



Department of
**Health, Social Services
and Public Safety**

An Roinn

**Sláinte, Seirbhísí Sóisialta
agus Sábháilteachta Poiblí**

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Caring for Carers

Recognising, Valuing and
Supporting the Caring Role

Ministerial Foreword

The contribution of informal carers to the health and well-being of our general population is immeasurable. The census and other surveys indicate that there may be around 185,000 such carers in Northern Ireland, many of them young people and all of them facing difficult challenges in their everyday lives. It is absolutely vital that their contribution is recognised, respected and supported by Government and statutory agencies.

Caring is an issue which could affect us all at some point in our life. We may need care ourselves, or may choose to provide care for a friend or loved one. The assistance provided by carers cannot be overestimated and it is thanks to their dedication that thousands of people in Northern Ireland are able to retain their independence and continue to live in their local community. Caring is often rewarding but can also be very demanding, with carers devoting large parts of their own lives to the lives of others. The valuable role that carers play in our society must not go unrecognised.

This strategy has been developed in direct response to the recommendations contained in *Valuing Carers*, which were arrived at following detailed consultation with carers, voluntary groups and statutory bodies. It addresses in a practical way the support that carers want, and need, to allow them to continue caring, and to give them as much access as possible to the same opportunities that the rest of us enjoy. The strategy sets out what we have been doing and a vision of what still needs to be done to give carers the quality of life we believe they deserve. The basic rights of carers to accessible information, employment and training opportunities, and stronger support networks are addressed through this strategy. The changes proposed will make a real and valued difference to the range and quality of services provided to carers. Although not every aspect can be realised overnight, the strategy represents a firm campaign of action for Government over the coming months and years, which will be fully integrated into our existing priorities and plans.

Carers are vital contributors to our communities and deserve our full support and encouragement. I am confident that this strategy will improve the quality of life for thousands of carers and their families in Northern Ireland.

Shaun Woodward

Minister for Health, Social Services and Public Safety

Contents

Introduction	5
Background	10
Identification of and Interface with Carers	13
Information for Carers	21
Support Services for Carers	23
Young Carers	27
Training	30
Employment	34
Appendix 1 – Subgroups and recommendations from Valuing Carers	39
Appendix 2 – Summary of Further Key Actions	42
Appendix 3 – Framework for Support Services to Carers	45
Glossary of Terms	53
References	54

Section One - Introduction

Who are Carers?

- 1.1 Carers are people who, without payment, provide help and support to a family member or a friend who may not be able to manage without this help because of frailty, illness or disability. Carers can be adults caring for other adults, parents caring for ill or disabled children or young people who care for another family member.
- 1.2 Caring is an issue that can affect us all at any time irrespective of job or status and every caring situation is unique. Many carers would not identify with the term 'carer', rather they see themselves as dutiful parents, sons, daughters, partners or friends accepting and discharging a responsibility toward a friend or loved one. Therefore, the use of the term carer must be carefully considered.

What We Know About Carers in Northern Ireland

- 1.3 **Northern Ireland Census of Population 2001**¹ indicated that there are over 185,000 unpaid carers in Northern Ireland, equating to approximately 11% of the population. Of these, 60% are providing care between 1-19 hours per week, 15% providing care between 20-49 hours per week and 25% are providing care for more than 50 hours per week.
- 1.4 Recent analysis of the **2001 Northern Ireland Household Panel Survey**² provides an important source of information about carers and the relationship between caring, health, well-being and lifestyle.
- 1.5 On the prevalence of caring the survey indicated that:
 - 16% of respondents acted as carers with 27% of carers providing care for 20 hours or more per week.
 - Women were more likely than men to be carers (19% of adult women in Northern Ireland have caring responsibilities compared to 13% of adult men). As well as being more likely to be carers, women spend more hours caring than men. 49% of male carers provide help for less than 10 hours per week, while 55% of female carers provide assistance for more than 10 hours a week.

1 Northern Ireland Statistics and Research Agency – Table CAS025(NI) of the Northern Ireland Census of Population 2001

2 2001 Northern Ireland Household Panel Survey (ESRC & ISER - University of Essex) Research Update “Who Cares?” – Eileen Evason ARK (www.ark.ac.uk)

- 55% of carers in Northern Ireland are aged 45 years or over. Just over one in five (21%) are aged 60 years or over.
- 38% of carers assist someone living in the same household, more than half (55%) assist someone in another household, while 7% assist someone in their own household and someone in another household.
- Caring clearly has an impact on people's ability to earn a living. 65% of men under the age of 45 with caring responsibilities are in employment compared with 74% of men in the same age group without caring responsibilities.
- Although the difference in the proportions of female carers and non-carers who are not in employment is relatively small, their reasons for not working differ substantially. Almost one third (32%) of non-employed female carers under the age of 45 describe themselves as engaged in full-time home care compared with only 17% of those without caring responsibilities.

1.6 On who is caring for whom the survey indicated that:

6

- Nine out of ten carers care for someone related to them – 44% care for a parent and 22% care for a partner or spouse.
- 43% of those caring for elderly parents or in-laws, also have the additional responsibility of dependent children.

1.7 On the lifestyle and health and well-being of carers the survey indicated that:

- 61% of carers have some health problems.
- While the majority (68%) rated their health as good or excellent over the preceding 12 months, 11% said their health had been poor.
- 55% of carers report membership of religious, voluntary and community groups and other groups.
- 40% report talking to their neighbours most days, while 20% report contact with neighbours only once or twice a month or less.
- Almost half of carers meet people from outside their immediate household most days, but 8% report such contact only once or twice a month or less.
- Crucial aspects of social well-being and social inclusion involve the feeling that there is someone who will listen, someone who will help in a crisis. Approximately one in ten carers have no one outside the immediate household who would help if they were depressed, 7% have no one who would listen to them and 10% would have no one to speak to in a crisis.

- 68% of carers report that financial constraints limit their activities. While 61% of carers say they are living comfortably or doing all right, 30% describe themselves as just getting by and 9% are finding it quite or very difficult to manage.
- Only 9% of carers are in receipt of the Carers' Allowance.

1.8 While there may be common themes in relation to the basic need for support, we know that people who provide care for others are a very diverse group, with equally diverse needs. A man of 70, caring for his wife with dementia, will 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.

Why Should We Care About Carers?

1.9 We do not need to understand each individual's circumstances or motivation in what is often a very personal and private activity but we do need to recognise the existence and the value of carers, both to the person they care for, and to the wider community.

1.10 It is clear that carers enable many thousands of vulnerable people who need support, to continue to lead independent lives in their local communities. At the same time carers reduce the amount of input that health and social services and other agencies need to make. It is essential that we act positively to protect the interests of carers and to foster a climate where they can continue to care for as long as they wish and are able to do so, without jeopardising their own health and well-being, financial security, or reducing their expectations of a reasonable quality of life. We want to enable carers to make more choices for themselves and to have more control over their lives. We want services to recognise carers as individuals in their own right. So we are giving new support to carers.

1.11 It is expected that in the future there will be an increasing demand for care largely due to the fact that people are living longer, resulting in a growth in the numbers of older and more frail people with complex needs living in the community. In addition, many people, for example, individuals with learning difficulties or dementia now have longer term care needs. These changes have obvious implications in terms of the demands placed on carers who themselves are getting older and more in need of support.

- 1.12 The number of people over 65 in Northern Ireland will increase from 274,000 in 2004 to 458, 000 in 2042 – an increase of 67%. The number of people over 85 will increase by 139% in the same period. At present there are approximately 4 people of working age for every pensioner but by 2042 there will be approximately 2.³
- 1.13 While the number of people needing care is set to rise, social trends could, in the future, have an effect on the number of available carers. The growth in the number of lone parents, falls in birth rates, higher divorce rates, the increase in the numbers of people living alone and greater family mobility may all have an impact on the numbers of people available to assume a caring role. In addition, the growing number of women who are employed outside the home will have implications for the number of carers, since women have traditionally fulfilled the caring role.
- 1.14 A very large number of those people who receive community care services to help them to manage their own lives are dependent on the care and support of a carer. Government policies for community care depend, in large part, upon the continuing contribution of carers; indeed carers are seen as forming the backbone of community care. **People First - Community Care for Northern Ireland in the 1990s**⁴ acknowledged the crucial role that carers play in providing care. The paper states, “the family...continue to be the major supplier of social and personal care, and the obligations of kin and affection will remain powerful motivators. It is in society’s interest to sustain that motivation and to see that appropriate packages of support are assembled for people who are able and willing to care for others”.
- 1.15 A document produced by DHSS in 1995, **Dementia in Northern Ireland – Report of the Dementia Policy Scrutiny**⁵ also recognises the important contribution made by carers. The report devotes a section to the needs and rights of carers, stating “carers are an invaluable resource and play an important part in the care process from the onset of dementia. Caring exacts a heavy price on carers and, if we wish them to contribute fully to supporting people with dementia, it is important to recognise that they too require timely and effective support.”

