

CARERS Scotland

the voice of carers

Carers and their Rights

A guide to the law relating to carers

About Carers Scotland

Carers Scotland is the voice of carers.

Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner.

Carers give so much to society yet as a consequence of caring, they experience ill health, poverty and discrimination.

Carers Scotland is an organisation of carers fighting to end this injustice.

We will not stop until people recognise the true value of carers' contribution to society and carers get the practical, financial and emotional support they need.

Carers Scotland is here to improve carers' lives.

- We fight for equality for carers. We want carers to have the same right as everyone else to an ordinary life – a fair level of income, access to support to protect their health and well being and access to the world of work, leisure and education
- We seek to empower carers. We want carers to be actively involved in the design, development and delivery of services. We want carers to be recognised and involved as key partners in the provision of health and social care services.

Carers Scotland achieves this by

- campaigning for the changes that make a real difference for carers
- providing information and advice to carers about their rights and how to get support
- mobilising carers and supporters to influence decision-makers
- gathering hard evidence about what needs to change
- transforming the understanding of caring so that carers are valued and not discriminated against

About this Guide

This Guide provides information on the legal rights of carers as they apply in Scotland. It has been published by Carers Scotland's Action for Carers and Employment initiative.

This Guide is **not intended to be a definitive statement of the law**. Much of the content relates to guidance, which is often subject to significant differences in interpretation. Therefore, we advise all carers when considering a challenge to a local authority or NHS board to consult an appropriately qualified advisor. The Law Society of Scotland can refer you to a solicitor who is qualified and experienced in community care law. The Society can be contacted on 0845 113 0018.

For advice on whether you may be able to receive public assistance in challenging decisions, contact the Scottish Legal Aid Board, 44 Drumsheugh Gardens, Edinburgh, EH3 7SW. Tel: 0131 226 7061.

A number of sections within this guide refer to cases taken by carers and disabled people in England. However, little case law exists in Scotland in relation to community care issues. However, the cases cited could provide guidance and backup to any potential challenge in Scotland. Again, we would advise contacting an appropriately qualified advisor.

Acknowledgments

With thanks to:

Luke Clements: This guide is an updated and revised version of an original publication by Luke Clements written for carers in England and Wales. Luke Clements is a recognised authority on community care law. He is a Reader in Law at Cardiff Law School at the University of Wales and a member of the Law Society's Mental Health and Disability Committee. Luke is also legal adviser to Carers UK and drafted the Carers (Recognition and Services) Bill.

Fiona Collie, Carers Scotland's Policy Officer, who undertook the task of revising the original publication to reflect the distinctive requirements of the Scottish legal and policy context.

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Foreword

Carers make a unique and immense contribution to society and to those they look after.

Despite the contribution that unpaid carers make to society, they are routinely denied their rights to equal opportunities, services and resources.

It is hoped that this guide will enable carers to achieve better outcomes for themselves and for those they care for, and empower them to exercise these rights; and promote the vision of carers, outlined in the seminal report 'The Future of Unpaid Care in Scotland'. This vision is founded on the rights of carers:

- to have their contribution to society recognised
- to choose when, how and if they care
- to be treated as 'people first and carers second'
- to have their caring viewed as a positive life choice, and

“underpinned by the human conditions of love, empathy and devotion to human beings”.

Unpaid carers have the right to expect no less.

Patrick J Begley
Director

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1. Introduction

- 1.1 This guide outlines the principle rights of carers to support from health and social work authorities. Its publication coincides with the introduction of a duty on NHS bodies to develop and implement strategies to inform carers of their rights and to the initial stages of the implementation of a 10 year programme to support carers in Scotland.
- 1.2 This guide does not seek to address carers' entitlement to welfare benefits – but at para 8.1 links are given to information sources where this information can be obtained.
- 1.3 The Community Care & Health (Scotland) Act 2002 provided Ministers with the power to require NHS boards to produce carer information strategies. In April 2006, guidance was published for NHS boards placing a duty on each to produce detailed strategies on the ways in which they will inform carers of their rights, signpost carers to appropriate local support and provide training for carers to support them in their caring role. These strategies will be implemented from 1 April 2007.
- 1.4 The Community Care & Health (Scotland) Act 2002 marks a major cultural shift in the way carers are viewed. It introduced for the first time:
 - a right for carers to have a separate assessment of their needs, regardless of whether or not the person for whom they cared requested an assessment
 - a right for carers of all ages to receive an assessment, including young carers
 - a duty on local authorities to inform carers of their right to an assessment
- 1.5 The 2002 Act is underpinned by the principle of carers as key partners in care. For the first time, guidance emphasised the key role that carers play;

The fundamental principle underlying the new legislation provisions is that local authorities, the NHS and other support agencies should recognise and treat carers as key partners in providing care. Carers are “key” partners because they are different from the other partners in the care-giving system in their status and their contribution. Carers are usually the main care-providers for the person they look after, but unlike other care providers they are not paid to provide that care. Carers generally have a close personal relationship with, and commitment to, the person they care for. For all these reasons carers play a unique role in the overall provision of care to the person they care for, and in care in the community as a whole. (CCD 2/2003 3.1.1)

- 1.6 In relation to the need for a specific NHS obligation to carers – the statistics tell their own story. If there are in excess of 600,000 carers in Scotland and if over a third of them suffer ill health as a consequence of their caring responsibilities – then by any stretch of the imagination this is a major health concern.
- 1.7 This guide focuses primarily on two Acts of Parliament - each of which is directly concerned with the needs of carers. Further details on these Acts along with supporting guidance can be found in Section 3: Carers’ Legislation.

- **Carers (Recognition & Services) Act 1995,**

promoted by Malcolm Wicks MP

- **Community Care & Health (Scotland) Act 2002**

promoted by the Scottish Executive

2. Definitions

Who is a carer?

- 2.1 There is no single definition of a 'carer'. The law makes reference to carers in many contexts. In general, when a social work department is deciding what services to provide for a disabled person, it should consider the views of significant people in that person's life. This will include people who provide some form of care for that person (usually partners, family members, friends or neighbours) be that physical care or emotional support, advice or advocacy support etc. In this guide a carer is a person who provides care to another person and is not paid for providing that care (nor is she or he providing the care as a volunteer placed into the caring role by a voluntary organisation).

- 2.2 Some academic writers have used the term 'informal carer' to distinguish actual carers from care workers who are often wrongly described as carers. Many carers actively dislike the term, seeing nothing informal about caring for substantial amounts of time. The term is not therefore used in this guide.

Care workers and volunteers

- 2.3 The Carers' Acts do not provide rights to persons who provide the care by virtue of a contract of employment or as a volunteer for a voluntary organisation.

Carers with substantial caring responsibilities

- 2.4 Whilst the views of all carers are relevant when social work departments or the NHS are making decisions about the needs of a disabled person – certain carers are entitled to additional assistance from social work departments. These are carers who 'provide or intend to provide a substantial amount of care on a regular basis'. Such carers have a statutory right to a 'carers assessment'. The meanings of 'substantial' and 'regular' are considered at para 3.10 below.

Disabled person

- 2.5 A carer is defined by reference to his or her caring role in respect of a 'disabled person'. The law defines disabled people (for the purposes of carer and community care legislation¹) as persons who are²:

blind, deaf or dumb or who suffer from mental disorder of any description, and other persons aged eighteen or over who are substantially and permanently handicapped by illness, injury, or congenital deformity

- 2.6 It follows that anyone with a mental disorder (for instance depression or dementia or a learning disability etc) is considered by the law to be a disabled person.
- 2.7 There are some people who may be on the borderline of this definition. People who have drug or alcohol related problems are considered to be disabled people for the purposes of carer and community care law and people with Chronic Fatigue Syndrome (sometimes referred to as ME) would also generally be considered to fall within the definition. Children with hyperactive and attention deficit disorders (sometimes referred to as Attention Deficit Hyperactivity Disorder (ADHD) and Attention Deficit Disorder (ADD)) should – if professionally diagnosed as having such a disorder – be considered to be within the definition. Even if there is no such diagnosis, such children would fall within the definition of a 'child in need' (see para 10.5 below). The same would be the case for a child diagnosed as having a milder form of Asperger's syndrome.

Social work departments

- 2.8 This guide is predominantly concerned with the obligations of local authorities towards carers. For the sake of brevity this guide uses the phrase 'social services' (or social work departments) when referring to these authorities. There are 32 local authorities in Scotland.

3. Carers' Legislation

Carers (Recognition and Services) Act 1995

- 3.1 This Act was to provide for the assessment of the ability of carers to provide care. It was the first time that legislation attempted to address specifically the needs of carers and the first steps taken to define the rights for carers. Its key purpose was to provide legal recognition of carers and to support carers through the community care assessment process. Carers were able to request an assessment for themselves, within the assessment process for the service user.

Carers (Recognition and Services) Act 1995

www.opsi.gov.uk/acts/acts1995a.htm

- 3.2 Supporting policy guidance (Scottish Office Circular: SWSG11/96) was produced for local authorities, outlining how the Act should be implemented. This details the assessment process and the links between these assessments and the support of disabled people.

Scottish Office Circular: SWSG11/96

Carers (Recognition And Services) Act 1995: Policy And Practice Guidance

www.scotland.gov.uk/library/swsg/index-f/c162.htm

Community Care and Health (Scotland) Act 2002

- 3.3 This Act aimed to deliver major improvements in community care services, including free nursing and personal care, broadening access to direct payments, deferred payments so that residents can postpone selling their homes to pay for residential care, the expansion of local joint working and pooled budget arrangements between health boards and local authorities.

3.4 The new provisions introduced for carers included:

- right to assessment in their own right
- a duty on local authorities to inform carers of their right to an assessment
- a duty on local authorities to take into account carers' views when putting together a community care package
- rights to assessment for parent carers, and young people under 16
- a duty on NHS Boards to produce Carer Information Strategies, detailing how they will provide information to carers, including their right to an assessment.

3.5 These new rights are underpinned by the key principle that local authorities, the NHS and other support agencies should recognise and treat carers as key partners in providing care (see para 1.5).

Community Care & Health (Scotland) Act 2002

www.opsi.gov.uk/legislation/scotland/s-acts2002a.htm

3.6 Detailed policy guidance was produced for local authorities, health boards and the voluntary sector on the effective implementation of the Act and its rights for carers.

Scottish Executive Health Department Circular: CCD2/2003

Community Care & Health (Scotland) Act 2002:

New Statutory Rights for Carers: Guidance

www.sehd.scot.nhs.uk/publications/CC2003_02full.pdf

3.7 More recently, guidance has been produced for NHS Boards on the development of Carer Information Strategies. These strategies will be implemented from April 2007.

Scottish Executive Health Department Letter: HDL (2006) 22
NHS Carer Information Strategies:
Minimum Requirements and Guidance on Implementation
www.show.scot.nhs.uk/sehd/mels/HDL2006_22.pdf

New and emerging policy

- 3.8 There are a range of new policy directives and legislation which, in the future, may offer additional rights and support for carers. Carers Scotland produces regular updates as they occur at the link below.

www.carerscotland.org/Policyandpractice/Keylegislationandpolicy

4. Social work obligations to Carers - overview

Introduction

- 4.1 All carers have certain basic rights: largely a right to have their views taken into account by a social work department when it is considering how best to make provision for a disabled person.
- 4.2 Carers that provide, or intend to provide a 'substantial' amount of care on a regular basis have additional rights, in that they are entitled to have a separate 'carer's assessment'.
- 4.3 In most cases, the role and views of a carer will be considered by the social work department when it is undertaking an assessment of the disabled person. Section 6 below briefly outlines the key components of a community care assessment - i.e. the assessment that social work departments undertake when deciding what support it should provide for a disabled person.

