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Health Department  
Directorate of Primary and Community Care

Dear Colleague

## NHS CARER INFORMATION STRATEGIES: MINIMUM REQUIREMENTS AND GUIDANCE ON IMPLEMENTATION

### 1. INTRODUCTION

**Definitions.** In this letter and in its Annexes, the following terms are used:

“**Strategy**” means an NHS Carer Information Strategy

“**the 2002 Act**” means the Community Care and Health (Scotland) Act 2002

“**the 1968 Act**” means the Social Work (Scotland) Act 1968

“**the 1995 Act**” means the Children (Scotland) Act 1995

“**carer**” means a person of any age who provides, or intends to provide, care on a regular and substantial basis, as defined in section 12AA of the 1968 Act and section 24 of the 1995 Act. That is, carers of any age caring (or intending to care for) adults or disabled children.

### Purpose of this HDL

1.1 This HDL relates to the preparation and submission by Health Boards of NHS Carer Information Strategies for carers who may have rights under section 12AA of the 1968 Act and/or section 24 of the 1995 Act. That is, carers of any age caring, or intending to care, for adults or disabled children. There are 3 purposes to this HDL:

- to introduce a legal requirement on NHS Boards to prepare and submit to Ministers an NHS Carer Information Strategy;
- to provide statutory guidance linked to that requirement; and
- to provide additional best practice recommendations on how to develop and implement a Strategy.

24 APRIL 2006

#### Addresses

##### For action

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LA Chief Executives

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## Legal Requirements and Best Practice Recommendations

1.2 This letter places a legal obligation on each NHS Board under section 12 of the 2002 Act to:

- prepare and submit an NHS Carer Information Strategy to Scottish Ministers by **31 October 2006**;
- to meet in that Strategy the minimum requirements set out in Annex A to this letter; and
- to engage with carers, carer organisations, local authorities and other stakeholders in developing a Strategy, as required in Annex A.

1.3. Annex A to this letter sets out for easy reference, the minimum requirements that a Strategy must meet. It also suggests additional best practice recommendations that Boards might wish to include in their Strategy, in line with established good practice and Scottish Executive policies on health and social care. These requirements and recommendations are also set out in the main body of the statutory guidance which is attached at Annex B to this letter.

## Statutory Guidance

1.4. Annex B provides statutory guidance (issued by the Scottish Ministers under section 26 of the 2002 Act) to NHS Boards on:

- the purpose, background and policy context to such Strategies
- the scope, format and content a Strategy should take
- how a Strategy needs to be developed in consultation with stakeholders
- general principles that should underpin a Strategy
- how a Strategy should operate within differing spheres of NHS activity
- training issues for NHS staff
- training issues for carers
- accountability and monitoring arrangements
- timescales for submitting a Strategy

### PLEASE NOTE

**This HDL does not apply to professional carers or carers providing care as a volunteer for a voluntary organisation. "Professional carers" covers carers who provide (or will provide) care under a contract of employment or a contract for services.**

## 2. NHS RESPONSIBILITIES TO CARERS

2.1 HDL (2006) 12 *Delivering For Health: Guidance on Implementation* sets out how the NHS should implement the plan for Scotland's health, *Delivering for Health*, and sets out key goals in Section 2. It states that the delivery of these goals will require an integrated model of health service delivery which provides care as locally as possible; provides systematic support for people with long term conditions and their carers; reduces the health inequality gap and actively manages hospital admissions. It also recognises that systematic support for people with long term conditions and their family carers will have a direct effect in minimising hospital re-admissions, emergency admissions and delayed discharge and reducing pressure on primary care.

2.2 NHS Carer Information Strategies and key aspects of *Delivering for Health* are intended to deliver more effective partnership working between the NHS and family carers by recognising the role of carers as key partners in the provision of care and as the largest component of the Scottish care 'workforce'. This key role is fully understood by the Executive and supporting carers is central to our health and social care agenda.

## 3. PARTNERSHIP

3.1 NHS Boards are required to develop and implement NHS Carer Information Strategies. Increased joint working with local authorities, the voluntary sector, patients and carers through Community Health Partnerships and the Joint Future Agenda requires NHS Boards to work collaboratively with these partners in order to deliver integrated, person-centred care. NHS Carer Information Strategies are to be developed within this partnership approach.

