshire	C		PRT	✓	
Cornwall	LA	✓		✓	
Corporation of London	✓			✓	
Coventry	C		PRT P		
Croydon	C			Y EM✓	✓
Cumbria	C			✓Y	
Darlington	C	✓	P		
Derby City	C			✓EM	
Derbyshire	C			✓	
Devon	✓	✓		✓	✓
Doncaster	C	✓	P P(Y)		
Dorset		✓		Y✓	
Dudley	C		P		
Durham	C	✓	PRT P		
Ealing	✓	✓		✓Y	✓
East Riding					
East Sussex	C		P	✓	
Enfield	C	✓		✓Y	✓
Essex	C	✓	PRT	✓	
Gateshead	C				
Gloucestershire	C✓		PRT	EM	
Greenwich	✓		PRT	✓Y EM	✓
Hackney	✓		PRT	✓Y EM	✓

Halton	C✓			✓	
Hammersmith & Fulham			PRT	✓EM	✓
Hampshire	✓	✓	PRT	✓Y	✓
Haringey	✓			✓	✓
Harrow	C		PRT	✓	
Hartlepool				✓	
Havering	C✓	✓		✓	
Herefordshire				✓	
Hertfordshire	C	✓	PRT✓		
Hillingdon	C		P	✓EM	✓
Hounslow	C	✓	LA (P)		✓
Hull				✓	
Isle of Wight		✓			
Isles of Scilly					
Islington	C		P	✓	
Kensington & Chelsea	C			✓	✓
Kent	C		P	✓	
Kingston upon Thames	C			✓	✓
Kirklees			P		
Knowsley	C		PRT		
Lambeth	C			✓	
Lancashire	C✓	✓	✓	✓	✓
Leeds	C	✓	PRT P		
Leicester City	C		PRT	EM	
Leicestershire			PRT		
Lewisham	C		P	Y✓	✓
Lincolnshire	✓	✓	PRT		
Liverpool	C✓	✓	✓		
Luton	C	✓			
Manchester	C	✓	PRT		✓
Medway Towns					
Merton	C			✓	✓
Middlesbrough				✓	
Milton Keynes	C		P		
Newcastle-upon-Tyne		✓			✓
Newham	C	✓		✓EMY	
Norfolk	C	✓		✓	✓
Northamptonshire	C	✓	PRT		
Northumberland	C	✓			
North East Lincolnshire	C			✓	
North Lincolnshire			✓		
North Somerset	C		P	Y	
North Tyneside		✓	PRT		✓
North Yorkshire	C	✓	PRT P P(Y)		✓
Nottingham City	C				
Nottinghamshire	C		PRT	EM✓	
Oldham			P		
Oxfordshire	C		PRT	EM	
Peterborough	C		PRT		

Plymouth	✓	✓		✓	
Poole	✓	✓		✓	
Portsmouth		✓			
Reading	C	✓	PRT	✓	
Redbridge	C✓		P	EM✓	✓
Redcar & Cleveland				✓	
Richmond upon Thames	C	✓		✓	
Rochdale	C✓			✓	
Rotherham	C	✓		✓	
Rutland			PRT		
Salford	C			✓	
Sandwell	C	✓	PRT P		
Sefton	C	✓	PRT		
Sheffield	C		PRT		
Shropshire	C	✓		✓	
Slough	C	✓			
Solihull	C	✓			
Somerset	✓	✓		✓	
Southampton				Y	
Southend		✓			
Southwark	✓		PRT	Y✓	
South Gloucestershire	C		PRT	✓	
South Tyneside	C		P	✓	
St Helens	C	✓	P		
Staffordshire	C	✓		✓	
Stockton-On-Tees				✓	
Stoke On Trent				✓	
Suffolk	C✓		PRT	P	
Sunderland			PRT		
Surrey	C	✓	✓	✓ Y EM	
Sutton	C✓	✓	PRT✓	✓	
Swindon			PRT		
Tameside	C✓		✓		✓✓
Telford & Wrekin					
Thurrock		✓		✓	
Torbay		✓		✓	
Tower Hamlets	C		PRT	Y EM✓	
Trafford			PRT		
Wakefield				✓	✓
Walsall			PRT		
Waltham Forest	C			Y EM✓	
Wandsworth	C LA		PRT	Y	
Warrington	C			✓	
Warwickshire	C	✓	P		
West Berkshire		✓			
West Sussex	✓	✓	P		✓
Westminster	✓		P	✓	✓
Wigan	C	✓		✓	
Wiltshire	C	✓	PRT	✓	

Windsor/Maidenhead	C	✓			
Wirral	C LA✓	✓		✓	
Wokingham	C	✓		✓	
Wolverhampton	C		P (EM)		
Worcestershire	C✓		P		
York		✓	P		