The rights of all carers

4.4 As noted above, all carers (regardless of whether they provide, or intend to provide, regular and/or substantial amounts of care) have the right to have their views taken into account by a social work department when it is considering how best to make provision for a disabled person.

4.5 The law states that when undertaking a community care assessment, social services must (amongst other things): ³

- Consider whether the person has any carers and, if so, also consult them if the authority “thinks it appropriate”
- Take all reasonable steps to reach agreement with the person and, where they think it appropriate, any carers of that person, on the community care services which they are considering providing to meet his needs

4.6 In this respect, important policy guidance issued by the Scottish Executive Health Department in 2003⁴ advised that local authorities should ‘seek and take account of the views of both the cared-for person and the carer before deciding what support to provide’ and ‘ensure that the care package meets the wishes and needs of both the cared for person and their carer as far as possible and appropriate’. The guidance emphasises that authorities should ‘not assume that the carer’s contribution will continue at any set level’ and should ‘recognise the caring responsibility that the carer is willing and able to take’.

Carers who provide a substantial amount of care on a regular basis

4.7 In addition to having their views taken into account, when the person for whom they care is being assessed, certain carers have the right to a ‘carer’s assessment’. These are carers who provide (or intend to provide) a substantial amount of care on a regular basis. Such carers can refuse an assessment - but even if they do so, the law requires that their ‘ability to manage’ their caring role must nevertheless be taken into account⁵

4.8 Two different statutes regulate the nature and outcomes of a carer's assessment. These are:

- The Carers (Recognition & Services) Act 1995
www.legislation.hmso.gov.uk/acts/acts1995
- The Community Care & Health (Scotland) Act 2002
www.opsi.gov.uk/legislation/scotland/acts2002

The above links provide access to the texts of the Acts, as worded when enacted. The 1995 Act has since been amended by the 2002 Act.

4.9 Of the two Acts that deal directly with the needs of carers, the 1995 Act contains the core statutory responsibilities. It introduced the concept of a 'carer's assessment'. The 2002 Act extended the rights of carers, to include the right to receive a carer's assessment independently of any assessment of the cared for person. It introduced a statutory obligation on social services to inform carers of their rights.

What is 'a substantial amount of care'?

4.10 As noted above, people who provide (or intend to provide) 'a substantial amount of care on a regular basis' are entitled to a separate carer's assessment. Neither of the Carers Acts defines what is meant by the word 'substantial' and so to a degree the decision rests with individual social work departments – albeit that in deciding how to interpret this phrase, authorities must take into account the relevant guidance.

4.11 The Scottish Executive Health Department has elsewhere given advice on the interpretation of the word 'substantial' where it appears in a community care statute – and advised that it should be given a wide interpretation which fully takes into account the individual's circumstances.⁶

4.12 Essentially, therefore, the word should be used subjectively, and this must also be the case in the context of the Carers' Acts.

4.13 Local authorities will, therefore need to adopt a flexible approach to this question and focus on the 'impact of caring'. It follows that what may not be a substantial amount of care to a 25-year-old carer may be otherwise if provided by a 7 or 87-year-old carer. Likewise if the caring task is physically demanding, then the question of what is or is not substantial will depend in part on the physical strength of the carer; again, if the carer has recently recovered from a serious mental illness, then even five hours' care may be substantial to him or her. A morning or evening caring task will be substantial to a carer who works nine to five but not necessarily for one who does not – and so on.

4.14 Guidance issued under the 2002 Act is helpful in defining what 'regular and substantial' care means. The Guidance⁷ (para 3.5.2) states:

When interpreting 'substantial and regular' local authorities should focus on the impact of caring on the individual carer and their family; take into account a range of factors; always take a wide view of the extent and nature of the carer's role as a whole; take account of situations where the caring role is sporadic and difficult to forecast; recognise that the carer's role may fluctuate, particularly where the cared for person has mental health difficulties that reappear periodically; recognise that the needs of the cared-for person may be unpredictable, particularly where they have drug or alcohol problems; recognise that carers may also need to combine caring responsibilities with other family responsibilities or activities, including parenting, employment or education.

In particular to address the following questions.

- Is the caring role sustainable?
- How great is the risk of the caring role becoming unsustainable without additional support?

4.15 The assessment of the 'sustainability' of the caring relationship is further considered at para 5.28 below.

'Intending to provide'

4.16 A carer may be entitled to a carer's assessment even if s/he is presently providing no care - provided the authority is satisfied that s/he is

intending to provide a substantial amount of care on a regular basis. The intent underlying this provision was explained by the guidance that accompanied the Carers (Recognition and Services) Act 1995, LAC (96)7 (at para 16)⁸:

By including carers both providing or intending to provide care, the Act covers those carers who are about to take on substantial and regular caring tasks for someone who has just become, or is becoming, disabled through accident or physical or mental ill health. Local and health authorities will need to ensure that hospital discharge procedures take account of the provisions of the Act and that carers are involved once planning discharge starts.

Disputes as to whether a carer provides ‘substantial’ amounts of care

- 4.17 As noted above, all carers - regardless of whether or not they provide regular and substantial amount of care - are entitled to have their views taken into account during the community care assessment process (see para 4.4 above).
- 4.18 Whilst a social work department is under a duty to undertake assessments of carers who provide regular and substantial amount of care, it also has a power to assess carers even if their caring responsibilities are not deemed ‘substantial’. In many cases good practice will dictate that such an assessment be undertaken in any event.
- 4.19 Not infrequently, a local authority will not be able to decide upon the extent of a carer’s responsibilities without undertaking a ‘carer’s’ assessment. Where there is uncertainty an assessment should take place.

What is ‘a regular basis’?

- 4.20 Carers who provide a substantial amount of care, are entitled to an assessment provided that they also do so on a ‘regular basis’. In this context, ‘regular’ should be distinguished from ‘frequent’; it merely

connotes an event which recurs or is repeated at fixed times or uniform intervals. The Practice Guidance to the 1995 Act⁹ points out that:

Some users with mental health or substance misuse problems or with conditions such as neurological disorders, dementia, cancer or HIV/AIDS will have care needs which vary over time but may present regular and substantial burdens for carers.

- 4.21 It follows that an ongoing severe but sporadic caring responsibility would meet the criteria of 'regular and substantial' since it amounts to a 'regular concern'.

5. The Carers Assessment

Which social work department is responsible?

- 5.1 Social work departments have a general duty to assess certain carers, when requested so to do. However it may not always be clear which social work department is actually responsible for undertaking the assessment. The guidance to the Community Care & Health (Scotland) Act 2002¹⁰ gives direction on boundary problems in particular where the carer lives some distance away from the user. It advises that, in general, that the carer's local authority should work in partnership with the other authorities affected and that local agreements for handling such cases should be developed. However, usually the authority where the disabled person lives should take the lead in assessing the carer under the 2002 Act. (para 3.5.3)

Delegation of assessments

- 5.2 The duty to assess under the Carers Acts is a social services function but they have powers under Section 4 of the Social Work (Scotland) Act 1968 and the Carers (Recognition and Services) Act 1995 to involve other bodies or persons in helping them to carry out their functions. Policy Guidance under the Act states that (at para 6.9.1)¹¹

Authorities should recognise that...extends the opportunity to involve a range of staff in assessment, and stresses the principle that the most appropriate professional should be responsible for carrying out an assessment, coordinating other contributions and identifying the support or resources needed. However, local authorities should be aware that they ultimately remain statutorily responsible for the overall performance of the assessment.

The carer must request the assessment

- 5.3 The right to a Carer's Assessment is triggered once a carer has requested that one take place. This should be carried out as soon as reasonably practicable or immediately in an urgent case. This is in contrast to a disabled person's community care assessment - which is not triggered by a request but 'by the appearance of need'.¹² Of course the ability to request an assessment depends upon knowing such a right exists. There is accordingly a duty on social services to inform carers of their right to make such a request. This right is considered under the next heading 'the duty to inform'.

The duty to inform

- 5.4 Although carers consistently rate the provision of information as one of their top priorities, research suggests that almost half of them are not even advised of their right to an assessment when the person they care for is being assessed.

- 5.5 What is not generally appreciated is that there is a very considerable turn-over of carers - with approximately 178,000 adults becoming carers every year.¹³ This again makes an information strategy of great importance since it is unlikely that many of the 'new carers' will be aware of their rights, or of the support available.

Likewise, many of those ceasing to be carers may be in need of information concerning their options - e.g. employment, training and benefits advice.

The specific duty

- 5.6 Section 12A of the Social Work (Scotland) Act 1968 and Section 24A of the Children (Scotland) Act 1995 as amended by Section 9 and Section 11 of the Community Care & Health (Scotland) Act 2002 place a duty on social work departments to inform carers of their right to a Carers Assessment. This duty arises when any carer they come into contact with appears to be eligible to have a formal assessment.
- 5.7 It is a proactive obligation. The social work department must first decide whether the carer *provides or intends to provide a substantial amount of care on a regular basis*, and if it is thought that the carer does, then the social work department must inform him or her of the right to request an assessment. It is then up to the carer to decide whether or not to ask to be assessed. However local authorities should also ensure that all carers have access to general information, not only carers who seem eligible for an assessment.
- 5.8 Local authorities should aim to make the information available in formats (para 5.2.2)¹⁴ that are accessible (including tapes and video) and appropriate (especially for young and older carers, carers with learning disabilities and carers from minority ethnic groups). Local authorities should provide access to translation and interpreting services where necessary.

The extent of the obligation to ‘inform’ carers

- 5.9 The nature and extent of the information that social work departments are required to provide is wide ranging. Guidance (para 5.2.2)¹⁵ to the 2002 Act states:

Local authorities should: offer information on the assessment process and on the appropriate complaints procedure should the carer wish to complain about the assessment or its outcomes; offer carers information about other support and help available to them including any local carers’ centre or carers’ support groups and advice on issues such as benefits, Independent Living Fund and other services.

5.10 Social work departments are, as a consequence of Section 1(2) Chronically Sick and Disabled Persons Act 1970, under a duty to provide general information about the range of services available to disabled people (whether provided by that authority or by 'any other authority or organisation'). Guidance on this duty¹⁶ emphasised that its purpose was to ensure that 'those who might benefit by help, and their families, should know what help is available to them and this is to be secured both by general publicity and by personal explanations.'

5.11 Follow up guidance also stressed the importance of information provision¹⁷ stating that:

1.3 It is the responsibility of the practitioner to ensure that this published information reaches potential users and carers who are considering seeking assistance. The availability of such material should help practitioners in their task but will also mean that they will be more open to public challenge on the quality of service they provide.