3 Northern Ireland Statistics and Research Agency – Population Projections (2002 based)
4 People First Community Care in the 1990s – DHSS 1991
5 Dementia in Northern Ireland – Report of the Dementia Policy Scrutiny – DHSS 1995

1.16 ***The Review of Community Care – First Report***⁶ reaffirms:

“The contribution carers make towards helping people remain in their own homes and staying independent cannot be overstated. This level of service could not be delivered by the formal care system and this important fact should be recognised and supported. We need to think of ways in which the system can recognise the valuable role of carers and provide more comprehensive support for them.”

Section Two - Background

2.1 As Minister for Health, Social Services and Public Safety within the former Executive, Bairbre de Brún commissioned a strategy for carers in October 2000. She identified the key aim of the Strategy as “identifying practical measures that would make a real difference to the lives of carers”. In drawing up recommendations for a strategy the Department consulted a reference group of carers and organisations representing carers to find out what they saw as solutions to the difficulties they face in carrying out their caring role. Carers identified five principles as the key requirement of any strategy development.

What Carers Told Us

- 10
- 2.2 **Carers are real and equal partners in the provision of care.** Carers must be recognised and included as real and equal partners at every level of public sector planning and service delivery – from individual care planning to designing a service. A carer has a unique relationship with the person they care for. In their partnership with carers, other agencies or care providers should recognise and value that relationship, and the care given by the carer in their joint responsibility for the person being cared for. Carers must have equal status with other providers of care.
- 2.3 **Carers need flexible and responsive support.** All carers are individuals with their own needs, caring for people with a huge range of needs and abilities in what can be very complex and emotionally charged relationships. One solution will not fit all – carers need real choices based on relevant, timely and accessible information.
- 2.4 **Carers have a right to a life outside caring.** Carers need rest, relaxation and a social life and if they wish to work outside the home, they should have the opportunity to do so.
- 2.5 **Caring should be freely chosen.** Carers should be allowed to decide what level of caring support, if any, they can offer at any particular time.
- 2.6 **Government should invest in carers.** To make any real impact on carers’ lives, resources are required. Carers are involved in providing care and like any other provider of care they need resources to carry out this role. Most of the resources which carers devote to caring are their own – their time, energy and emotional commitment but in order to carry

on caring, carers need support. Support of any kind that a carer receives to enable them to continue caring should be seen as a legitimate right.

2.7 The outcome of this consultation was reported in **Valuing Carers**⁷ and was published in April 2002. The report contained a total of 19 recommendations, all of which were accepted. Additionally, carers were identified as a priority group under the former Executive's Promoting Social Inclusion (PSI) programme and an inter-departmental Carers Working Group was established and tasked with developing a strategy to improve the practical support given to carers.

2.8 The **Valuing Carers** reference group had already identified 4 main areas where action could be taken to help carers and each of the 19 recommendations they made as a result of their consultation fell into one of these main areas:

- **information and training;**
- **support services;**
- **employment; and**
- **help for young carers.**

The PSI Carers Working Group decided to use the 19 recommendations contained in **Valuing Carers** as a starting point for developing **Caring for Carers**. To ensure all the recommendations were properly examined and addressed, the recommendations were allocated to sub-groups, with leaders from the main working group and appropriate representation from carers and their representative organisations (Appendix 1). The 6 key themes around which the strategy has been developed were:

- **IDENTIFICATION OF AND INTERFACE WITH CARERS**
- **INFORMATION FOR CARERS**
- **TRAINING**
- **EMPLOYMENT**
- **SUPPORT SERVICES**
- **YOUNG CARERS**

2.9 A significant amount of progress has already been made in implementing various aspects of this Strategy including securing new investment for the expansion of respite services for carers. However further work is still required to fully implement the Strategy and a summary of the proposed actions can be found at **Appendix 2** of this document.

Section Three - Identification of and Interface with Carers

Identifying Carers

- 3.1 Identifying carers at the earliest possible time is important in ensuring that they get the right information at the right time.
- 3.2 Many people carrying out a caring role do not identify themselves as carers: they are just people who are 'taking care of Dad'; 'looking after my sick daughter'; 'standing by my partner through thick and thin'. They may not be aware of the support services available to them and therefore are not likely to ask for support.
- 3.3 The majority of carers identified their family doctor or General Practitioner (GP) as the first place that they would look to for information about how to get help but many GPs do not feel equipped to fulfil this "signposting" role. The establishment of Local Health and Social Care Groups (LHSCGs) offers an opportunity to better address carers' needs by carrying out locality based needs assessments in order to inform the commissioning of appropriate services. The LHSCGs provide a framework which supports primary care professionals in working closely together with other parts of the HPSS and with other statutory, community and voluntary organisations and agencies that can contribute to improving health and well-being.

13

RECOMMENDATION FROM VALUING CARERS

- (a) The Local Health and Social Care Groups should have a central role to play in identifying carers
- (b) It should be a key objective for the Groups that they have mechanisms in place to enable them to take a holistic view of health and well-being and to address the health, social care and associated needs of both the person being cared for and the carer linking closely with other local agencies especially community and voluntary organisations.

- 3.4 All health and social care professionals, including GPs, are well placed to identify the presence of an informal or family carer. The Department will issue Guidance advising these professionals that they must identify the presence of a carer and the level of care being provided, and record it in

a readily accessible way on all patient/client and carer records, paper and electronic. In responding to the needs of the patient/client, professionals must have regard to the impact on the carer of any change in the management plan in relation to the patient/client. Where a carer is identified, health and social care professionals must offer a carer's assessment in order to take a holistic view of the health and well-being and associated needs of the carer. Boards and their LHSCGs should provide support to independent contractors in meeting this requirement.

- 3.5 It is essential that HSS Boards, including their LHSCGs, and HSS Trusts collate the information gathered on carers and their needs and take it into account fully in reaching their commissioning and service delivery decisions. The Department will issue principles for good practice in this respect.

Sharing Information

- 3.6 On assuming a caring role, carers need information about the condition of the person to be cared for and about what will be expected of the carer in the present and for the future. Such information is vital in enabling potential carers to decide what, if any, care they can provide and what support they will need to enable them to provide and to continue to provide care should they choose to do so.

14

RECOMMENDATION FROM VALUING CARERS

General practitioners and other clinicians should seek their patient's consent to provide information to the carer about the patient's illness or disability, medication and symptoms.

- 3.7 The Department recognises that carers need information on the health, care and treatment needs of the person they are caring for. They especially need information about medication such as when it is to be taken and about recognising side effects. They need information to enable them to deal with the symptoms of some illnesses and to know when to ask for professional help.
- 3.8 The HPSS 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 GPs

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 secure 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.

- 3.9 GPs, other clinicians and all professionals will be advised that they must actively encourage patients to consent to the sharing of information about their illness or disability, medication and symptoms. The Care Management process should also include a specific requirement to seek consent to disclosure of relevant information to a carer. Professionals should stress to the patient, the importance and benefits of sharing this information with the carer, and how it will help to improve their future care.
- 3.10 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.
- 3.11 Where consent is not forthcoming, GPs, other clinicians and professionals, should consider whether there is a public health interest, and refer to paragraphs 5.6 and 5.7 in ***The Protection and Use of Patient and Client Information***⁸ for further advice.

15

Carers' Assessments

- 3.12 Early intervention individually tailored to the needs of the carer and the person being cared for is crucial in avoiding a breakdown in the caring situation. Good assessment processes are key to developing appropriate and quality services for carers. A carer's assessment should identify what the carer brings to the caring role, what additional support is available from family, friends and local community and focus on identifying what information, training or services are required to support the carer. The assessment process is of value even where additional service provision does not flow from a carer's assessment.