SUPPORT FOR CARERS BY LOCAL AUTHORITY AREA					B) Wales
Local Authority	Sitting/ respite service	CNA Branch	Carers Centre/ Drop in centre/ Carers project	Carers worker/ development officer	Other LOCAL groups specifically for carers
Blaenau Gwent	C			✓ Pt	
Bridgend	C				✓
Caerphilly				✓ Y	✓
Cardiff	C, EM	✓		✓ Pt	✓
Carmarthenshire	C	✓		Y	
Ceredigion	C	✓			
Conway	C	✓		✓ Pt Y	✓
Denbighshire	C		Sh	✓ Pt Y	
Flintshire	C	✓	Sh	✓ Pt Y	
Gwynedd	LA		PRT	✓	
Merthyr	C	✓		Y	
Monmouthshire	C			✓Pt	✓
Neath Port Talbot			✓	✓	✓
Newport	C			✓Pt	✓
Pembrokeshire	C	✓	PRT	✓	
Powys	C	✓	PRT	✓3Pt Y Pt	
Rhondda Cynon Taf	C			✓Y	✓
Swansea	C	✓	✓	✓	✓
Torfaen	C	✓			✓
Vale of Glamorgan	C	✓		✓ Pt	
Wrexham	C		PRT	✓ Pt Y Pt	
Ynys Mon	C		Sh	✓	

SUPPORT ARRANGEMENTS FOR CARERS			C) NORTHERN IRELAND		
HSS Trust	Sitting/ respite service	CNA Branch	Carers Centre/ Drop in centre/ Carers project	Carers worker/ development officer	Other LOCAL groups specifically for carers
Down Lisburn	C	✓	✓		✓
North & West Belfast	CT✓	✓	PRT ¹		✓
South & East Belfast	C✓	✓	✓		✓
Ulster Community & Hospitals	C✓		✓	Y ² ✓	✓
Causeway	CT✓		✓		✓
Homefirst	C	✓			✓
Armagh & Dungannon	CT✓		✓		✓
Craigavon & Banbridge	CT✓	✓	PRT ✓	Y ✓	✓
Newry & Mourne	CT✓		✓	✓	✓
Foyle	CT ✓	✓	✓	✓	✓
Sperrin Lakeland	✓		✓	✓	✓

¹ Belfast centre is a city-wide service.

² This is a province-wide service.

SUPPORT FOR CARERS BY LOCAL AUTHORITY AREA			D) SCOTLAND		
Local Authorities in Scotland	Sitting/ respite service	CNA Branch	Carers Centre/ Drop in centre/ Carers project	Carers worker/ development officer	Other LOCAL groups for carers
Aberdeen City	C	✓	PRT		
Aberdeenshire	C			✓	✓
Angus	C		PRT		
Argyll & Bute	C	✓	PRT		✓
Edinburgh City	C		PRT		
Clackmannanshire	C		PRT (Falkirk)		✓
Comhairle Nan Eilan Slar (Western Isles)	C/LA		Mobile Info Unit		✓
Dumfries & Galloway	C	✓	PRT		
Dundee	C	✓	PRT		
East Ayrshire	C		PRT	✓	✓
East Dunbartonshire	C				
East Lothian	C		PRT		✓
East Renfrewshire					
Falkirk	C		PRT		✓
Fife	C	✓	PRT		✓
Glasgow City	C	✓	PRT/LA		✓
Highland	C	✓	PRT		✓
Inverclyde	✓				✓
Midlothian	C				✓
Moray	C				✓
North Ayrshire	C		PRT		
North Lanarkshire	C	✓			✓

Orkney Islands	C		PRT		
Perth & Kinross	C		PRT		
Renfrewshire	✓		PRT		✓
Scottish Borders	C		PRT		✓
Shetland Islands	C/LA				✓
South Ayrshire	C		PRT		✓
South Lanarkshire	C		PRT		✓
Stirling	C		PRT		✓
West Dunbartonshire					✓
West Lothian	C ✓				✓

The lack of a specified carers' officer does not mean that strategic planning of carers' services is not being actively pursued in many of the Scottish local authorities. Many authorities have carers' strategy groups or are involved in Carers Forums (included under 'Other Local Groups For Carers').

Source: Carers' National Association, Princes Royal Trust, Crossroads, Daybreak (Wales).

KEY TO TABLES	
<p>Col 1 – Sitting/respite service:</p> <p>C services provided by Crossroads</p> <p>LA services provided by the local authority</p> <p>T services provided by community HSS Trust (NI)</p> <p>EM one for ethnic minority carers</p> <p>✓ services provided by another agency</p> <p>Col 2 – CNA branch:</p> <p>✓ branch in the area</p>	<p>Col 3 – Carers centre/drop in centre/carers project:</p> <p>PRT Princess Royal Trust centre/project</p> <p>LA local authority centre or project</p> <p>Sh shared with another area</p> <p>P project, but not known if there is any centre</p> <p>✓ any other centre or project</p> <p>Col 4 – Carers worker/development officer:</p> <p>✓ one for all carers</p> <p>Y one for young carers</p> <p>EM one for ethnic minority carers</p> <p>Pt part-time</p> <p>Col 5 – Other local groups specifically for carers:</p> <p>✓ other local carers group available</p>