5.12 NHS Boards will be required to implement Carer Information Strategies from 1 April 2007 and will have a duty to inform carers of their potential right to an assessment. Guidance¹⁸ details a range of information that NHS staff should provide including:

(Section 6) - signposting information about sources of local and national support, including short break services/respite, access to support groups, independent advocacy and counselling:

- general or specific information on medical condition/treatment in accordance with patient confidentiality, the condition and treatment of the cared-for person, including information on side effects of treatment (even if confidentiality precludes disclosure of diagnosis);
- moving and handling of patients, the administration of medication, feeding, dealing with the behavioural aspects of the cared-for person;
- the availability of financial support through the benefits and tax credit system;
- information on guardianship under the Adults With Incapacity (Scotland) Act, if appropriate;
- for mental health carers specific information on their legislative rights;
- health and well-being, including information and training on stress management techniques, healthy diets and physical exercise;
- local concessionary, other transport schemes and patient transport arrangements to enable carers to attend NHS appointments with the cared-for person;
- information on aids and adaptations;
- information on housing support, including ability to be housed nearer the person they care for;
- information on complaints procedures both against NHS Boards and local authorities;
- information on regulation of services and of the health and social care workforce;
- information on the assessment process;
- information on direct payments;
- information on local forums where carers, including young carers, can input on service planning and development.

The setting and format of the assessment

Private meeting

- 5.13 Guidance under both the 1995 and 2002 Acts have emphasised the importance of carers having the opportunity to have their assessments in private – i.e. away from the disabled person, if the carer so chooses.
- 5.14 This guidance states that 'local authorities should ensure that both carers and cared-for person always have the opportunity to discuss their need individually' and 'recognise that the wishes and interests of the cared-for person and carer may not always coincide, and involving them at the same time may not allow all the relevant factors to be appreciated.' (para 6.10.1)¹⁹

Advocacy / support

- 5.15 Social services should ensure that carers are aware that they can have access to advocacy support where needed. Commonly this may take the form of a Carers Support Worker from a carers centre attending to provide practical or merely moral support. It may however range from a family friend to a specialist advocate.

The actual assessment process

- 5.16 Although both the 1995 Act contained provisions enabling 'directions' to be issued by the Secretary of State²⁰ concerning the format of carers assessments, these powers have not as yet been used. The policy guidance²¹ accompanying the 1995 Act gives limited and general advice on the form such assessments should take, whereas slightly more detail is provided in the practice guidance²² including:

9.1 The assessment is not a test for the carer. It should not be prescriptive but recognise the carer's knowledge and expertise. The assessment should listen to what they are saying and offer an opportunity for private discussion in which carers can candidly express their views . . .

- 5.17 Guidance²³ under the 2002 Act provides a little more assistance in detailing the key purposes of a carer's assessment. (para 6.4) The guidance, for instance, stresses that 'local authorities should be ready

to give carers information about the type of services that may be available to help them articulate their needs or identify the kind of support that would help them' and that the authorities should 'recognise and draw on their knowledge'.

5.18 Not infrequently social work departments have handed carers a questionnaire which they have then been asked to complete themselves. This process is acceptable, provided (1) the carer is agreeable and (2) provided the local authority appreciates that this is not an assessment - merely a preliminary stage; and (3) provided the questionnaire is not so daunting that it has the effect of deterring carers from progressing further. As the guidance²⁴ (para 6.11) explains, authorities can 'offer carers the opportunity to use self-assessment as part of their assessment process' but that they should 'involve carers and local carers groups in the development of any self-assessment tools'. They should offer carers 'a range of assessment tools to help meet their needs'. (para 6.10.1)

5.19 There is no specific guidance concerning the assessment process. However, guidance²⁵ on interpreting 'substantial and regular' does reinforce the preventative approach emphasised in the 1996 guidance (para 9.6)²⁶ 'in many instances, ensuring a carer has early access to advice and practical help will reduce the subsequent need for increased levels of support, and may prevent future breakdown in the caring relationship. Local authorities should recognise the value of early intervention to sustain carers'.

5.20 However, the guidance does emphasise that the assessment process and policy to recognise and support carers is aimed to achieve 'good outcomes for carers'.

'Good outcomes for carers will occur when: the carer is able to cope better with their caring role; the carer gets a regular break from caring; the carer is better informed and more knowledgeable about their caring role and the needs of the person they care for; the carer feels valued, supported and listened to'. (para 3.3.1)²⁷

The Carer's Assessment: key issues

5.21 As noted above, people who provide (or intend to provide) 'a substantial amount of care on a regular basis' are entitled to a carer's assessment. The law requires that these assess the sustainability of the caring relationship. The Assessment must assess the carer's 'ability to provide and to continue to provide care' for the person s/he cares for²⁸.

Sustainability

5.22 The 1995 and 2002 Acts require an assessment of the carer's 'ability to provide and to continue to provide care'. As noted above (see para 4.14 above) the guidance²⁹ issued under the 2002 Act advised that:

Local authorities should focus on the impact of the caring role on the individual carer and their family and address the following questions:

- Is the caring role sustainable without additional support?
- How great is the risk of the caring role becoming unsustainable without additional support?

5.23 The guidance³⁰ to the 2002 Act suggests that in determining what is 'sustainable' four crucial dimensions of the carer's assessment are to (para 6.4):

- establish what level of care the carer is willing and able to provide, and to determine whether their caring role is sustainable;
- determine what the carer needs to maintain their own health and wellbeing; and decide how these resources can best be provided;
- determine what resources the carer needs to support them in their caring role; and decide how these resources can best be provided;
- identify the care provided by the carer and the carer's views so that they can be taken into account before the local authority decides what package of care to provide to the cared-for person.

The following paragraphs consider some of these issues in more detail:

Choice

5.24 Coercion and compulsion have no place in the language that describes caring relationships. Whilst parents have responsibilities towards their children and spouses are liable to maintain each other - the law recognises that it is impossible to compel one individual to provide care for another. Good practice therefore dictates that carers should have the right to choose the nature and the extent of their caring responsibilities. Ultimately if a failure of care occurs - the state has a positive obligation to provide support.

5.25 The practice guidance to the 1995 Act³¹ described the proposition in the following terms:

In assessing the carer's ability to care or continue to care, care managers should not assume a willingness by the carer to continue caring, or to continue to provide the same level of support. They will wish to bear in mind the distinction between caring about someone and caring for them. Many carers continue to care deeply about a person even though their ability to care for them may change.

5.26 The choice available to carers should relate not only to the quantity of care they provide but also the quality or type of the caring roles they are prepared to assume. As the practice guidance to the 1995 Act³² explains:

... it is important that care managers do not make assumptions about carers' willingness to undertake the range of caring tasks, particularly those related to intimate personal care. This is highlighted in a discussion with spouse carers⁵⁹ which emphasises the difficulties faced by some husbands or wives when their ability to cope with changed behaviour or personality and/or tasks involving physical intimacy is taken for granted ...

Health

5.27 The guidance on NHS Carer Information Strategies 2002 Act³³ (para 1.6.1) describes the importance of information and support addressing the health impacts on carers, in the following terms:

There is growing evidence that caring can have a detrimental impact on the physical, emotional and mental health of carers and that their health is increasingly at risk as their caring responsibilities increase. When a caring relationship breaks down (often because unsupported carers can no longer cope), it can result in the admission of the cared-for person, the carer, or both, to hospital or local authority care. This is particularly an issue where older carers are caring for spouses, partners or friends or adult children with learning disabilities. Many parent carers of children with complex needs and challenging behaviours face high levels of stress over long periods. Without additional support, severe strain is often placed on the wider family, impacting on the development of other siblings. Unpaid carers, like paid care staff, require support to fulfil their roles, such as information, training, financial and emotional support, equipment and adaptations and breaks from caring.

5.28 There is substantial evidence to suggest that significant caring responsibilities can be harmful. A Princess Royal Trust for Carers' report³⁴ found that:

- 85% of carers had found that caring had an adverse impact on their health, with particularly high-risk groups including those who looked after people with serious or mental and physical illnesses, and long-term carers.
- caring had been to the detriment of the mental well-being of almost 90% of carers
- over 40% said their physical well-being had been affected by caring

5.29 Similar research by Carers UK³⁵ found that:

- 55% of carers reported they had significant health problems;
- 43% reported they had sought medical treatment for depression, stress or anxiety since becoming a carer (these problems were

particularly apparent in young carers and carers looking after mentally ill people).

- 5.30 Guidance, whilst recognising that assessments must address the needs of carers to maintain their own health and wellbeing, does not specify this further. However, the physical and emotional health of a carer is likely to be considered under criteria considering the risk of the caring role breaking down or being unsustainable without additional support. In addition, guidance on NHS Carer Information Strategies (para 2.1.5)³⁶ notes:

Maintaining the health of Scotland's unpaid care force therefore requires a health service which identifies carers and their health needs early, and pro-actively supports carers to look after their own physical and mental health needs. This support needs to be through a wide range of health checks and preventative programmes, information on dietary health, signposting and referral to appropriate agencies who can offer peer and emotional support as well as supporting carers to access leisure opportunities and breaks from caring.

Managing daily routines and 'involvement'

- 5.31 Carers should have the same life chances as anyone else. The fact they are providing care should not disentitle them to opportunities available to people who do not have caring responsibilities. To argue otherwise would be to suggest that it is legitimate to discriminate against carers in a way that would not be acceptable for any other group. If it is unacceptable to assert that disabled people should not expect to work or participate in education or expect to have meaningful personal relationships, then how could it possibly be suggested that this is not also the case for carers?
- 5.32 Carers' Assessments should therefore address the extent to which caring responsibilities interfere with the carers' ability to manage their daily routines as well as the extent to which they inhibit the freedom of carers to maintain relationships, employment, interests and other commitments alongside their caring responsibilities.

5.33 Practice guidance from the 1995 Act³⁷ notes that a carer's assessment should address: the carer's 'willingness and/or ability to continue to provide care; options available to the carer, particularly a carer who is in employment' and 'other responsibilities eg. work, family/child care commitments'.

Employment, training, education and leisure activities

5.34 There is little guidance or legislative requirement to enable carer's assessments to take account of a carer's employment status or their opportunities to access training, education and leisure activities. Practice guidance from the 1995 Act (see para 5.3 above) makes reference to the additional responsibilities that a carer may have and the 2002 guidance encourages local authorities when interpreting 'substantial and regular' to consider the impact of a carer's employment status³⁸.

Promoting carers' employment

5.35 Very significant numbers of carers are of working age - possibly 80%.³⁹ Research suggests that 60% of carers providing substantial amounts of care have given up paid work to care and that of these 70% find themselves financially worse off as a result.⁴⁰ A number of research reports have found that carers repeatedly stress the value of being able to go out to work⁴¹ and that possibly 80% would return to work if they could.⁴² It appears that caring is not only damaging to the health of many carers (see para 5.27 above) but that it can also be economically crippling, with research suggesting that carers lose an average of £9,000 pa by taking on significant caring responsibilities and having to reduce working hours.⁴³

Emergency leave employment rights

5.34 Carers have limited rights to take (unpaid) time off work to care for a dependent. This right is found in section 57A(1) Employment Rights Act 1996⁴⁴ of which provides:

57A. - (1) An employee is entitled to be permitted by his employer to take a reasonable amount of time off during the employee's working hours in order to take action which is necessary-

- (a) to provide assistance on an occasion when a dependant falls ill, gives birth or is injured or assaulted
- (b) to make arrangements for the provision of care for a dependant who is ill or injured,
- (c) in consequence of the death of a dependant,
- (d) because of the unexpected disruption or termination of arrangements for the care of a dependant, or
- (e) to deal with an incident which involves a child of the employee and which occurs unexpectedly in a period during which an educational establishment which the child attends is responsible for him/her

5.35 'Dependant' is defined widely in relation to persons who live in the same household⁴⁵ and there is a general obligation upon carers who take such time off work, to tell the employer the reason for the absence as soon as practicable and how long the absence is likely to last.⁴⁶ In relation to the situations detailed in sub-sections (a) - (c) above, the event which requires the carer to take time off need not be 'unexpected'. Any time off work claimed as a result of this statutory provision is to be taken as unpaid leave.