## 4. ACCOUNTABILITY

4.1 Under an NHS Carer Information Strategy, and its associated monitoring arrangements, the Scottish Executive will expect to see strong evidence of progress across the NHS in identifying carers, providing them with information and signposting them to local carer support agencies. Boards should also be able to demonstrate that carers are being provided with appropriate information by NHS staff and professionals throughout the patient/carer journey, as already happens in areas of good practice. To ensure this is delivered a Strategy requires accountable managers within the NHS to be identified and annual progress reports to the Executive.

## 5. RESOURCES

5.1 The NHS already provides information to patients and carers, under the Patient Focus and Public Involvement agenda. Much of the information that carers need is already available, particularly through local carer support groups and national organisations working in the voluntary sector. The Executive recognises that there are resource implications for the NHS in terms of staff training and for training carers. However, some Boards have already taken steps to make staff "carer aware" through existing training modules and through innovative changes to work practices. There is also clear evidence that supporting carers can lead to significant and immediate resource savings for the NHS in key clinical areas; the guidance attached to this HDL highlights this.

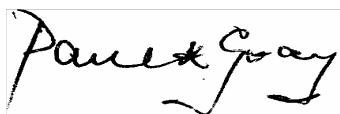
5.2 In recognition of this, the Executive expects, as it does for implementation of *Delivering for Health*, that action can be taken within current spending plans to re-direct existing resources towards preventative support for patients and carers to both improve patient/carer health and to realise savings elsewhere. We recognise that the pace of implementation of local Carer Information Strategies will depend on the extent to which such re-direction is possible. In developing their Strategies, NHS Boards are expected to prioritise those actions expected to achieve the greatest benefits for carers within the lifetime of the Strategy (3 years). Future implementation will need to be considered in the context of Boards' success in implementing preventative support as well as future public spending plans. As existing NHS staff are trained in carer awareness and as new staff are similarly trained through core curricula the training requirements on Boards should lessen over time.

5.3 NHS Education Scotland (NES) has indicated that it will use this guidance to inform its future educational planning cycles. NES is keen to support this agenda through its educational quality assurance programmes and through a variety of Continuing Professional Development Initiatives. The Executive will engage with NES over the summer of 2006 to take this forward. We will also work to ensure that carer awareness is integrated systematically into the core curriculum for trainee/graduate health and social care staff.

## 6. CONCLUSION

6.1 This letter will be supplemented shortly with a further letter highlighting examples of good practice in identifying, signposting and referring carers, including practice models from Boards already engaged in this activity.

6.2 I would ask that Chief Executives take forward the development of NHS Carer Information Strategies in line with this letter and also in line with the messages contained in *Partnership for Care* and *Delivering for Health* about the importance of supporting carers. Please accept my thanks for your support in this important initiative.

A handwritten signature in black ink, reading "Paul Gray", enclosed in a thin black rectangular border.

PAUL GRAY  
Director of Primary Care and Community Care

**NHS CARER INFORMATION STRATEGY: MINIMUM REQUIREMENTS**

Background

1. Under section 12(1) of the Community Care and Health (Scotland) Act 2002 (“the 2002 Act”), the Scottish Ministers may require any NHS Board to **prepare and submit to them a Strategy** for:

(a) informing carers who appear to the Board to be persons who may have rights under section 12AA of the Social Work (Scotland) Act or section 24 of the Children (Scotland) Act 1995 that they may have such rights; and

(b) ensuring that information about such rights is available **free of charge** to carers.

2. In requiring an NHS Board to prepare a carer information strategy, the Scottish Ministers may specify:

(a) the **date by which the strategy is to be submitted** under section 12(1) or the period within which it is to be prepared under section 12(1);

(b) the **form and extent of the strategy** and (subject to section 12(1)) the matters which it is to include;

(c) the **consultation that the NHS Board must undertake** in preparing the strategy; and

(d) the **period** to which the strategy is to relate.