3.13 Carers say there are a number of positive outcomes for them in having an assessment even where practical services may be restricted because of financial constraints. They value:

- recognition of their role;
- a chance to talk through the issues and consider their own needs;
- information about the condition of the person cared for and its likely progression;
- information which can be provided on other support available, such as carer groups and local statutory and voluntary services;
- a sense of shared responsibility, particularly where any support offered is on a regular basis;
- increased confidence to take up services; and
- peace of mind from knowing how to make contact in the future.

3.14 Research suggests that making the desired outcomes of interventions explicit at the assessment stage helps care managers and providers to focus on improving individual quality of life, which in turn helps carers maintain the caring role for as long as they wish.

16

RECOMMENDATION FROM VALUING CARERS

Guidance on carers assessments should make it clear that Health and Social Services Trusts should inform carers of their right to a separate assessment and should require that the results of such an assessment be separately recorded.

3.15 The Carers and Direct Payments (Northern Ireland) Act 2002 (the 2002 Act) came into effect on 29 March 2003 and requires each Trust to make information generally available in its area about the right of a carer to an assessment, and to take steps to ensure that carers in its area have access to such information. The 2002 Act also states that, where a Trust is aware that someone is providing care, it must notify the carer of his or her right to request an assessment. Under the 2002 Act, carers are given the right to have an assessment of their own ability to provide (and to continue to provide) care for the person cared for:

- where they provide or intend to provide a substantial amount of care on a regular basis for another individual aged 18 or over; and
- the Trust is satisfied that the person cared for is someone for whom it may provide or arrange for the provision of personal social services.

- 3.16 This right to assessment exists even where the person cared for has refused an assessment of his or her own needs by the Trust, or has refused the delivery of personal social services following assessment.
- 3.17 A carer's assessment under the 2002 Act is carried out in order:
- to determine whether the carer is eligible for support;
 - to determine the support needs of the carer (i.e. what will help the carer in their caring role and help them to maintain their own health and well-being); and
 - to see if those needs can be met.
- 3.18 The Department, following the introduction of the 2002 Act in March 2003, issued specific guidance on Carers Assessments. This guidance, entitled **Carers Assessment & Information Guidance**⁹ has been reviewed and updated and revised guidance was issued in April 2005.
- 3.19 The guidance clearly states that Trusts should inform all carers providing or intending to provide care on a regular and substantial basis of their right to a separate assessment and requires that the results of such an assessment must be recorded and a copy given to the carer. Professionals should adopt a "carer centred" approach to assessment. This may be achieved by listening to carers and seeking to achieve outcomes which, while being specific and relevant to the individual carer, also meet the test of supporting the carer in their caring role or helping them to maintain their own health and well-being.
- 3.20 In addition, the Department has commissioned the development of a single comprehensive assessment tool. Although the principal product of this work will be a validated single assessment tool for the health and social care needs of older people, it is being designed with a view to further development for other groups who may need care and support. The single assessment tool will include a prompt for the offer and completion of a carer's assessment and a specific requirement to seek the consent of the person cared for to the sharing of relevant information with the carer.

Discharge from Hospital

- 3.21 At the time of discharge from hospital, 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. The **Guidance**

on Discharge of Hospital Patients,¹⁰ issued by the then Department of Health and Social Services to Health and Social Services Boards and Trusts in November 1998, states that: “users and carers should be fully involved in assessments prior to discharge; that they should be aware of the implications of any decisions taken; that care plans should be agreed with them; that there should be opportunities for them to discuss any concerns; and that sufficient time is allowed for alternative acceptable arrangements to be made.” It is clear that these standards are not always met.

RECOMMENDATION FROM VALUING CARERS

The Department of Health, Social Services and Public Safety should remind Health and Social Services Boards and Trusts that carers should be fully involved in the timing of discharge from hospital and that carers should be given all the information that they require about the future care of the patient. Hospital discharge processes should ensure that carers are identified and that the presence of a carer is included in the discharge letter to the GP.

18

- 3.22 All Trusts must ensure that carers are identified at the time of admission, involved in discharge planning and their details with a contact number are included in all discharge letters, including those to GPs. Trusts will be advised that they must have a clear policy for discharge. The policy must include identifying a person who has overall responsibility for ensuring that carers are fully involved in the planning process when a client/patient is being discharged from hospital. Trusts will formally monitor and review these policies with carers on a regular basis to ensure effective implementation.
- 3.23 Where a person under 18 years of age is providing or intending to provide substantial and regular care, an appropriate referral to the relevant child care team must be made. As a general principle, a sufficient level of service should be provided to the ill or disabled person so as to prevent these young people from having to take on inappropriate levels of responsibility for providing care. The wishes of the young person must be respected when considering the planning

and delivery of services and, where appropriate, they should be supported in contributing to the caring role in a way that does not compromise their health, well-being or developmental needs.

- 3.24 Guidance for service managers, practitioners and carers on discharge planning from hospital or other institutional care, will be developed and issued by the Department.

Support for Older Carers

- 3.25 The **2001 Northern Ireland Household Panel Survey**, indicates that 55% of carers in Northern Ireland are aged over 45 years old, with over a fifth of all carers aged 60 plus. A report commissioned by Help the Aged with support from Carers UK suggests that the number of older carers is increasing and that they form an increasing number of all carers probably as a result of policies aimed at enabling older, ill, or disabled people to remain in their own homes for as long as possible. The report indicates that older carers are likely to offer higher levels of personal and physical care than carers in other age groups. Many older carers are not only caring intensively for many hours per week, but often they have been caring over a long period of time, and in addition may be caring for others while suffering from health problems themselves. More overall support is needed for older carers so as to alleviate the impact of caring in old age.

19

RECOMMENDATION FROM VALUING CARERS

Health and Social Services Boards and Trusts need to be particularly proactive in seeking out and supporting older carers.

- 3.26 Trusts will be asked to pay particular attention to the needs of older people who are themselves providing substantial care to others. Older people who are providing care may be more likely to suffer health and well-being problems and Trusts will need to be very sensitive to changing needs and demands for support, and the need for such support to be provided in the most flexible manner. Trusts will regularly review services to older carers, continuously seeking to improve the range of support provided. Direct Payments also provides a vehicle for

older carers to assert more control over the type of support they receive and when they receive it.

3.27 The Department, through the Social Services Inspectorate, are in the process of carrying out an inspection of the social care support services for carers of older people, with a particular emphasis on the impact of these services on carers and the caring role. This inspection will establish the nature, range, and quality of social care support services for the carers of older people commissioned and provided by Boards and Trusts on a direct or partnership basis. This will be achieved by: developing a set of standards; establishing the type, range and volume of current service provision for carers of older people; conducting an audit of current service provision for carers of older people, to include the way in which carers of older people are involved in the provision of services, individually and collectively; and examining how services are organised and delivered. The inspection will also help to refine issues for further examination and highlight good practice. The published standards will identify what carers can reasonably expect from services and will provide the basis for self-audit by organisations commissioning and/or providing social care services to the carers of older people.

Section Four - Information for Carers

Information Handbook for Carers

- 4.1 The 2002 Act requires Trusts to make information generally available in its area about the right of carers to request an assessment and to take steps to ensure that carers in their area have access to such information.
- 4.2 Access to relevant information has been identified as crucial to carers. They need the right kind of information in the right format and at the right time. Whilst almost all the information that carers need is already available somewhere, carers may not be aware of the existence of particular information which can help them. It is important that information for carers is accessible. Carers should have access to up to date information about where to get help locally.

RECOMMENDATION FROM VALUING CARERS

Health and Social Services Trusts and organisations representing carers should consider developing handbooks for carers about local services.

21

- 4.3 An index of services, A-Z for Carers, will be developed setting out the range of statutory and voluntary organisations that provide advice and information for carers on a regional basis. That guide will be widely available in GP surgeries, Health Centres, Libraries etc. Trusts, in association with the voluntary sector, will also provide information packs setting out details of services specific to the local Trust area.

Use of Information Technology

- 4.4 It is also important that full use is made of information technology by providing information that is up to date and easily accessible. Young carers in particular have suggested providing information in this way.

RECOMMENDATION FROM VALUING CARERS

The Department of Health, Social Services and Public Safety working with other government departments as appropriate should look at ways of improving the information available on the internet about the services to carers in Northern Ireland and should work to increase awareness of the availability of such information

- 4.5 A regional website, the Carers Information Network (CIN) (www.carersinfo.net), has been set up to improve the health and well-being of carers by making it easier for them to get the information they need, when they need it. The website contains information on, and links to employment, education, health and social services, social security benefits, voluntary organisations etc.