Flexible working rights

5.36 Parents with children under 6, or disabled children under 18, who have worked for their employer for at least 26 weeks have the right to apply for flexible working arrangements.⁴⁷ Employers have a statutory duty to consider such requests seriously, and will only be able to refuse when there is a clear business reason or where the employee has made an application for flexible working in the past 12 months. In order to exercise this right the employee needs to make an initial written application to the employer. An employee can request a change to the hours they work, a change to the times they work, or to work from home. Since any changes will be permanent it is important to consider the future implications carefully. This may include any drop in salary, and the impact that any reduction in hours may have on state benefits such as Working Tax Credit.

5.37 From 6 April 2007, section 12 (1B) of the Work and Families Act 2006⁴⁸ extended the right to request flexible working to carers of adults. To qualify under this legislation, a carer must be or expect to be, caring for a spouse, partner (who the carer lives with), civil partner or relative or, live at the same address of the adult in need of care. The term 'relative' includes parents, parent in-law, adult child, adopted child, siblings (including those who are in-laws), aunts, uncles, grandparents and step-relatives. Employees who have worked for their employer for at least 26 weeks can apply to make a permanent change to their terms and conditions. Only one request is allowed in a year. Employers can refuse a request, but must give good reasons.

Promoting carers' involvement in education, training and leisure activities

5.38 There is no legislation specifically promoting carers' involvement in education, training and/or leisure activities. However, NHS Carer Information Strategies will enable carers to access training opportunities to support them in their caring role.⁴⁹

Eligibility criteria and carers' assessments

5.39 Although there is no guidance binding local authorities to assess risk in an individual's caring role, in practice, social work departments do grade the extent of risk to the sustainability of the caring role into (normally) one of three categories - namely 'low, medium and high'. The grading system is a formal determination of the degree to which a carer's ability to sustain that role is compromised or threatened by the absence of appropriate support.

5.40 Although the grading system has strong similarities with the eligibility criteria that regulate disabled people's assessments (see para 6.4 below) the consequences of a categorisation are different. If a disabled person's is assessed as having a 'high' need, then this means that the local authority is under a duty to make services available to meet that need.

5.41 However a categorisation of 'high' in relation to the caring role does not mean that the local authority is under any duty to make services available to the carer - since there is no duty under the 2002 Act to provide services. The Act makes 'no statutory provision for carers to

receive services directly as a result of their carer's assessment'. Where the carer's assessment identifies a need for support in the caring role, this 'may be provided in the form of community care services to the cared-for person, or other resources provided directly to the carer'⁵⁰ (para 7.1.3).

5.42 However, the categorising of a risk to the sustainability of a caring role as 'high' may bring with it an obligation by the authority to take steps to ensure that support is made available to prevent this state of affairs continuing. Although in such a situation the local authority is not obliged to provide the carer with services it may be obliged to act. For example, a local authority would require to have regard to the results of the carer's assessment when carrying out a community care assessment to assess the needs of the cared for person. When assessment of the needs of the cared-for person has already been carried out, the carer's assessment may prompt the local authority to carry out a further community care assessment review. This assessment could include additional services needed by the cared for person in light of the support required by the carer. The local authority may then be under a duty to provide these services to the cared for person by the provision of community care services.

6. Services to support carers

- 6.1 A carer's assessment may have many outcomes. The mere presence and involvement of a sympathetic social worker will often provide considerable support and recognition: indeed it was because this aspect was so highly valued by carers that those promoting the 1995 Act chose to name it the Carers (Recognition and Services) Act. The assessment process should also be an opportunity for the assessor to advise the carer of the information and support services that are available.
- 6.2 The legislative purpose of the assessment, however, is to provide information that enables the social work department to decide what additional services to provide to the disabled person or what support is needed by the carer.

- 6.3 If these services are provided to the disabled person, then they will be provided under the community care or Children Act legislation.

Community care services

- 6.4 The object of a carer's assessment under the 1995⁵¹ and 2002⁵² Acts is to identify his or her 'ability to provide and to continue to provide care'. Whilst the Act makes no provision for services for carers, the outcome of such a carer's assessment will not infrequently be an increase in the community care services provided for the disabled person.

- 6.5 This is because the carer's assessment, by focusing on the sustainability of the caring relationship, may identify areas where it is no longer sensible or safe for the carer to continue providing care - or where the carer is simply unwilling to continue. In such cases the care plan will need to be modified to ensure that the disabled person continues to receive the care that is needed - albeit that this care will be provided by someone else.

- 6.6 Thus, if a carer is no longer willing or able to provide help to the disabled person with (for example) bathing, the disabled person's care plan will need to specify how this need is to be met in the future.

Likewise if a carer is no longer able to remain with the disabled person (because s/he has obtained employment or simply needs to take a break) then the care plan will need to specify how the disabled person's need for supervision/support at such times will be met in the future.

Respite / short break care

- 6.7 It follows from the above analysis, that respite care services are services provided to a disabled person, which enable the carer to take a break from his or her caring responsibilities. In other words, respite care support is legally a community care service not a service provided under any Carers' Act.

- 6.8 'Respite care' is not a phrase used by the law. In general terms, if a disabled person needs someone to sit with them, whilst their carer takes a break, the sitting service is a service provided under s2(1)(a) Chronically

Sick and Disabled Persons Act 1970 - which refers to 'the provision of practical assistance' in the home. Likewise if a disabled person needs to spend a short time in a care home whilst the carer takes a break, then legally this is the provision of 'residential accommodation' - either under s21 National Assistance Act 1948 if the disabled person is 18 or over, or under s17 Children Act 1989 if a child.

- 6.9 The importance of timely respite care/short break services has been repeatedly highlighted by research, guidance and case law. By way of example, guidance to the 1995 Act referred to research that suggested that 'some of the most cost effective care packages were where carers continued to perform caring tasks but were given sufficient support and respite to enhance their well being and maintain their own health'.⁵³

Withdrawing / not providing respite care

- 6.10 Respite care services are services provided to disabled people, to ensure that they are not at risk of harm when their carer takes a break or is otherwise unable to provide him or her with care. As with all disabled people's services, once a local authority has decided that such a care need must be met, then it is under a duty to provide services to meet that need. The courts and Ombudsman have repeatedly emphasised that a failure to provide such support will be unlawful. Thus in a 2000 case (concerning a placement in a residential care home) the courts stated:⁵⁴

Once a local authority determines that an individual's needs call for a particular provision, the local authority is obliged to make that provision. In particular having decided that an individual requires the provision of a permanent place in a nursing home ... a local authority could not ... refuse to make such a provision simply because it did not have the necessary resources.

- 6.11 In relation to waiting lists, the court and Ombudsman have been similarly forceful. The Ombudsman in a complaint report concerning Essex⁵⁵ has stated:

The Council believes it does not have to provide a care service or funding for care immediately it has decided that it is necessary to provide the service to meet a person's assessed needs. It considers that it is acting correctly by having a waiting list on which the time a person may have to wait for resources to become available is indeterminate and depends to a significant extent on the needs and priority of other people on the waiting list and those who may come on to the list. That cannot, in my view, be correct.

- 6.12 An Ombudsman's complaint against North Yorkshire County Council⁵⁶ illustrates the approach of the Court and Ombudsman. The complaint concerned a 17 year old person with multiple and profound mental and physical disabilities. Although primarily cared for by her parents she attended a special day school and for over 10 years went one weekend every month for respite care to an independent residential respite care centre - where she was delivered by the school bus on Friday afternoon and collected on Monday morning - providing the parent carers with a monthly break.
- 6.13 Because of a shortfall in its funding, the independent home advised the parents that it was no longer able to provide weekend respite care. The parents were devastated by this news. The council indicated that they would not provide any substitute weekend respite care and although the parents complained - the effect of this loss of service resulted in them both having nervous breakdowns and their marriage of 25 years ended.
- 6.14 The Ombudsman was extremely critical of the local authority's failings: extracts from her lengthy report, include

The Council says that because it was not responsible for the closure of (the independent respite centre), it cannot be held responsible for the withdrawal of Marie's provision. I do not accept this. It is the Council, not (the independent respite centre), which has statutory responsibility for providing for Marie's needs. If (the independent respite centre) could not, for whatever reason, meet those needs, the Council had a duty to find, in the locality, somewhere else where Marie would feel equally settled and in which her parents would have confidence. ... I have noted too with

disappointment that the Council did absolutely nothing to make (the parents) aware of the statutory provision for carers. There cannot be another family whose need will have been more pressing. The Council's efforts at publicising the Carers (Recognition and Services) Act fall far short of what the Government has said it should do. ... It is perhaps appropriate to mention at this point the comment of the Review Panel in dismissing part of (the parents complaint) on the grounds that weekend respite was not necessary to meet Marie's needs but their wishes. This comment, combined with the Council's policy that carers must negotiate with service providers when their respite can be accommodated, does not, in my view, sit comfortably with government guidance. Government guidance says that services must be user driven, that users should not have to fit into what is available and that parents should be allowed to choose the pattern of use which suits them best. In a family coping against such odds and with another child to consider, I suspect their needs and their wishes are probably indistinguishable.

Carers' services

6.15 There is no statutory provision for carers to receive services directly as a result of a carer's assessment⁵⁷. Carers can receive support in the form of community care services provided to the cared-for person or other support provided directly to themselves. This could include counselling, training or referral to carer support services e.g. a carers' centre. However local authorities should recognise⁵⁸ that carers may have support needs in their own right that are not related to their caring role and that as such they can be assessed as person in need under the 1968 Act or, if under the age of 18, as a child in need under the 1995 Act.

7. The rights of disabled people: an overview

Community care assessments

7.1 If a carer is seeking assistance from the social work department, the first stage will in general be for the disabled person to have an assessment of his or her needs for social care support services. If the disabled person is over 18, this assessment will be known as a 'Community Care

Assessment' or 'Single Shared Assessment' whereas if the disabled person is under 18, the assessment will be known as a 'Children Act Assessment'. These two procedures differ slightly - and are briefly described below. They can both, however, be broadly considered as having three key stages. The social worker must:

- Gather all relevant information concerning the disabled person's needs and requirements. This will include meeting with the disabled person and discussing his or her needs as well as contacting significant information sources such as family, carers, GPs, housing etc.
- Decide which of the various requirements identified during the first stage 'call for the provision of services by the social work department'.
- Construct a care plan to detail how these needs will be met by specified services.