Requirements

3. The Scottish Ministers require NHS Boards under section 12(1) of the 2002 Act to prepare and submit a Carer Information Strategy (a “Strategy”) to them by **31 October 2006**. For the purposes of section 12(2) the following specifies matters which each Strategy **must** include and other best practice recommendations which we recommend are included in a Strategy.

Links to Annex B

4. Annex A lists the minimum requirements of an NHS Carer Information Strategy, and suggested best practice recommendations for ease of reference. These requirements and recommendations are repeated in appropriate sections of the full guidance, attached at Annex B. The reason for repeating them in Annex B is so that they can be explained in context of the relevant policy background.

## **Minimum Requirements**

### **1. General**

**As a minimum an NHS Carer Information Strategy must:**

- identify work already done with local partners to develop a joint information strategy for carers
- specify arrangements for the involvement of carers, carer organisations, local authorities and other key stakeholders in developing and reviewing the NHS Carer Information Strategy
- specify arrangements for involving young carers, through local organisations/bodies representing young carers, in developing and reviewing the NHS Carer Information Strategy
- specify arrangements for the involvement of carers from minority ethnic groups and other equality groups in developing and reviewing the NHS Carer Information Strategy

### **2. Content**

**As a minimum an NHS Carer Information Strategy must:**

- demonstrate how NHS Boards have identified, in discussion with carers, carer organisations, the wider voluntary sector and local authority partners:
  - the information carers need;
  - how it will be provided; and
  - by which lead agency
- describe how local joint agreements on issues of consent have been reviewed in order to ensure that they adopt the principles set out in the NHS Carer Information Strategy and facilitate the proactive provision of information to carers.
- develop strategic proposals to address the identification and information needs of specific carer groups such as young carers and carers from minority ethnic communities.
- ensure that NHS staff as a minimum are able to signpost carers that they come across on their day to day duties to a local carer support agency and, if patient confidentiality allows, to appropriate national organisations supporting patients, users and carers for specific conditions. For example: Alzheimer Scotland, National Schizophrenia Fellowship (Scotland), MS Society (Scotland), Parkinson's Society (Scotland).

### 3. Delivery In NHS Operating Systems

#### As a minimum an NHS Carer Information Strategy **must**:

- describe the practical steps which will be taken to deliver the NHS Carer Information Strategy objectives systematically throughout the Board area
- describe how each NHS operating sphere/service and joint arrangements with local authorities, the voluntary sector, and private sector will support the objectives of the NHS Carer Information Strategy
- demonstrate how NHS Boards are promoting carer identification and the provision of targeted information to carers by GPs and Primary Care staff. This should demonstrate the link between practice involvement and the GMS contract Quality and Outcomes Framework, Practice Management Indicator 9 involving carer identification and referral as well as activity to set up carer registers in line with the Direct Enhanced Services Directions 2006.
- demonstrate how hospital staff ensure that carers are routinely identified and given targeted information and how staff ensure that carers are signposted to appropriate support services and made aware of their right to an assessment
- set out how carer identification, the provision of targeted information to carers, carer signposting on to sources of advice and support, and advising carers of their right to an assessment is integrated into hospital discharge procedures and admission procedures
- set out how NHS Boards are making community-based pharmacists aware of their role in supporting the Strategy.

### 4. NHS Staff Training

#### As a minimum an NHS Carer Information Strategy **must**:

- set priorities for staff training in agreement with local partners, including carers, carer organisations and local authorities.
- include detailed action plans for the training of staff over the lifetime of the Strategy, outlining how carer awareness, carer identification, the provision of information to carers, advising carers of their right to an assessment, carer signposting to sources of advice and support and working with carers as key partners are being mainstreamed into NHS practice; specifically through induction programmes, pre-qualification professional training, continuous personnel development and professional training and leadership development
- include in action plans details on training for staff on culturally-sensitive issues for carers from minority ethnic communities
- include in action plans details on training for staff on issues relating to young carers