Support Networks

- 4.6 In some cases, carers will get information from initial contact with the social security benefits system. Others may obtain information through contact with voluntary organisations, and carers who are looking after someone with a particular health or care need may contact a voluntary organisation that specialises in helping people with those needs. No single source of information is available and carers may have to find their way through a maze of organisations in the statutory and voluntary sector.

22

RECOMMENDATION FROM VALUING CARERS

All organisations, which have contact with carers, whether statutory or voluntary, need to see their role as part of a wider network of support for carers and be able to refer them to services, which can support them.

- 4.7 The availability of the A-Z Index and the Carers Information Network will facilitate the development of local support networks and Trusts are encouraged to work closely with the voluntary sector to support the establishment of such support groups. Information on such groups will be made widely available within the local Trust area.

Section Five - Support Services for Carers

5.1 In order to address all the issues and recommendations in this section, a Framework for Support Services to Carers (Appendix 3) has been developed and issued to HSS Trusts. That framework will help Trusts to examine the ways in which support to carers can be best provided and will help them to develop new and more flexible services in consultation with carers and their representative organisations.

Partners in Care

5.2 Clearly carers need support in carrying out their caring responsibilities and if carers are to be seen as real and equal partners in the provision of care, as we believe they must, it is vital that they are involved in service planning. Involving carers and their organisations is an important way of ensuring that services are responsive to their needs. Service providers should establish what services are available in their areas, and the extent to which they are used. Services should be tailored to fit the needs of users and carers and not those of the provider.

5.3 A range of flexible, practical support services needs to be in place for the person being cared for and the carer. Clearly the provision of a proper service to the person being cared for is crucial to alleviating the burden on the carer. The Carers and Direct Payments Act (NI) 2002 gives Trusts the authority to offer carers support services in their own right. Services to carers are not defined in the Act and guidance has been issued by the Department stating that social care professionals should be innovative and imaginative in this regard.

5.4 It is very important to make a clear distinction between 'outcomes' and 'services'. Any outcome valued by the carer may be considered as a legitimate use of Trust resources if it will genuinely support the carer in their caring role, or help them maintain their own health and well-being. The service most likely to provide the desired outcome will depend on the individual carer's circumstances. However, decisions on the provision of services to carers must be taken in line with other Trust priorities. It should be remembered that carers will often need support in their own right after the caring role has ceased.

RECOMMENDATION FROM VALUING CARERS

Health and Social Services Boards, Trusts and other providers should review their service provision for carers with carers.

Breaks from Caring

5.5 Carers have a right to a life outside caring. This means time to pursue their own interests, see their friends, go to church or catch up with work around the house. Carers need breaks from caring but too often they do not get breaks or the breaks are provided in an inappropriate way. Carers often have little choice about the timing or the type of break. A range of respite care must be provided to suit the needs of both the carer and the person being cared for – week-long, one evening a week, weekend, overnight, short breaks in residential care – different options will suit different people. Respite care should not be seen exclusively as alternative residential care. Respite could also, often more appropriately, be provided by somebody coming into the home. There is also a need for emergency cover to be available, for example, for carer illness.

24

5.6 What carers want most of all during a break from caring is to know that the person being cared for is well looked after and secure. Carers' needs should be considered on an individual basis and they should have a choice about the type of service available to give them a break and about the timing of the break.

RECOMMENDATION FROM VALUING CARERS

Health and Social Services Boards and Trusts should review the provision currently being made for carers' breaks and the information on which they base their funding decisions to determine what carers want. Carers and people needing care should be involved in the review. This should form part of the general review of services for carers mentioned above.

Co-ordinating Support for Carers

- 5.7 Research into carers' experiences demonstrates that their relationships with statutory organisations are of key importance. Not knowing or understanding "the system", they rely on the social worker, district nurse or GP to tell them what to do or who to go to for help. It can even take carers a long time to recognise themselves as carers and to acknowledge that they need help.
- 5.8 The Department has allocated additional money for community care services such as rehabilitative packages, carers' breaks and support for family carers, and plans to continue to do so where such resources are available. However, changes in awareness of, and attitude to, carers could also make a significant difference. For example, of the ten recommendations made in the Carers UK research into hospital discharge¹², seven were about improving awareness, sensitivity, providing information, communication, referral and signposting.
- 5.9 Carers told us that the creation of a carer liaison or co-ordinator post in each Trust could help to bring about improvements in these areas and could provide a focal point for dealing with issues affecting carers.

25

RECOMMENDATION FROM VALUING CARERS

A carer liaison or co-ordinator post should be created in each Health and Social Services Trust.

Carers Groups

- 5.10 Carers also need emotional support in coping with their caring role. Many carers obtain this through contact with other carers in a similar situation. Such contact can help to provide carers with information about the services which they need, but also about how to cope with caring and with reassurance that they are not alone in feeling the strains and stresses of caring. Carers have told us that they value carers groups and that the groups are a good means of involving carers in the community by providing a focus for their involvement in local decision-making.

- 5.11 Groups for carers of people with specific illnesses can be valuable sources of information as well as providing support for carers. Groups open to all carers can be helpful in encouraging carers to focus on themselves.
- 5.12 All carers should have access to local carer support services which we believe are best run and managed by the voluntary sector, particularly when carers themselves are involved in the management arrangements.

RECOMMENDATION FROM VALUING CARERS

Both localities based and disability specific groups should be encouraged and supported at local level.

Section Six - Young Carers

Identifying and Assessing Young Carers

- 6.1 Young carers generally care for members of their immediate family whether a parent with a physical illness, disability, mental health problem or alcohol or drug dependency; a grandparent who is frail, ill or disabled or a brother or sister who is ill or disabled. The experience of growing up in a family where either a parent or a brother or sister is ill or disabled can bring both rewards and difficulties, and it is important to record that many young carers want to care – they see their role as being part of the dynamics in their family and would not want to stop caring. They do, however, need recognition, understanding and support. All carers need support but because of the potential for adverse impact in the longer term on their educational, social and emotional development, children undertaking caring responsibilities have particular needs.
- 6.2 As a general principle a sufficient level of service should be provided to the ill or disabled person so as to prevent young people from having to take on inappropriate levels of responsibility for providing care. The wishes of the young person must be respected when considering the planning and delivery of services, so as to afford him or her the opportunity to contribute, where appropriate, to the caring role in a way that does not compromise his or her own developmental needs.

RECOMMENDATION FROM VALUING CARERS

Guidance to Boards and Trusts on carers' assessments should stress the need to ensure that young carers are identified and that services are put in place to ensure that their education and development do not suffer because of their caring responsibilities.

- 6.3 Carers' Assessment and Information Guidance, which was issued by the Department in April 2005, stresses the responsibility that Boards and Trusts have to ensure that they identify children whose parents or other relatives have specific needs because of illness or disability. These children must be given the opportunity to enjoy the same life chances as all other children and Trusts may provide services to ensure that their education and development do not suffer.

Information for Young Carers

6.4 Young carers are often reluctant to come forward because they are afraid of what may happen to them and their families should it become known that they are caring for someone. They also may not want other young people to know about their situation. This is especially true in the case of adolescents who feel that the need to be the same as everyone else and not stand out is important. Whatever the reason, this secrecy can lead some young carers to feel isolated from other young people within their school or community. This hampers them from getting information about services and support, and many young carers do not realise that there are people who can help them. They have told us that they need information that is easily accessible. As with all carers, they mentioned information on the health and care needs of the person being cared for, how to do practical things for the cared for person such as help him or her go to the toilet and where to get help if they want it. They suggested a website as the most practical method of making such information available. Information should be made available on the Internet about services to carers and the needs of young carers should be specifically taken account of in so doing.

28

RECOMMENDATION FROM VALUING CARERS

The Department of Health, Social Services and Public Safety should make the information needs of young carers a specific consideration when looking at ways of improving the information about services to carers available on the Internet.

- 6.5 The Carers Information Network (CIN) website (www.carersinfo.net) provides information relevant for young carers and will also provide links to other websites which young carers will be interested in, for example, Barnardos Young Carers. In addition, OnlineNI (www.onlineni.net/index/individuals), provides a wide range of contacts on public services, and other support organisations.
- 6.6 Pupils have access through their school computer network to the Carers Information Network or, outside of school hours, can access the internet at their local library.