7.2 When undertaking a community care assessment social services must follow detailed guidance issued by the Scottish Executive⁵⁹. In addition there is a plethora of other guidance - which is specific to certain user groups, for instance, the single shared assessment process guidance⁶⁰ for older people.

7.3 When undertaking a Children Act assessment the local authority must follow detailed guidance is Volume 1: Regulations & Guidance: Support and Protection for Children and their Families⁶¹.

7.4 **An example of a community care assessment**

Albert is 85 and lives with his wife who is his main carer. He has dementia which has now progressed to a stage that he is forgetful and without his wife's help, he would neglect himself. He is physically frail and has fallen on a couple of occasions recently when trying to get upstairs to the toilet.

Stage 1

The social worker will try and get as much information about Albert's wishes and requirements as is possible. This will include trying to discover what his interests and preferences are, in addition to key

questions such as his need for basic physical care. At this stage, the views of his wife and other significant people in Albert's life should be obtained even if these people do not want, or qualify, for a carers' assessment. The views of the local health service must also be sought⁶² as well as enquiries made about the suitability of his housing⁶³ and alternatives (for instance sheltered housing etc).

Stage 2

The second stage of an assessment requires the social worker to make a decision about which of the needs identified in the first stage, require the social work department to provide or arrange for the provision of services. In order to ensure that people in the greatest need get priority for services, every social work department must publish its 'eligibility criteria'. This is a scale which is divided into 'high' 'medium' and 'low' - with each category being described in some detail. The social worker must then grade the person's individual circumstances into one or more of these categories. Put very simply the social worker asks 'what will happen if the authority does not respond to the identified need' (e.g. help getting up, help with feeding and so on)?'. What will the consequence be for Albert? In doing this the local authority should initially ignore the help that Albert receives from his wife, his main carer. Most local authorities have decided that they will provide services for people who are found to fall into the critical or substantial categories. A person will fall into such categories if, put simply, a failure to provide a service would result in them suffering significant harm.

If this test is applied to Albert's needs (and his wife's input ignored) and the question posed 'what would happen if he did not have any help getting dressed in the morning; or help in the bathroom; or help in the preparation of food; or just keeping an eye on him to make sure he did not fall etc?'. The answer would almost certainly be that 'he would be likely to suffer significant harm'. Accordingly the social work department will be under a duty to meet these needs.

It is at this stage that the authority should offer and undertake a carer's assessment of Albert's wife to see if she is willing and/or able to continue to meet some or all of his care needs (see Section 5 above).

Stage 3

Having undertaken a carers assessment of the sustainability of his wife's caring role and ascertained which of Albert's various needs she is willing and able to meet, the social work department is then legally obliged to draw up a 'care plan' which describes the services that it will provide, or arrange to meet his remaining care needs. The law also requires

social work departments, to offer the disabled person 'direct payments' (if capable of managing these - alone or with assistance). This means that instead of the local authority providing (or arranging for the provision of) the services, the disabled person is given the cash equivalent with which to buy the services him/herself.

7.5 **An example of a Children Act assessment**

Rupee is 8 years old and lives with her parents. She has significant learning disabilities and challenging behaviour associated with her autism. She has an older brother aged 11. Rupee's social care needs will be assessed by the social work department under the Children Act procedures.

Stage 1

The social worker will try and get as much information about Rupee's social care needs. This will include trying to discover what her interests and preferences are as well as looking at the impact her disability may be having on her parents and her brother. This part of the assessment might find that Rupee's mother wishes to return to work, but is unable to do so due to the exceptional demands made by Rupee, and that Rupee's brother was providing her with large amounts of care. The question of her mother's wish to work is considered at para 12.3 below - as is the question of their responsibilities towards 'young carers' (see section 10 below).

Stage 2

The second stage of an assessment requires the social worker to decide what services should be made available to Rupee and/or her family. It may be decided that the demands made by Rupee are such that on occasions she needs to be apart from her family - that they all have a break from each other - sometimes referred to as a short break or 'respite care'. This might mean that Rupee will stay elsewhere for a period (for instance with temporary foster parents) or that someone will come to her home and sit with her, whilst other family members leave for a short time on their own. In assessing whether this support should be made available, the social work department will again have regard to the consequences - what would happen - if no help was provided as discussed above.

Stage 3

The final stage (as with the community care assessment example above) requires the preparation of a 'care plan' which explains what services the social work department will provide or arrange in order to meet the needs of Rupee and her family. This might, for instance spell out when, where and how often respite care support will be provided, what other general assistance will be made available, detail adaptations or equipment required in the home etc.

8. The NHS's Responsibilities

General carer obligations

- 8.1 The 1995 Acts did not place any obligation on the NHS to address the support needs of carers. Given the extensive research concerning the caring-related health problems that carers experience, this was a cause for considerable concern.
- 8.2 However, the 2002 Act⁶⁴ provided Ministers with the power to require NHS Boards to develop carer information strategies to inform carers of their entitlement to assessment. And, in supporting guidance⁶⁵ highlighted the vital role of the NHS:

'The NHS has a vital role to play in identifying and supporting carers.' The Scottish Executive white paper, Partnership for Care⁶⁶ stresses that 'staff throughout the NHS should work closely with carers as key partners in the provision of care... Through the implementation of Single Shared Assessment NHS staff will become increasingly involved in assessments of carers and the people they care for, and this guidance recognises the growing role of the NHS in supporting carers'

Specific NHS carer obligations

- 8.3 In April 2006, the Scottish Executive issued guidance requiring NHS bodies to produce Carer Information Strategies by 31 October 2006, for implementation in April 2007 (now extended until 1 May 2007). This guidance⁶⁷ details minimum requirements for each strategy in 'ensuring that NHS staff identify 'regular and substantial' carers irrespective of their age and advise them of their potential right to a carer's assessment under either Section 12AA of the Social Work (Scotland) Act 1968 or Section 24 of the Children (Scotland) Act 1995'.⁶⁸
- 8.4 The primary purpose of the Strategy is to ensure that "carers receive appropriate information systematically to give practical effect to the requirement on the NHS to work with carers as key partners in the care management process and particularly at key stages of the patient/carer journey". It "seeks to deliver systematic carer identification and provision of information to carers, based on existing good practice."⁶⁹ (See para 8.14 below)
- 8.5 The guidance also requires NHS Boards to consider, "the training needs of carers" in particular 'expert carer' training, aimed directly at supporting carers in their caring role and targeted specifically at carers with intensive, or potentially growing, caring responsibilities.
- 8.6 This training is fairly far reaching and should include "person centred training for carers" including advice on physical and emotional well-being including demonstrations on moving and handling techniques and stress management, and advice on specific conditions such as caring for someone with dementia, physical disabilities, mental health problems, special needs, etc.⁷⁰

Hospital discharge

General rights

- 8.7 All patients are owed a duty of care by the NHS to take reasonable care of them. When it is thought that they are ready to be discharged from a hospital, this duty of care broadens: it is then shared with the social work department.

- 8.8 Patients have, in general,⁷¹ no right to remain in a hospital and can be discharged against their wishes provided that the NHS and social work authorities consider that it is safe (i.e. have satisfied themselves that it would not be negligent by exposing the patient to an unnecessary or involuntary risk of harm).
- 8.9 The relationship between the NHS and social services in the discharge process is also shaped by central government guidance.^{72 73}

Patient and carer involvement

- 8.10 These guidance documents emphasise that 'regular liaison between health, social work, housing professionals and the older person and their carer about the likelihood of discharge is essential, especially if there are indications that the older person may not require extended hospital care.'⁷⁴ They further stress the importance of patients and their carers being 'kept fully informed about how procedures for hospital assessment and discharge will work.'⁷⁵
- 8.11 Updated guidance extends this further:

'The individual's interests must remain central to discharge planning. The assessment and discharge planning process should at all stages be person-centred and should always involve regular consultation with the individual and his or her carer. Decisions to be made about any aspect of the individual's care should take into account the needs and wishes of the individual (and his or her carer) at all times. It is crucial that consultation through the assessment and discharge planning process is co-ordinated and that the individual and his or her carer have the quickest possible access to services.'⁷⁶

- 8.12 This awareness is not restricted to adult carers; both the Community Care & Health (Scotland) Act 2002 and the guidance to NHS boards on the development of Carer Information Strategies place the same duty on informing carers under the age of 16 of their right to a carer's assessment.

8.13 Carers have often considered themselves marginalised by discharge arrangements, particularly with patients being sent home too early leaving their carers to cope with unacceptable caring situations. Guidance reinforces that any discharge protocol must set out 'arrangements for informing and involving carers at all stages of the discharge process, establishing the level of care they are able and willing to provide and offering support where necessary.'⁷⁷

Information / communication

8.14 NHS Carer Information Strategies require NHS Boards to provide information to 'all carers they come across in their day to day activities, in particular information to help support the carer in their caring role, advising carers of their potential right to assessment and signposting carers onto sources of support and advice.'⁷⁸ The guidance further identifies information provision as an ongoing process:

Information provision for carers must be carried out as a continuous process throughout the caring situation. Information giving is not a one-off exercise. Key stages where information needs should be addressed are: hospital admission; diagnosis; first treatment; changes to treatment; and discharge.⁷⁹

8.15 The guidance extends further to address issues of patient consent in relation to communication and information.

Patient consent is sought as a first step, where appropriate, as a basis for providing information to carers, and where tension arises between the needs of carers and patients, mediation is fully explored. Where consent is withheld, for the provision of personal information, carers are provided with as much information as can be shared without breaching patient confidentiality, including information on:

- medication, where the carer is required to dispense medication;
- treatment, particularly in relation to side-effects that may impact on the carer; and

- practical issues relating to care at home and long term care.

Where patients are unable to consent though incapacity, practitioners work with partners and/or immediate family, sharing information as appropriate so that full consideration can be given to possible action under the Adults with Incapacity (Scotland) Act 2000.⁸⁰

9. Financial issues

Carers welfare benefits

- 9.1. This guide does not address carers benefit entitlement. Details of the range of benefits that may be available to carers can be obtained from Carers Scotland at www.carerscotland.org/Information/Financialhelp. The entitlement rules for carers allowance can be accessed at the Department for Work and Pensions website at:- www.dwp.gov.uk/lifeevent/benefits/carers_allowance.asp

Paying for services provided by social work departments

- 9.2 Social work departments are permitted to charge disabled people for many of the community care services they receive. Different rules exist depending upon whether the service consists of a place in a residential home or a service provided in the community.
- 9.3 Although this guide does not address the charging rules for disabled people's services, two very important points of direct relevance to carers are:

Separate treatment of carers & disabled people's income

- 9.4 The charging rules for disabled peoples' services stress that it is only the disabled person's financial circumstances that can be taken into account in relation to charges for residential care. This means that even if the carer and disabled person are civil partners/married, their financial circumstances should not be aggregated.

- 9.5 Thus the guidance on charging for residential care accommodation, the 'Charging for Residential Accommodation Guide'(CRAG)⁸¹ states:

The local authority has no power to assess a couple according to their joint resources. Each person entering residential care should be assessed according to their individual means, although liability of a married person to maintain their spouse [see para 9.9 below] should be considered in each case.

- 9.6 The same rules do not seem to apply in relation to non-residential care services. Supporting guidance to local authorities in relation to the S8-12 Community Care & Health Scotland Act (2002) states⁸² that local authorities should:

'recognise that they cannot levy charges on carers for support or resources provided to sustain their caring role as a result of a carer's assessment' and;

'apply existing rules and discretion about charging and assessment of income to ensure as far as possible that charges levied on the cared-for person do not adversely affect carers'.

- 9.7 However, local authority charging policies for care at home services vary from local authority to local authority. CoSLA guidance⁸³ to local authorities on charging for non residential services that enable people to remain in their own home notes that the original charging structure⁸⁴ is "ambiguous where it refers to 'reasonable' or 'reasonableness', both of which could be contested", in particular as it 'largely treats couples as individuals, their overall position is not clear as both may benefit from services provided, and for benefits purposes they would be treated as a family unit'. At the moment, guidance does not preclude a carer who is part of a couple being jointly assessed for the liability to pay charges for services for the disabled person. It is, as noted above, possible that this could be challenged.

Liable relative rules

- 9.8 Until 2007, if a person was resident in accommodation provided by or secured by a local authority under the Social Work (Scotland) Act 1968

or under s25 of the Mental Health (Care and Treatment) (Scotland) Act 2003 carers who were the spouse or parent of that person could be required to contribute to the cost of their care. (Under the 'liable relative' rules, s42 National Assistance Act 1948). However, s62 of the Adult Support and Protection (Scotland) Act 2007⁸⁵ repeals this rule.

Treatment of property when a disabled person enters a care home

9.9 Chapter 7 of the CRAG guidance⁸⁶ deals with the question of when the value of a disabled person's home should be taken into account, for the purposes of residential home charging purposes. The general rule is that the capital value of a property or former home is taken into account in full (less 10 per cent for disposal costs) unless one of the following disregards apply:

- i) The value of a resident's home is disregarded for the first 12 weeks of a permanent admission to residential care.
- ii) The value of a dwelling normally occupied by a resident as his or her home should be ignored if his or her stay in a residential care or nursing home is temporary.
- iii) Where the resident no longer occupies a dwelling as his or her home, its value should be disregarded where it is occupied in whole or in part by:
 - the resident's partner or former partner (except where the resident is estranged or divorced from the former partner - unless a lone parent); or
 - a relative⁸⁷ of the resident or member of his or her family (ie, another person for whom the resident is treated as responsible) who:
 - is aged 60 or over, or
 - is aged under 16 and is a child whom the resident is liable to maintain, or
 - is incapacitated.⁸⁸
- iv) Where the resident has acquired property which s/he intends eventually to occupy as his or her home, the value should be

disregarded for up to 26 weeks from the date the resident first takes steps to take up occupation, or such longer period as is considered reasonable;

- v) Local authorities have an overall discretion to disregard the capital value of premises, not covered by the above exceptions, in which a third party continues to live.⁸⁹

Paragraph 7.007 of CRAG suggests that:

Local authorities will have to balance the use of this discretion with the need to ensure that residents with assets are not maintained at public expense. It may be reasonable, for example, to disregard a dwelling's value where it is the sole residence of someone who has given up their own home in order to care for the resident, or someone who is an elderly companion of the resident particularly if they have given up their own home.

- 9.10 It follows that the value of a home will be ignored if the disabled person enters a care home permanently and the carer who remains is either his or her spouse or common law partner. If however this is not the case, the statutory disregard only applies if the carer is a relative (including an 'in-law') and is either 60, or a child or step child of the disabled person, or 'incapacitated'. If this is not the case, then the carer should ask the local authority to exercise its discretion to ignore the value of the home - and many local authorities do do this - especially if the carer has provided care for a number of years.

Deferment of fees

- 9.11 Deferred payments were introduced in July 2002 under the Community Care and Health (Scotland) Act 2002. They allow people to avoid selling their homes up-front to meet their care home fees by entering into a legal agreement to have part of their fees paid by their local authority and the balance settled from their estate. A deferred payment agreement is a legal agreement between the local authority and the individual which defines the portion of a person's care home fees to be deferred and provides for the grant to the local authority of a standard security over the home to cover the deferred amount⁹⁰.

10. Carer/Service User conflict

General principles

10.1 The guidance that accompanies the 2002 Act⁹¹ (CCD 2/2003) gives general advice as to appropriate local authority responses where there is (or may be) conflict between a carer and the disabled person, including:

- There will be cases where the person whose care is being planned lacks the capacity to consent to the involvement of carers, or to the care plan itself. In these situations best practice suggests that the carers should be involved as much as possible. Currently local authorities have a responsibility to make decisions to protect the welfare of the person being cared for. Local authorities should also 'consider the implications of the Adults with Incapacity (Scotland) Act 2000' which allows for other people to make decisions on behalf of these adults about things like arranging services, managing finances and property and medical treatment. The main ways other people can make decisions on behalf of an adult with impaired capacity are by applying for a power of attorney, intervention or guardianship order. (para 6.12.1)
- If disagreements occur between the person and their carer, local authorities should 'work closely with the cared-for person, the carer and other members of the family to seek to resolve situations and provide support' and 'provide access to mediation and advocacy services which can play an important role in exploring and resolving tensions between carers and cared-for persons'. (para 6.12.1).
- If it is felt to be inappropriate to involve the carer, local authorities should retain a written account of why it was felt to be inappropriate. This should show that the carer's involvement has been actively considered and, if excluded from care planning, the reasons why. The 'reason for any decision not to do so' must be 'fully recorded' (para 7.6.1).

Where a disabled person refuses a community care assessment

10.2 Under the Carers (Recognition and Services) Act 1995 carers did not have a right to a 'free-standing' assessment (unless of course they were

entitled to a community care assessment in their own right, by virtue of being an elderly, ill or disabled person). Carers only qualified for a carer's assessment when the person for whom they cared was 'being' assessed. The carer's assessment had therefore to coincide with the disabled person's assessment. The Policy Guidance under the 1995 Act⁹² confirmed that this would also arise:

where a re-assessment of the service user is taking place, either as part of a review or because of a change in circumstances of either the user or carer arising for example, from a deterioration in the health of the user or a change in the carer's ability to continue to provide care.

10.3 The requirement that the carers assessment coincide with a disabled persons community care assessment caused some problem in practice - not least when a social worker was confronted by a disabled person who was refusing to take part in an assessment. To overcome this difficulty S8-12 of the Community Care & Health (Scotland) Act 2002 provides for a free standing right to a carer's assessment for carers (including those aged under 16) who care for a disabled adult or child. All that is required in such cases is that:

- the carer provides or intends to provide a substantial amount of care on a regular basis for a disabled person; and
- the carer requests the assessment

Where a disabled person refuses community care services

General good practice

10.4 Not infrequently a disabled person will be refusing to accept services which would be of great benefit to the carer - for instance respite care (such as a sitting service or a short term placement in a care home - designed to give the carer a break). Frequently these can only be resolved by skilled and sustained social work. The courts have repeatedly held that social service departments cannot take a simple refusal of help (by

a disabled person) at face value. They should continue to try and engage with the person.⁹³

- 10.5 The obligations on a local authority in such a situation are well illustrated by a 2004 Local Ombudsman report. In this case a carer was enduring very considerable mental anguish because his autistic brother was continually getting into difficulties and seeking his help. Because of the brother's autism, he was unable to form relationships and rejected an offer by the social services department to undertake a community care assessment. In the Ombudsman's report she observed (at para 133):

I accept of course that the Council cannot force services upon an unwilling person. However, the Council took Mr K Hill's refusals of some services or failure to persist with others at face value, instead of questioning whether he was in fact making an informed decision to refuse service or considering the implications for his brother. It is understandable that Mr K Hill might prefer his brother to continue to provide care rather than to accept more help from strangers, but the Council could not reasonably rely on Mr W Hill to continue providing the same direct input to his brother's care, especially when he had explained his own difficult situation to them. They needed to find a way to work with both brothers on this issue. It is clear from the more successful interaction with Mr K Hill of the community nurse, the psychologist, and the worker from the voluntary caring organisation who became involved later, that it is possible to structure interaction with Mr K Hill in such a way as not to trigger his refusal of service through anxiety at having to cope with the person providing it. Why could not Council staff have done the same?

Exclusion from services

- 10.6 On occasions the disabled person may be excluded from services because of his or her behaviour. Often the behavioural difficulty will be a manifestation of the disabled person's impairment - and in such cases the local authority's obligations are to work with this problem and find a resolution. A failure to do this could result in enormous problems for the carer. The Local Ombudsman has criticised councils that have excluded disabled people from services in such cases. In a 2005 report⁹⁴ the Ombudsman cited with approval the following reference in the White Paper Valuing People:

Excluding people with learning disabilities from services if they are found to be difficult to handle or present with challenging behaviour represents a major source of stress for carers, who may be left unsupported to cope with their son or daughter at home. This practice is unacceptable and families must not be left to cope unaided. No service should be withdrawn on these grounds without identifying alternative options and putting a suitable alternative service in place where possible. Decisions to exclude a person with learning disabilities from a service should always be referred to the Learning Disability Partnership Board, which will be responsible for the provision of alternative services in such cases.⁹⁵

11. Young carers

- 11.1 Carers who are under the age of 18 are generally referred to as 'young carers'.
- 11.2 The Carers (Recognition and Services) Act 1995 and S9 Community Care & Health (Scotland) Act 2002 apply to all carers irrespective of their age. In addition to the benefit of a carer's assessment under the 1995 and 2002 Acts young carers are entitled to services in their own right, under the Children (Scotland) Act 1995.

Rights under the Carers (Recognition and Services) Act 1995 and Community Care & Health (Scotland) Act 2002

- 11.3 Young carers, if they are providing or intending to provide a substantial amount of care on a regular basis, are entitled to an assessment under the 1995 Carers Act. Although this is directed at establishing their ability to provide and continue to provide care (the continuation of which may not be appropriate - see below) its primary objective under the 2002 Act is to 'safeguard the interests and promote the welfare of the young carer, and to ensure that they are not taking on inappropriate levels or types of caring by ensuring the family has access to alternative support.'⁹⁶

Young carers and the Children (Scotland) Act 1995

11.4 In addition to the 1995 and 2002 Acts, the Children (Scotland) Act 1995 places a duty on social work departments to help young carers (in certain circumstances – see 11.5).

11.5 For a young carer (or any child) to benefit from help under the Children (Scotland) Act 1995, it is necessary for him/her to come within the definition of a 'child in need' Under s93(4) Children (Scotland) Act 1995 a child is 'in need' if:

- he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority ...; or
- his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services; or
- he is disabled; or
- he is affected adversely by the disability of any other person within his or her family.

11.6 Section 22(1)(a) Children (Scotland) Act 1995 places a general duty on social work departments to safeguard and promote the welfare of children within their area who are 'in need', and empowers authorities to provide almost unlimited services towards this goal. This reflects the spirit of Section 12 of the Social Work (Scotland) Act 1968 which gives local authorities a general duty to promote social welfare by making available advice, guidance and assistance "on such a scale as may be appropriate" for their area.

11.7 The Children (Scotland) Act 1995 assessment procedures and service provision arrangements for young carers are the same as for any other child in need. Section 22(1)(b) emphasises that a principal purpose for the provision of services to children in need is to promote the upbringing of such children by their families.