6.7 A DVD/video on young carers will be produced for distribution as a training aide among staff within the Health and Social Services and the Education sectors. The DVD/video will raise awareness about the impact of caring on the lives of young people and assist staff in identifying young carers, considering what support best meets their needs and how they can obtain this support. Within schools it may also be used as a tool for discussion among pupils, alerting them to how caring can impact on their lives and providing information on how they can access support.

Educational Support for Young Carers

6.8 Young carers have told us that school is a big issue for them. Homework and performance at school can be affected by their caring responsibilities. They can find it hard to concentrate because of worrying about their situation and the person that they are caring for, but many of them will be reluctant to talk about their situation. Nevertheless teachers can provide valuable, sensitive support to young carers.

6.9 Establishing and maintaining links with schools and advising and assisting them in supporting young carers should be a key task for the co-ordinators that we recommend be appointed in each Trust area.

29

RECOMMENDATION FROM VALUING CARERS

The Department of Education should remind schools and teachers of their role in supporting young carers.

6.10 Schools and all staff have a duty under the Education and Libraries (NI) Order 2003 to safeguard and promote the welfare of all their pupils and to provide guidance as well as advice to them on educational and other matters. This is done by teachers playing their part in implementing the school's pastoral care policy. That policy now embraces all aspects of a young person's life while at school or under the care of a school.

6.11 Schools are well placed to respond to the particular needs of young carers, as pupils have access to Year Head or form teachers (or similar structures), and other support mechanisms such as the Education and Welfare Service by the Education and Library Board. The Department of Education will be updating the guide for Pastoral Care in Schools and will take the opportunity to bring the position of young carers to the fore.

Section Seven - Training

Assessing Training Needs and Providing Training for Carers

7.1 Carers are involved in providing care and like any other care provider they need resources to carry out this role. They are in the best position to identify what training needs they have and bring this to the attention of their Trust. It would be unacceptable to expect a care provider to do their job without training. It is clear that training is very important in alleviating the burdens placed on carers in the community. The comments and recommendations that we go on to make in this part rely heavily on the report ***Training for Carers in Northern Ireland – Issues and Opportunities***¹³. The report, which was published in May 2001, examines the training available to carers in Northern Ireland and looks at the extent to which such training is accessible and relevant to the needs of carers. The carers who put forward their views to the authors of the report listed some of the areas where they considered training was required. These included:

- training on the use of aids and equipment;
- training on lifting and bathing;
- training on giving medicine and first aid and on dealing with, for example, catheters, PEG tubes and colostomies;
- training on behavioural management; and
- specialist training such as sign language.

7.2 The report found that organisations providing training to carers are for the most part voluntary and that coverage is very patchy across Northern Ireland. It concluded that support should be provided to allow local services, responsive to local needs, to be expanded and developed through partnership, planning, and the dissemination of best practice. The report contains some 20 detailed recommendations and indicates that the lead responsibility for developing policy with regard to carers and training should rest with the Department of Health, Social Services and Public Safety.

RECOMMENDATION FROM VALUING CARERS

The Department of Health, Social Services and Public Safety should ensure that Health and Social Services Boards and Trusts play appropriate roles in assessing training needs and providing training for carers taking account of the recommendations of “Training for Carers in Northern Ireland – Issues and Opportunities”.

- 7.3 Trusts are responsible for assessing carers’ training needs, and for ensuring agreed training needs are met. They may commission training from a range of providers in order to meet these needs. In order to ensure a consistent and transparent approach each Trust must develop a protocol, appropriate for their systems and structures, that clarifies issues such as who can refer; eligibility for training; and how training provision is delivered and co-ordinated. A framework will be provided as part of the Good Practice guidance outlined below.
- 7.4 Carers’ assessments will include a trigger question that will indicate that a carer may have training needs and allow referral for a training needs analysis. This will ensure that carers training needs are identified at an early stage, and in a systematic way. However, a carer’s assessment is not the only route into accessing training support, as referral for training needs analysis could come from a range of sources.
- 7.5 Good Practice Guidance for Trusts, taking into account the recommendations contained in ***Training for Carers in Northern Ireland – Issues and Opportunities***, is being developed and will be issued by the Department. The Guidance will comprise of a number of key elements including:
- a framework covering all aspects of carer training;
 - proposed training needs assessment and referral forms;
 - a charter for carer training; and
 - a voluntary code of practice for providers of training and development opportunities.

Complaints

- 7.6 Carers have told us that they find it difficult to make complaints about community care services. They are dependent on the services and are often anxious about the possible withdrawal of the service should they make a complaint.

- 7.7 These difficulties are exacerbated by two particular problems that carers report about the complaints system. Firstly, they regard it as slow, complicated and confusing. The system is off-putting to those who are already tired and under stress. Secondly, many carers lack confidence in the current system because they do not perceive it as independent. Generally the people dealing with the complaint are the same people responsible for delivering the service.
- 7.8 In the long term most carers would like to see the current system replaced by one that is simpler, quicker, more transparent and more independent.

RECOMMENDATION FROM VALUING CARERS

- a) The training of front line staff should be improved so as to ensure that they understand the value of dealing sympathetically with, and learning from, complaints. The importance of conveying an open and positive attitude to those who have issues to raise should be stressed.
- b) Support should be provided for the training and development of carer advocates who could guide and support carers through the process.

32

- 7.9 As well as identifying what training needs they have, carers are also well placed to inform the design, planning and delivery of training. The Good Practice Guide will advise Trusts that the training of professional and other care staff should involve users and carers in course design and delivery. The Guide will also stress that complaints provide a positive means of learning and improving services and ensuring that staff recognise the value of the complaints process, and as a result will welcome complaints for what they are.
- 7.10 A Regional Complaints Review Group is currently developing proposals in relation to a revised HPSS Complaints Procedure. The Review Group considers that competent and appropriately trained staff would provide a more effective resolution of complaints and that organisations should:
- create an environment where learning can take place; and
 - concentrate on developing the awareness of front-line staff to the value of satisfying complainants early on, and to establish protocols for an open, positive response to complaints.
- 7.11 The Department intends to carry out a public consultation on the HPSS Complaints Procedure before the final procedure document is produced.

7.12 A pilot “carer peer mentoring scheme” has been researched and designed, and will be tested in the Northern Board area as part of a joint carers initiative between Carers Northern Ireland and the Northern Board. These carer advocates will be able to guide and support carers through the complaints process. A report will be published with findings and recommendations. The Department will then consider how this can best be implemented across Northern Ireland.

Section Eight - Employment

Carer-Friendly Employment

- 8.1 Many people who are providing care may be trying to balance paid work with their caring responsibilities. The **Health and Social Well Being Survey 1997**¹⁴ found that the peak age for caring in Northern Ireland is 45 to 64, and that some 34% of carers are in full-time employment. Carers will often be amongst the most experienced employees.
- 8.2 Carers in paid employment value their work as an important part of their lives. It not only provides much needed financial security and a break from caring but increased self-esteem and a sense of identity separate from their role as a carer. However, combining paid work with caring can be a difficult balancing act and the resulting stress can lead to an employee having to give up work particularly if they feel unsupported or if there is a lack of flexibility in the workplace.
- 8.3 Carers' needs can be quite simple – the assurance that they can leave work on time or have access to a telephone during the day to ensure that all is well at home. As caring responsibilities increase, greater flexibility may be required to allow carers to continue to work. They may need time off for emergencies or time out of the workplace to attend hospital appointments. They may need to rearrange or reduce their working hours.
- 8.4 Many employers understand the business benefits of accommodating carers' needs. Replacing a carer who resigns can be difficult and expensive - a clear policy of support for carers reduces absenteeism and improves productivity. Support for working carers enhances the corporate image of social responsibility and enables the employer to demonstrate commitment to equality of opportunity.
- 8.5 Legislation has already been put in place to give all employees including carers the right to time off to deal with a family emergency. Article 10 of the Employment Relations (Northern Ireland) Order 1999, which came into operation on 15 December 1999, gave employees a right to time off work to deal with unexpected or sudden emergencies affecting dependants, and to make any necessary longer-term arrangements.

Employees do not have to complete a qualifying period in order to be entitled to take time off in an emergency. They have this right from day one. More details can be found in the Department of Employment and Learning (DEL) guidance **Time off for Dependants**¹⁵ The Prime Minister announced in May 2004 his intention to extend to carers the same right to ask for flexible working arrangements, which is currently enjoyed by parents of school age children.