11.8 Section 22(3)(a) Children (Scotland) Act 1995 enables local authorities to provide services not only to the 'child in need' but to anyone else 'if

it is provided with a view to safeguarding and promoting the welfare' of the child in need. Accordingly this could be to a sibling young carer (if the child in need is, for instance, a disabled child) even if that young carer is not considered to be a 'child in need' in his or her own right.

- 11.9 The practice guidance under the 1995 Carers Act (at para 14) referred to specific guidance⁹⁷ which stated that:

Many young people carry out a level of caring responsibilities which prevents them from enjoying normal social opportunities and from achieving full school attendance. Many young carers with significant caring responsibilities should therefore be seen as children in need.⁹⁸

- 11.10 A key determinant therefore is whether the young carer's caring responsibilities are 'significant'. In this respect the Practice Guidance to the 1995 Carers Act⁹⁹ points out (at para 15.2) that young carers should not be expected to carry out 'inappropriate' levels of caring. It follows that when undertaking a Community Care Assessment of a disabled or ill parent, the local authority must ensure that support mechanisms are put in place to prevent a young carer undertaking unreasonable caring responsibilities - or indeed suffering in any other inappropriate way.

Accordingly if a young carer was unable to get to school, because of his or her parent's disability, then this transport need should be addressed in the parent's community care assessment (see also para 12.5).

- 11.11 Whilst the aim of a carer's assessment under the 1995 Carers Act is to assess the ability of the carer to continue providing care, the guidance emphasises this is not so in relation to young carers. Here the emphasis should be on establishing 'how the disabled person is assisted with his/her care needs and parenting responsibilities and cover whether or how the children might be helping' and ensuring that that 'young carers are not expected to carry inappropriate levels of caring responsibilities.'¹⁰⁰

11.12 The most recent policy guidance concerning the assessment of young carers issued by the Scottish Executive Health Department in relation to guidance for the s9 Community Care & Health Act 2002 states (amongst other things):

Assessing the needs of young carers

The interests of the young person must be at the centre of any young carer's assessment, but the assessment process should consider the whole family situation, and aim as far as possible to provide support to the whole family. Local authorities should:

- consider the whole family situation;
- work directly with other family members, and explain the assessment process and the expected outcomes;
- try to work with the family, though where this proves impossible, remember that the interests of the child must remain paramount.¹⁰¹

Where a young carer is caring for an ill or disabled parent, the assessment and support for the young carer should focus on supporting the parent to live independently so that their capacity to act as a parent is supported, not undermined. Local authorities should:

- focus on enabling ill or disabled parents, or other adults with parental responsibility, to live independently, and supporting their own parenting role;
- ensure that the child's own developmental needs are being adequately met;
- aim to remove inappropriate responsibilities from the child.¹⁰²

Because of the wide range of factors relevant to young carers' needs, their educational development, and the differing needs of the person being cared for, a number of agencies and bodies are likely to have a role to play in young carer's assessments, and effective joint working between these different bodies is vital. Local authorities should:

- ensure close joint working with other bodies to enable a full understanding of the young carer's situation involving: local authority children's services; local authority community care services; local authority education services; the NHS; voluntary sector bodies; school; health or youth workers;

- ensure assessment tools are suitable for children and young people and include opportunities for self-assessment;
- establish agreed protocols for working between bodies, and review them regularly.¹⁰³

12. Parent Carers

- 12.1 People with parental responsibility for a disabled child (i.e. a person aged under 18) are in general entitled to an assessment under Carers (Recognition and Services) Act 1995 and s11 Community Care & Health (Scotland) Act 2002. It is self-evident that most parent carers provide a 'substantial amount of care on a regular basis'. Neither the 1995 nor the 2002 Acts includes a stipulation (found in social security law) that the care provided to a disabled child must (for instance) be 'substantially in excess of the normal requirements of persons of his age'.¹⁰⁴
- 12.2 Parent carers have a right to a separate assessment under the 2002 Act in addition to their needs being fully addressed in their child's Children Act assessment.
- 12.3 Parent carers (like all other qualifying carers) do not have specific rights to have their employment status taken into account in any carer's assessment under current legislation.
- 12.4 The problems that parent carers experience in relation to maintaining employment are considerable, not only due to the substantial demands often made by a disabled child, over and above those made by a non-disabled child. The additional problem concerns the shortage of childcare facilities able to care for disabled children. For example, many working parents can benefit from the existence of 'after-school' clubs to provide childcare - whereas these clubs may not be able (or prepared) to care for disabled children with challenging or specialist needs.

Disabled parents

12.5 A number of research reports¹⁰⁵ have highlighted the problems experienced by parent carers who are themselves disabled. Many encounter particular difficulties in their dealings with the statutory authorities, due to the way these agencies are configured. Not uncommonly the adult and children services will be unclear as to who should take the lead. For example, if a mother's impairment is such that she is unable to arrange for her child to be transported to school - is this a childcare or adult care responsibility? Research has emphasised that although the law can cause confusion in this area, if the legislation is used flexibly, appropriate packages can be delivered. It also emphasised that the approach in such cases should be to:

'think parent' and view disabled parents in the same way as non-disabled parents: the vast majority want to parent their children well. They may require additional support to do this, including where mainstream sources of parenting and family support for non-disabled parents are inaccessible to disabled people.

13. Carers of mental health service users

13.1 People with mental health problems are entitled to a community care assessment, in common with other disabled people. The Mental Health (Care & Treatment) (Scotland) Act 2003¹⁰⁶ provides additional rights for people accessing mental health services and increased safeguards¹⁰⁷. The Act places a duty on local authorities to undertake an assessment of needs where certain conditions are met, and gives patients, their carers and their named persons the right to request an assessment of needs from the local authority or health board;

- it gives all people with mental disorder the right of access to independent advocacy services and puts a duty on Health Boards and Local Authorities to ensure the availability and accessibility of advocacy services;
- it gives patients the right to nominate a named person who has the right to be kept informed of the patient's status in certain circumstances set out in the Act and may act on behalf

of the patient, including making applications and appeals to the Tribunal;

- it gives patients the right to make an advance statement regarding how they would wish to be treated or not treated;
- it provides a framework of safeguards for different kinds of treatment, including neurosurgery for mental disorder and electro-convulsive therapy; and
- it gives patients (and others on their behalf) the right of appeal against detention in conditions of excessive security.

13.2 Under Section 25 of the Act, a local authority has a duty to provide, or secure provision of, care and support services for persons who have or who have had a mental disorder and are not in hospital. They may also provide, or secure provision of, such services to patients who have or have had a mental disorder and who are in hospital. Care and support services include residential accommodation and personal care and personal support, but not nursing care. ¹⁰⁸

13.3 Section 26 of the Act imposes a duty on a local authority to provide, or secure the provision of, services to promote the well-being and social development of persons who have or who have had a mental disorder who are not in hospital. A local authority may also provide or secure the provision of such services for those patients in hospital.¹⁰⁹

These services include:-

- the provision of social, cultural and recreational activities; and
- training and assistance in obtaining and undertaking employment for such of those persons as are over school age¹¹⁰

13.4 Section 27 of the Act places a duty on a local authority to provide facilities for, or assistance with, travel for persons with mental disorder who are not in hospital as that authority may consider necessary to allow such persons to attend and participate in the services provided under sections 25 and 26 outlined above. Local authorities may similarly provide assistance for persons in hospital who have or have had a mental disorder. ¹¹¹

13.5 Carers of people with a mental health problem are entitled to an assessment under the Carers' Acts of 1995 and 2002 (if providing or intending to provide regular and substantial care). Guidance on the 2002 Act¹¹² invites local authorities, when deciding whether or not the carer's role is 'substantial and regular', to consider the fact that 'the carer's role may fluctuate, particularly where the cared-for person has mental health difficulties that recur periodically' when interpreting 'substantial and regular'.

13.6 In addition, Section 1 of the Mental Health (Care & Treatment) Scotland Act 2003 sets out the principles according to which people performing functions under the Act must discharge those functions. These include (as far as it is reasonable and practical to do so):

- taking account of the needs and circumstances of the patient's carer and the importance of providing such information to any carer as might assist the carer care for the patient,
- taking account of 'the views of the patient's named person, carer, and any guardian or welfare attorney so far as it is practical and reasonable to do so.'¹¹³

13.7 Section 2 of the Act requires that any functions under the Act in relation to a child with mental disorder should be discharged in the way that best secures the welfare of the child. In relation to carers, in particular it is necessary to take into account:

- the views of any carers
- the carer's needs and circumstances which are relevant
- the importance of providing any carer with information as might assist them to care for the patient¹¹⁴

13.7 Finally, Section 228 of the Act requires the local authority and/or Health Board to consider the need of a person for an assessment for community care and/or health services when this is requested in writing by either the patient, their primary carer or their named person. The local authority and/or Health Board must respond within 14 days of receiving the request, indicating whether they intend to undertake an assessment, and if not, why not.¹¹⁵

14. Carers and the Human Rights Act

- 14.1 The Human Rights Act 1998 came into force in October 2000, and incorporated the European Convention of Human Rights into UK law. Research from Carers UK shows that carers' may be able to challenge decisions by public authorities that affect their rights under this Act. It is not our intention to detail these rights and potential challenges within this Guide.
- 14.2 However, Carers Scotland and Carers UK have produced a research report 'Whose rights are they anyway? Carers and the Humans Rights Act' together with a summary 'Spotlight on Human Rights' which can provide further information.
- 14.3 For more comprehensive information and advice on the Act and its potential impact on carers, we would recommend contacting an appropriately qualified advisor.

References

1. There are significant differences between this definition and the legal definition of a “disabled person” for the purposes of disability discrimination law (i.e. in relation to employment, access to services, transport and so on)
2. Section 94(1), Social Work (Scotland) Act 1968
3. S8 Disabled Person (Services, Consultation and Representation” Act 1986
4. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department
5. Section 12AA Social Work (Scotland) Act 1968 and Section 24 of the Children (Scotland) Act 1995.
6. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department
7. CCD2/2003 (as above), 2003
8. SWSG11/96: Carers (Recognition & Services) Act 1995: Policy & Practice Guidance, Scottish Office
9. SWSG11/96: Carers (Recognition & Services) Act 1995: Policy & Practice Guidance, Scottish Office
10. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department
11. SWSG11/96: Carers (Recognition & Services) Act 1995: Policy & Practice Guidance, Scottish Office
12. Carnwath J in R v Gloucestershire County Council ex p RADAR (1995) 1CCLR476; [1996] COD 253
13. In the Know: the importance of information for carers, Carers UK, 2006
14. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department
15. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department
16. DHSS Circular 12/70 at para 5
17. Care Management and Assessment - A Practitioners Guide (HMSO 1991) at para 1.3
18. HDL (2006) 22: NHS Carer Information Strategies: Minimum requirements and guidance on implementation, Scottish Executive Health Department
19. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department
20. Section 1(4) Carers (Recognition and Services) Act 1995
21. SWSG11/96: Carers (Recognition & Services) Act 1995: Policy & Practice Guidance, Scottish Office
22. SWSG11/96: Carers (Recognition & Services) Act 1995: Policy & Practice Guidance, Scottish Office at paras 9-10 for adult carers and paras 14-15 for young carers
23. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department
24. CCD2/2003 (as above), 2003
25. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department