8.6 In accordance with the key principle that carers have a right to a life outside caring we believe that carers of working age should be encouraged and enabled to remain in work. Where carers are unable to or do not wish to combine paid work with caring, help should be provided to enable them to return to work when their caring responsibilities cease. It is worth noting that forthcoming Age Discrimination Legislation will, in all probability, lead to a raising of the age of retirement. If this were the case, it would provide some flexibility for older carers to return to work, if that is what they choose to do.

8.7 There are a number of actions that employers can take to encourage and enable carers to remain in work. They could:

- ensure that managers are aware of the business reasons for supporting carers and that they understand the organisation's employment policies;
- train and support managers to ensure that employment policies are applied consistently and fairly;
- identify and publicise employment policies and support provision that will assist carers;
- ensure that all employees understand the needs of carers. Staff who work in personnel, welfare or occupational health should be aware of the organisation's employment policies and local support services for carers. The information on Carers Information Network (CIN) (www.carersinfo.net) may be valuable in this regard; and
- use flexible employment policies to accommodate the needs of carers. Flexible working patterns such as part time working, job sharing, annualised working hours, and flexitime, are already offered by many employers and can help carers remain in work. Special

leave provisions such as unpaid leave and career breaks which are often targeted at parents could also be explicitly extended to carers.

- 8.8 Employers here face many challenges but we believe that more employers should be encouraged to adopt carer-friendly policies. Many employers already have significant numbers of carers in their employment and all indications point to the numbers rising in the future with, for example, the higher levels of employment among middle aged women – the group which has traditionally taken on the major share of caring.

RECOMMENDATION FROM VALUING CARERS

We recommend that the relevant departments draw up and put in place a programme of work to promote the adoption of good practice in carer-friendly employment.

36

- 8.9 Between June 2000 and December 2003, DEL ran a Work-life Balance Campaign, which was overseen by a Ministerial Advisory Group. The purpose of the campaign was to raise awareness among employers in Northern Ireland of the benefits (to them and their employees) of implementing flexible working policies that enabled employees to achieve a better balance between work and life outside work. The needs of carers to have flexible patterns of work was one of the many issues raised throughout the awareness campaign. The formal awareness campaign on work-life balance came to an end in December 2003. The Department for Enterprise, Trade and Industry (DETI) and DEL are considering future activity in this area.
- 8.10 In its response to this consultation document, DEL on behalf of the PSI Carers Group will highlight the need for future work on work-life balance issues to continue to include a focus on the needs of carers. DEL will also recommend in its response that carers should participate in work-life balance public events where possible. It is hoped that this will lead to greater flexibility and increased awareness.
- 8.11 In relation to encouraging carer-friendly employment practices, the Northern Ireland Civil Service (NICS) is a major employer in Northern Ireland and should lead by example in this area. The NICS has undertaken a Review of Dependent Care Provisions in the NICS. The implementation of the review's findings will improve understanding of,

and support for, staff within the service who have caring responsibilities. As a result of the review, a website entitled “NICS Carers”, <http://online.bds.nics.gov.uk/nicscarers/>, was launched in 2004. The site covers a range of practical issues which are relevant not only to carers working in the NICS, but to carers everywhere in Northern Ireland.

- 8.12 In terms of younger carers engaged in further education studies, pastoral guidelines issued by the Department of Education to schools, which gives advice to teachers on supporting students with caring responsibilities, are being reviewed and updated. When this process is complete, DEL will examine the guidelines and assess the potential for read across to the Further Education sector.

Help for Former Carers

- 8.13 Carers who give up paid employment in order to meet their caring responsibilities can find it difficult to return to work when caring comes to an end. They may have lost confidence and feel out of touch with the world of work and its changes and may need “return to work” training and measures to build their confidence.

RECOMMENDATION FROM VALUING CARERS

The Department for Employment and Learning (DEL) should ensure that the range of training schemes available includes schemes designed to meet the needs of former carers.

- 8.14 DEL, through its JobCentres and the Jobs and Benefits Offices (JBOs) that it operates jointly with the Social Security Agency, provides a comprehensive service to help jobseekers to prepare for and to find employment. In particular, DEL’s Personal Advisers provide work focused interviews which help customers to identify their barriers to employment, to examine ways in which these barriers might be overcome, and to progress into work. DEL is increasing its customer base and carers are one of the groups of people included in this wider customer base. As and when DEL reviews its portfolio of training and employment programmes, the needs of carers, including former carers, will be taken into account.
- 8.15 Training and awareness for staff providing advice and guidance in JobCentres and JBOs, including Careers Officers, will highlight the particular needs / challenges of customers with caring responsibilities.

Training and awareness will focus on front line staff in JobCentres and Jobs and Benefits Offices and on relevant programme and policy branches. Frontline staff are supported by an IT system – the Electronic Staff Aid. This system enables staff to identify quickly and easily those services that are most appropriate for individual customers, including carers.

- 8.16 The provision of information to customers is an important element of service delivery. DEL, together with Social Security Agency colleagues, will ensure that every effort is made to advise carers of the services that are available to help them to find employment. This will include ensuring that DEL's internet site (www.delni.gov.uk) is linked to the Carers' Information Network (www.carersinfo.net).

APPENDIX 1

SUB-GROUPS AND RECOMMENDATIONS FROM VALUING CARERS

SUB-GROUP 1 - IDENTIFICATION OF AND INTERFACE WITH CARERS

- General practitioners and other clinicians should seek their patient's consent to provide information to the carer about the patient's illness or disability, medication and symptoms.
- The Department of Health, Social Services and Public Safety should remind Health and Social Services Boards and Trusts that carers should be fully involved in the timing of discharge from hospital and that carers should be given all the information that they require about the future care of the patient. Hospital discharge processes should ensure that carers are identified and that the presence of a carer is included in the discharge letter to the GP.
- (a)The new Local Health and Social Care Groups should have a central role to play in identifying carers
(b)It should be a key objective for the Groups that they have mechanisms in place to enable them to take a holistic view of health and well-being and to address the health, social care and associated needs of both the person being cared for and the carer, linking closely with other local agencies especially community and voluntary organisations.
- Guidance on carers' assessments should make it clear that Health and Social Services Trusts should inform carers of their right to a separate assessment and should require that the results of such an assessment be separately recorded.
- Health and Social Services Boards and Trusts need to be particularly proactive in seeking out and supporting older carers.

SUB-GROUP 2 – INFORMATION FOR CARERS

- All organisations which have contact with carers, whether statutory or voluntary, need to see their role as part of a wider network of support for carers and be able to refer them to services which can help them.
- Health and Social Services Trusts and organisations representing carers should consider developing handbooks for carers about local services.
- The Department of Health, Social Services and Public Safety, working with other government departments as appropriate, should look at ways of improving the information available on the Internet about services to carers in Northern Ireland, and should work to increase awareness of the availability of such information.

SUB-GROUP 3 – TRAINING

40

- The Department of Health, Social Services and Public Safety should ensure that Health and Social Services Boards and Trusts play appropriate roles in assessing training needs and providing training for carers taking account of the recommendations of “Training for Carers in Northern Ireland – Issues and Opportunities”.
- (a) The training of front line staff should be improved so as to ensure that they understand the value of dealing sympathetically with, and learning from, complaints. The importance of conveying an open and positive attitude to those who have issues to raise should be stressed.
(b) Support should be provided for the training and development of carer advocates who could guide and support carers through the process.

SUB-GROUP 4 - SUPPORT SERVICES

- Health and Social Services Boards, Trusts and other providers should review their service provision for carers with carers.
- Health and Social Services Boards and Trusts should review the provision currently being made for carers’ breaks and the information on which they base their funding decisions to determine what carers want. Carers and people needing care should be involved in the review. This should form part of the general review of services for carers mentioned above.

- Both localities based and disability specific groups should be encouraged and supported at local level.
- A carer liaison or co-ordinator post should be created in each Health and Social Services Trust

SUB-GROUP 5 – EMPLOYMENT

- We recommend that the relevant departments draw up and put in place a programme of work to promote the adoption of good practice in carer-friendly employment.
- The Department for Employment and Learning should ensure that the range of training schemes available includes schemes designed to meet the needs of former carers.

SUB-GROUP 6 - YOUNG CARERS

- Guidance to Boards and Trusts on carers' assessments should stress the need to ensure that young carers are identified and that services are put in place to ensure that their education and development do not suffer because of their caring responsibilities.
- The Department of Health, Social Services and Public Safety should make the information needs of young carers a specific consideration when looking at ways of improving the information about services to carers available on the Internet.
- The Department of Education should remind schools and teachers of their role in supporting young carers.