26. SWSG11/96: Carers (Recognition & Services) Act 1995: Policy & Practice Guidance, Scottish Office
27. CCD2/2003 (as above), 2003
28. Section 1 Carers (Recognition and Services) Act 1995
29. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department
30. CCD2/2003 (as above), 2003
31. SWSG11/96: Carers (Recognition & Services) Act 1995: Policy & Practice Guidance, Scottish office at para 9.8
32. SWSG11/96 (as above), 1996 at para 9.3
33. HDL (2006) 22: NHS Carer Information Strategies: Minimum requirements and guidance on implementation, Scottish Executive Health Department
34. Princess Royal Trust for Carers, Carers Speak Out Project: Report on findings and recommendations", October 2002
35. Carers UK, Missed Opportunities: the impact of new rights for carers, June 2003
36. HDL (2006) 22: NHS Carer Information Strategies: Minimum requirements and guidance on implementation, Scottish Executive Health Department
37. SWSG11/96: Carers (Recognition & Services) Act 1995: Policy & Practice Guidance, Scottish Office at para 10
38. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department at para 3.5.2
39. Office of National Statistics, Census 2001
40. Carers National Association (now Carers UK), Caring on the Breadline: The financial implications of Caring, 2000
41. Jan Clark, Independence Matters: An overview of the performance of social care services for physically and sensory impaired people, Social Services Inspectorate, 2003
42. Carers National Association (now Carers UK), The True Cost of Caring, Caring Costs, 1996
43. Caring Costs (as above), 1996
44. Inserted by s8 and Schedule 4 Part II of the Employment Relations Act 1999
45. s57A (3) Employment Rights Act 1996
46. s57A (2) Employment Rights Act 1996
47. s47 Employment Act 2002 (which amended Employment Rights Act 1996 primarily by way of the insertion of a new Part 8A to that Act) and see generally the DTI guidance Flexible Working: The right to request and the duty to consider, DTI 2003 at www.dti.gov.uk/er/individual/flexwork-pl520.pdf
48. s12(1b): Work and Families Act 2006 which amends s80F of Employment Rights Act 1996 (statutory right to request contract variation) <http://www.opsi.gov.uk/acts/acts2006/20060018.htm>
49. HDL (2006) 22: NHS Carer Information Strategies: Minimum requirements and guidance on implementation, Scottish Executive Health Department
50. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department at para 7.1.3
51. Carers (Recognition and Services) Act 1995
52. Community Care & Health (Scotland) Act 2002
53. SWSG11/96: Carers (Recognition & Services) Act 1995: Policy & Practice Guidance, Scottish Office at para 9.3

54. R v South Lanarkshire Council ex p MacGregor (2000) 4 CCLR 188
55. Complaint 00/B/00599 3 September 2001; and see also R v Islington ex p Rixon (1996) 1 CCLR 119
56. Complaint 01/C/03521 against North Yorkshire 19 August 2002. [the names used are not the real names]
57. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department at para 7.7.3
58. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department at para 6.7
59. SWSG11/91 Community Care in Scotland: Assessment and Care Management, Scottish Office
60. CCD 8/2001 - Single Shared Assessment of Community Care Needs, Scottish Executive Health Department
61. The Children (Scotland) Act 1995 : Regulations and Guidance : Support and Protection for Children and their Families, Scottish Office www.scotland.gov.uk/library/swsg/index-ls/indexb-e.htm
62. Section 47 (3) National Health Service and Community Care Act 1990
63. Section 47 (3) National Health Service and Community Care Act 1990
64. S12 Community Care & Health (Scotland) Act 2002
65. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department
66. Partnership for Care, Scotland's Health White Paper, Scottish Executive, 2003 www.scotland.gov.uk/Publications/2003/02/16476/18730
67. HDL (2006) 22: NHS Carer Information Strategies: Minimum requirements and guidance on implementation, Scottish Executive Health Department
68. HDL (2006) 22: NHS Carer Information Strategies: Minimum requirements and guidance on implementation, Scottish Executive Health Department at para 3.3.1
69. HDL (2006) 22 (as above), 2006 at para 3.13.3
70. HDL (2006) 22 (as above), 2006 at para 3.13.3
71. Unless they are entitled to continuing health care support, detailed under the Mental Health Act or have been in NHS accommodation for a prolonged period - such that it might be deemed their "home" for the purposes of Article 8 of the ECHR
72. MEL (1996) 22, NHS responsibility for continuing health care, Scottish Executive Health Department www.show.scot.nhs.uk/sehd/mels/1996_22.pdf.
73. SWSG 10/98 Community Care Needs Of Frail Older People: Integrating Professional Assessments And Care Arrangements, Scottish Office www.scotland.gov.uk/library/swsg/index-f/c216.htm
74. SWSG 10/98 (as above), 1998 at para 32
75. MEL (1996) 22 (as above), 1998
76. CCD 9/2003 - Framework For The Production Of Joint Hospital Discharge Protocols, Scottish Executive Health Department at para 10 www.sehd.scot.nhs.uk/publications/CC2003_09.pdf
77. CCD 9/2003 - Framework For The Production Of Joint Hospital Discharge Protocols, Scottish Executive Health Department - Annex "Hospital Discharge Protocols: Checklist of minimum requirements", 13

78. HDL (2006) 22: NHS Carer Information Strategies: Minimum requirements and guidance on implementation, Scottish Executive Health Department at para 3.3.2
79. HDL (2006) 22 (as above), 2006 at S6, para 1
80. HDL (2006) 22 (as above), 2006 at para 3.4.2
81. CCD1/2006, Revised guidance on charging for residential accommodation, Scottish Executive Health Department at para 4.001 www.show.scot.nhs.uk/sehd/publications/CC2006_01.pdf
82. S8-12 Community Care & Health Scotland Act (2002) at para 7.73
83. Guidance on charging policies for non-residential services that enable people to remain in their own home, CoSLA, January 2006
www.cosla.gov.uk/attachments/execgroups/sh/shchargingguidance2006.doc.
84. SWSG 1/97 Charging for Non Residential Sector Care, Scottish Office
www.scotland.gov.uk/library/swsg/index-f/c172.htm
85. s 62, Adult Support and Protection (Scotland) Act 2007
86. CCD1/2006 (see above), 2006, Chapter 7
87. "Relative" is specified as including: parents, parents-in-law, sons, sons-in-law, daughters, daughters-in-law, step parents, stepsons, stepdaughters, brothers, sisters, grandparents, grandchildren, uncles, aunts, nephews, nieces and the spouse or unmarried partners of any except the last give (para 7.004). The relevant point here is that this is an inclusive definition rather than an exclusive one.
88. The meaning of "incapacitated" is not defined by regulations by CRAG suggests that it includes a person receiving (or whose incapacity is sufficient to that required to qualify for) one of the following: "incapacity benefit, severe disablement allowance, disability living allowance, attendance allowance, constant attendance allowance, or an analogous benefit". Again this is an inclusive rather than exclusive definition (para 7.005).
89. Regulations Sch4, para 18
90. CCD13/2004, Deferred payments and other funding arrangements which allow care home residents to delay selling their homes, Scottish Executive Health Department.
www.show.scot.nhs.uk/sehd/publications/CC2004_13.pdf
91. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department
92. SWSG11/96: Carers (Recognition & Services) Act 1995: Policy & Practice Guidance, Scottish Office at para 8
93. See for instance R v Kensington & Chelsea RLBC ex p Kujitm (1999) 2 CCLR 340 at 3451 and R (Patrick) v Newham LBC (2000) 4 CCLR 48
94. Complaint No. 03/C/16371 against Stockton on Tees Borough Council, 18 January 2005, para 13.
95. Valuing People, para 5.7 and see also Circular HSC 2001/1=016: LAC(2001)23 para s 37 & 38
96. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department at para 9.5.1
97. Guidance letter CI (95) 12 Annex A, para 1.1
98. See also Chapter 6, para 20 of Volume 1, Children (Scotland) Act 1995 Regulations and Guidance "Support and Protection for Children and Families" which emphasises that children should not be expected to take on similar level of caring responsibilities as adults.
99. SWSG11/96: Carers (Recognition & Services) Act 1995: Policy & Practice Guidance, Scottish Office at para 15.2
100. SWSG11/96: Carers (Recognition & Services) Act 1995: Policy & Practice Guidance, Scottish Office at para 15.2 & 15.3

101. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department at para 9.7.1
102. CCD2/2003 (as above), 2003 at para 9.6.1
103. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department at para 9.11.1
104. s72(6) Social Security Contributions and Benefits Act 1992
105. See for instance the Social Services Inspectorate report, A Jigsaw of Services (2000) www.dh.gov.uk.assetRoot/04/01/99/04011199.pdf and Olsen, R and Tyres H, Supporting disabled adults as parents (2004) National Family and Parenting Institute Ref N34 www.jrf.org.uk/knowledge/findings/socialcare/n34.asp
106. Mental Health (Care & Treatment) (Scotland) Act 2003 www.opsi.gov.uk/legislation/scotland/acts2003/20030013.htm
107. A short introduction to the Mental Health Act, Scottish Executive Mental Health Law Team at Section C5 www.scotland.gov.uk/Publications/2005/07/22145851/58527
108. Volume 1 of the Code of Practice for the Mental Health (Care and Treatment) (Scotland) Act 2003, Scottish Executive (2005) at Chapter 2, part 4 www.scotland.gov.uk/Publications/2005/08/29100428/04289
109. Volume 1 of the Code of Practice (as above) at Chapter 2, part 4
110. Volume 1 of the Code of Practice (as above) at Chapter 2, part 4
111. Volume 1 of the Code of Practice (as above) at Chapter 2, part 4
112. CCD2/2003 Community Care & Health (Scotland) Act 2002: New Statutory Rights for Carers: Guidance, Scottish Executive Health Department at para 3.5.2
113. Volume 1 of the Code of Practice for the Mental Health (Care and Treatment) (Scotland) Act 2003, Scottish Executive (2005) at Chapter 1, paras 1-9
114. Volume 1 of the Code of Practice for the Mental Health (Care and Treatment) (Scotland) Act 2003, Scottish Executive (2005) at Chapter 1, para 26
115. Volume 1 of the Code of Practice for the Mental Health (Care and Treatment) (Scotland) Act 2003, Scottish Executive (2005) at Chapter 7, para 08

Action for Carers and Employment

Action for Carers and Employment (ACE) is a partnership initiative led by Carers UK, which works to support the inclusion of carers in training and work.

In Scotland, the initiative is led by Carers Scotland and was supported by the Equal Opportunities Commission and the Association of Directors of Social Work.

ACE is funded by the European Social Fund's Equal Community Initiative Programme.

A range of stakeholders have contributed to the initiative:

- work with employers to promote and develop flexible working policies
- work with health and social care providers to promote and develop flexible alternative care services and to promote change in the ways that carers are involved in the design, development, delivery and review of services.

The Action for Carers and Employment Project has produced a range of information for employers and carers which is available at:

www.carerscotland.org/employersforcarers

www.carerscotland.org/policyandpractice/workingforcarersandemployment

www.acecarers.org

CARERS Scotland
the voice of carers

Carers and their Rights

A guide to the law relating to carers

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This information is correct as of May 2007.

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