APPENDIX 2

SUMMARY OF FURTHER KEY ACTIONS

1. The Department will issue guidance to all health and social care professionals, including GPs, stating that they must identify the presence of a carer, and the level of care being provided, and record it in a readily accessible way on all patient/client and carer records, paper and electronic. Where a carer is identified, health and social care professionals must offer a carer's assessment in order to take a holistic view of the health and wellbeing and associated needs of the carer. (Paragraph 3.4)
2. The Department will issue guidance to all HPSS bodies, advising them that it is essential they collate the information gathered on carers and their needs, and take it into account fully in reaching their commissioning and service delivery decisions. (Paragraph 3.5)
3. The Department will advise all HPSS professionals that they should actively encourage patients to consent to the sharing of information about their illness or disability, medication and symptoms with their carers. The care management process will include a specific requirement to seek such consent. (Paragraph 3.9)
4. The Department has commissioned the development of a single comprehensive assessment tool for use with older people. It is anticipated that the completed tool will be ready for implementation throughout Northern Ireland in 2007. Any such assessment for community care services will include a prompt for the offer and completion of a carer's assessment and seek permission for the sharing of relevant information. (Paragraph 3.20)
5. HSS Trusts will be advised that they must have a clear policy for discharge. Guidance for Service Managers, Practitioners and Carers on Discharge Planning to support this, is being developed and will be issued by the Department. (Paragraphs 3.22 & 3.24)
6. Trusts will be advised that they should pay particular attention to the needs of older people who are themselves providing substantial care to others. (Paragraph 3.26)

7. On completion of an inspection of social care support services for carers of older people, the Department will publish standards for such services. The standards will identify what carers can reasonably expect from such services and will provide the basis for self-audit by organisations commissioning and/or providing such services. (Paragraph 3.27)
8. HSS Trusts will be advised that they should provide information packs for carers setting out details of information services specific to the local Trust area. (Paragraph 4.3)
9. An index of services, A-Z for Carers, will be developed, setting out the range of statutory and voluntary organisations that provide advice and information for carers on a regional basis. (Paragraph 4.3)
10. Trusts will be encouraged to work closely with the voluntary sector to support the establishment of carer support groups. (Paragraph 4.7)
11. A Framework for Support Services to Carers will be issued to HSS Trusts. The framework will help Trusts to examine the ways in which support to carers can be best provided and will help them to develop new and more flexible services in consultation with carers and their representative organisations. (Paragraph 5.1)
12. A DVD/video on young carers will be produced for distribution as a training aide among staff within the Health and Social Services and the Education sectors. (Paragraph 6.7)
13. Good Practice Guidance for Trusts, taking into account the recommendations contained in ***Training for Carers in Northern Ireland – Issues and Opportunities***, will be developed and issued by the Department. (Paragraph 7.5)
14. A pilot “carer peer mentoring scheme” is being researched and designed, and will be tested in the Northern Board area as part of a joint carers initiative between Carers Northern Ireland and the Northern Board. These carer advocates will be able to guide and support carers through the complaints process. A report will be published with findings and recommendations. The Department will then consider how this can best be implemented across Northern Ireland. (Paragraph 7.12)

15. In terms of younger carers engaged in further education studies, pastoral guidelines issued by the Department of Education to schools, which gives advice to teachers on supporting students with caring responsibilities, are being reviewed and updated. When this process is complete, the Department for Employment and Learning will examine the guidelines and assess the potential for read across to the Further Education sector. (Paragraph 6.11 & 8.12)

APPENDIX 3

FRAMEWORK FOR SUPPORT SERVICES TO CARERS

This section identifies the key issues in relation to support services for carers both individually and collectively. It provides guidance on the ways in which such support can be delivered and suggests further research into models that ensure that carers experience a responsive service designed to meet their individual needs.

Partners in Care

Partnerships with carers should be achieved at both an individual and strategic level. That is, carers should be involved not only in decisions about their own situation, but also where services are being designed to support carers. Carers should be involved where Boards and Trusts (and other agencies) are planning new services; reviewing existing services and undertaking evaluations of the services they provide. These organisations should actively involve people who are directly caring as well as representatives of carers groups.

45

Of fundamental importance is the relationship between carers and those professionals and staff who provide services both to them and to the person for whom they are caring. In most situations the carer or family is the authority on the person needing care and support. Yet carers often feel that their knowledge of the person and experience of caring is neither recognised nor valued. Creating partnerships that recognise the expertise of carers, ensuring that they are meaningfully involved in processes for planning and delivering services to the individual, is the building block for effective support.

To achieve genuine partnership the following principles should be incorporated into every planning process where there is a carer involved:

- identification of the carer with the main service user should be undertaken at the beginning of the process;
- identify the individuals who will provide services;
- the expertise of the carer should be recognised and respected;
- the expertise of the professional should be acknowledged and accepted;
- the legal/medical framework within which professionals have to operate should be recognised;
- information which is pertinent to the caring role should be shared;

- there should be consultation and negotiation about the type of support the carer feels they need and how this will be provided; and
- the carers situation should be reviewed periodically and changes to the level and type of support negotiated.

Practical measures should be in place to identify carers, including a protocol for identifying the main carer. This is an important issue particularly for primary care. Many carers would not identify with the term 'carer', therefore its use must be carefully considered. Staff should have training to ensure that carers are visible to them and heard by them.

Health and care systems frequently focus on individuals without considering their place within families and communities, yet families usually take primary responsibility for the care of those within them. All organisations involved in the delivery of services must see the individual within this wider environment of family, neighbourhood and community.

Assessments can be seen as a means of supporting the family and of considering both their strengths and the areas in which they need support. Care planning for the service user should be explicit about all who contribute to care and the nature of their contribution. Those who are affected should be offered support in order to avoid adverse consequences to their own health and well-being. It is in the interests of all concerned that social support networks be maintained.

46

Reviewing Services for Carers

Carer involvement when it works well can offer a service that is truly based on people's needs, enhancing choice for individuals and creating an environment in which carers, those being cared for, and workers, are treated with equal respect and consideration. Involving carers in reviewing the services they receive is a fundamental component of improving those services.

People who actually experience services are in the best position to point out which areas work well and which could be improved. A range of methods for involvement can be used but the key components for meaningful involvement should be present, including:

Access - extending from physical access to the design of structures and arrangements, including locations and times of meetings, that enable and encourage people's involvement to meaningful participation in planning and review processes.

Support - for personal development to increase confidence, and support to develop skills allowing people to participate fully and effectively.

Practical help – including accessible information, advocacy, payment and expenses, and alternative support arrangements for the person being cared for. Recognition also needs to be given to the time required to come to meetings prepared.

Working together – opportunities for carers to come together and work in groups with equal access regardless of age, race, gender or disability.

Feedback – be honest and be clear that change takes time but give some indication of the timeframe being envisaged. Keep carers informed of progress, or of reasons why progress has not, or cannot, be made.

Boards and Trusts should review services with carers on a systematic basis to ensure they are providing services sensitive to need. Ideally each programme of care should have a carer forum that would work with service providers to plan, manage and review services on an ongoing basis. As already highlighted, carers should be supported and trained to ensure meaningful participation but it is equally important that organisations develop inclusive carer friendly systems and support staff to involve carers. Boards and Trusts should develop policies to provide practical, including financial support, to carers, to participate in planning and reviewing services.

47

Support Services

Maintaining good health and well-being is very important for carers, however very often carers neglect their own needs because they become pre-occupied with providing care.

They may be too busy or are unable to make alternative care arrangements to facilitate necessary medical appointments for check-up, screening or investigation. They may not recognise early symptoms which suggest the need for a medical appointment, or perceive the need as non-urgent in the scheme of things given their day-to-day priorities.

Evidence suggests that carers are more likely to suffer from a great deal of stress than non-carers, with significant implications for health and well-being.

Awareness is the first stage in managing stress. Carers and professionals

should understand that good health and well-being is often within their own hands and within their own control. It does not however happen without effort, and this may be considerable given the demands and pressures of being a carer.

Health promotion activities are carried out within all Trust areas, however professionals must be mindful of the range of difficulties which impact on carers and a more proactive approach adopted to support and enable them to participate in planned health events and healthy lifestyle activities. In recognition of this, from 2005/06, the Department has made carers a priority group for receiving the influenza vaccine, and as such, they will be targeted in the winter advertising campaign.

Recognising carers as carers is critical to achieving good health and well-being. Missed medical appointments should be followed up, possibly through a standard letter from the GP, with an offer of contact with a professional to discuss any difficulties. A further example of such support is the GP outreach service provided by Belfast Carers Centre. Regular check-ups and screenings when arranged should be facilitated with appropriate support services. Timely and appropriate support is essential to the continued well-being of the individual who as a carer may be under pressure, worried or experiencing personal health difficulties. These might be readily alleviated or resolved by prompt referral to the appropriate service and follow up support offered and provided where necessary.

48

A break from caring is invaluable in reducing the psychological and emotional stress faced by many carers. Access to support services and breaks will help carers to continue to provide support to the person being cared for. Services that carers value include short term breaks, day activity and support in the home, particularly in an emergency or at times of crisis. Carers need these services to be accessible, consistent, reliable and safe. Also valued are opportunities for access to education, leisure and activities that promote health and well-being, such as alternative therapies.

Carers have consistently advised that the key to effective support is that the service they receive is flexible, meaning that the service should as far as possible fit with their individual needs and requirements. Arrangements for carers' breaks are often criticised because they are experienced as rigid and predetermined with limited choice. Likewise, domiciliary care services are sometimes viewed as limited in their ability to respond to individual need and changing circumstances as they adopt a standardised approach.

In addition, carers need to know how to access services in times of change and particularly crisis. As a minimum, all providers should work with families to draw up contingency plans for such events and these should be integrated within the care plan. In the longer term, Trusts need to increase their capacity to provide services at short notice and there is a need to determine which services should be available on a 24hr basis, seven days a week and how these could be provided.

There is clearly a need to re-shape statutory services to achieve flexibility. It is also clear that care workers need to be valued and reflected in the support and development available to them. Wholesale change, however, is difficult to achieve where there are concerns about the management of such services and the cost of changing service models.

There is value in 'testing' such models to demonstrate the impact on carers and the real cost and effectiveness of providing services in a more flexible way. The Department of Health, Social Services and Public Safety is examining how to commission such a project that would be steered by a coalition of families and carers and professional staff, where the family and carer membership is at least 50%.

Direct Payments provide an opportunity for carers to take more control over the decisions that affect their lives. The Carers and Direct Payments Act (NI) 2002 gives HSS Trusts the power to make Direct Payments:

- to carers (including 16 and 17 year old carers) for the services that meet their own assessed needs;
- to people with parental responsibility for disabled children;
- to disabled people with parental responsibility for a child; and
- to 16 and 17 year old disabled children for services that meet their own assessed needs.

However, there is a danger that direct payments are used only to purchase existing services. Families and carers need help to think creatively about what best suits their individual and collective needs. They need to be given the authority to design their own support package that is responsive, flexible and individualised. Trusts need to respond by accepting that often such support will not reflect a use of traditional services but that the support chosen is a legitimate use of resources.

Consumer/family governed initiatives in other countries have demonstrated how these ideals can be achieved by developing projects in which ordinary

people maintain a fair degree of personal influence. In these, the emphasis is on participation, dialogue, negotiation informality and relationships. The Department is examining how to support further developments in community support services to enable people to live independently in their own homes. As the concept is to develop projects from the carer's perspective, they will require time and financial investment but would serve to demonstrate the capacity for developing flexible support solutions.

Specific Carer Focused Services

Carer Co-ordinators

There are currently nine carer liaison or co-ordinator posts established within Trusts. In addition, there are 13 carer support posts that are either programme or location specific. The majority of acute Trusts, however, consider support for carers as a matter primarily for community Trusts. Two models and two key components have emerged from the development of these posts. The key components involve 'championing' the cause of carers within the Trust and raising awareness about carer issues (the Trust component), and developing the carer support infrastructure (the community component).

50

Of the two models, the first entails the carer co-ordinator being employed directly by the Trust, while the second model sees the function being contracted out to a carers association or carers organisation. Both models have merit and in general terms co-ordinators employed by Trusts have had the most impact on systems within the Trust, whereas those within carer organisations have put greater emphasis on developing and supporting the carer support infrastructure.

However, the potential for change is maximised where the carer co-ordinator is employed by the Trust.

All Trusts with experience of a carer co-ordinator report the benefits of the post and remaining Trusts, including acute Trusts, should appoint a carer co-ordinator with an appropriate level of support and access to resources. The primary functions should be:

- proactively raising awareness of carers issues within the Trust;
- establishing and supporting a Carers Forum in each Trust area which will promote and cultivate carers' networks across all programmes of care; and

- facilitating links between carers, carer organisations and the Trust.

Trusts should consider how best to involve carers in the appointment of the carer co-ordinator.

In addition, Trusts should identify two directors to champion the rights of carers at a strategic level within the Trust and identify a senior officer in each programme of care to represent the interests of carers within the programme.

In this way, the Trust component of the role will be managed effectively and the expected outcomes from this approach are greater carer involvement, promotion of carers assessments, innovative use of Direct Payments and greater availability of carer driven services and information.

Carers' Groups

Carers' Groups can play a vital role for many carers. They can be condition specific groups meeting in a local area and nurtured by larger professional organisations, or they can be the myriad smaller carer support groups who function independently of the input of such big organisations. Although many are small in size and may be limited in the scope of their interest, they can occupy a vital position in the lives of carers. For many, they can be the only local and immediate form of external support, a place where carers can receive help from others who know exactly what it is to be a carer. Carers welcome the opportunity to come together.

51

The challenge with groups like this is to ensure that the common themes and the enthusiasm that first brought them together can be maintained as time moves on. There are also practical issues to consider such as transport and accessibility issues and support to attend. A formal link between carers and the statutory provider enables carers to be real and equal partners in the provision of care. This can be provided by the carer co-ordinator for each Trust or by another organisation, be it Carers NI, or by the proposed Carers' Centres.

Carers' Centres

The feedback from carers indicates strong support for a carers' resource centre in each Trust area, in that it would provide a focal point for support to individuals and groups. The centre would facilitate the following outcomes:

- proactive engagement with carers and carers groups;

- the provision of a vital source of information, emotional support and advocacy;
- the identification of sources of help for carers and support carer related volunteering;
- communication with carers not in contact with services;
- co-ordination and support of the network of carer support workers in the area; and
- the identification of gaps in carer support and the stimulation of growth to meet identified need.

The resource centre would provide accessible premises for groups to meet and potentially arrange for carer-determined services to be available on site. These might include I.T. training, aromatherapy, and 'outreach' services to promote the community development aspects of carers support.

The centre would also support and promote the development of Carers Forums at each level. These forums could nominate individuals to a Regional Carers Forum under the auspices of the Department to inform future policy and strategy development.

52

DHSSPS is examining the ways in which local support services for carers can be improved including carers' forums and carers' centres. The Department believes that this can be best achieved by building upon the role of the Trust carer co-ordinator as the focal point for support to individuals and groups. The carer co-ordinator would be in a position to establish links with existing carers groups, identify their needs, make facilities available to them as necessary and offer advice and practical support.

Glossary of Terms

Care Plan	The outcome of an assessment. A description of what an individual needs and how these needs will be met.
Care Management	A process whereby an individual's needs are assessed and evaluated, eligibility for service is determined, care plans are drafted and implemented, and needs are monitored and reassessed.
Care Manager/Case Manager	A practitioner who, as part of their role, undertakes care management.
Carer	Carers are people who, without payment, provide help and support to a family member or friend who may not be able to manage at home without this help because of frailty, illness or disability.
Carer's Assessment	A process whereby the needs of a carer are identified and their impact on daily living and quality of life is evaluated.
Carer's Allowance	This is an allowance paid for looking after a person, for over 35 hours a week, who has an illness or disability. It is a taxable benefit and certain conditions apply.
Direct Payments	Money paid by Trusts that allows individuals to arrange for themselves the social care services that they have been assessed as needing.
Hospital Discharge	The process of leaving hospital after admission as an in-patient.
Respite Care	Temporary residential, nursing or social accommodation provided to an ill or disabled person to allow a carer a break from caring. Respite care may also be delivered in the cared for person's own home.

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Produced by:

Department of Health, Social Services and Public Safety
Castle Buildings
Belfast
BT4 3SQ

Telephone: 028 9052 2460 Textphone: 028 9052 7668

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