## 5. Training For Carers

**As a minimum an NHS Carer Information Strategy must:**

- identify in partnership with local authorities and local carer support agencies what training already exists for carers and how this will be developed and extended over the lifetime of the Strategy
- identify proposals for the development of a strategic approach to ‘expert carer’ training, aimed directly at supporting carers in their caring role and targeted specifically at carers with intensive, or potentially growing, caring responsibilities.
- set priorities for carer training in agreement with local partners, including carers, local carer support agencies and local authority partners. In doing so local training partners should explore the role of further education establishments and existing carer training packages, as well as the delivery of training using IT systems and technology.
- demonstrate delivery of person-centred training for carers, covering advice on physical and emotional well-being including demonstrations on moving and handling techniques (if appropriate) and stress management, and advice on specific conditions such as caring for someone with dementia, physical disabilities, mental health problems, special needs, etc

## 6. Accountability

**As a minimum an NHS Carer Information Strategy must:**

- identify a lead officer at General Manager or Senior Manager level to promote carer identification and information with responsibility to ensure effective development and implementation of the NHS Carer Information Strategy. Links with the Patient Focus and Public Involvement Designated Director should be a priority
- identify specific staff within primary care, acute staff and nursing teams to promote carer identification and to take responsibility for the provision of information to carers.
- indicate management and leadership arrangements with front-line staff
- specify functions and services which will be contracted to various key partners, eg, local authorities, voluntary sector organisations and the private sector

## 7. Monitoring

**As a minimum an NHS Carer Information Strategy must:**

- provide baseline information against which quality improvements can be measured
- identify joint performance indicators and outcomes for carers
- set out how Boards have worked work in partnership with carers, patients, NHS staff, local authorities, the voluntary sector and other relevant groups to agree indicators/outcomes and monitoring systems.

- demonstrate that NHS staff are aware of the need to identify carers and to signpost them to sources of support/advice
- set out arrangements to monitor and evaluate implementation of this Guidance – setting out auditing and accountability arrangements within the NHS and on a joint basis with local authorities, the voluntary sector and if appropriate the private sector
- set out how monitoring arrangements fit in with accountability for other areas such as Community Health Plans, Patient Focus and Public Involvement Action Plans, Hospital Discharge Guidance, Local Partnership Agreements, etc.
- ensure that effective monitoring arrangements are in place to establish accessibility to information for carers from minority ethnic groups, in line with the requirements of the Race Relations (Amendment) Act 2000 and Boards’ Race Equality Schemes.
- set out proposals for reviewing the NHS Carer Information Strategy in consultation with carers and other stakeholders
- ensure annual reports to Scottish Executive Ministers, on how Boards are implementing and evaluating their NHS Carer Information Strategy and setting out progress. Reports must be jointly signed by the NHS Board Chief Executive, the relevant local authority Chief Executive and representatives of the main carer groups/organisations operating within the NHS Board area. Such reports and the Strategy should be made publicly available, free of charge, to any person requesting them.

## **Best Practice Recommendations**

### **8. Policy Context**

**This guidance makes a best practice recommendation that an NHS Carer Information Strategy should set itself in context with other policies by including:**

- a description of how the Strategy sits alongside other key policies such as Patient Focus and Public Involvement, Delivering for Health, Joint Future, Partnership for Care, Community Health Partnerships, Health Improvement and the new Quality Improvement Framework for Children’s Services.
- a description of how the Strategy sits within jointly-developed local carers strategies, including young carer strategies
- a description of how the Strategy ensures that it supports equality responsibilities including Fair for All and requirements to implement Race Equality Schemes
- a description of the mechanisms in place that would initiate joint action with partner agencies when the Strategy identifies young carers who may appear to NHS staff to be at risk because of their caring role, or other associated factors.

## 9. General Principles

This guidance makes a **best practice recommendation** that an NHS Carer Information Strategy should contain a statement of general principles to underpin the Strategy, including:

- statements of principle recognising and treating carers as key partners in the provision of care. These statements should reflect the different position of young carers who must be engaged, consulted with, particularly in terms of developing the Strategy, and supported but not viewed as key care providers
- a statement of commitment that all levels of the NHS will work in partnership with carers in line with *Delivering for Health* and *Partnership for Care*.
- a statement which recognises the statutory duty placed on NHS Boards by the 2002 Act in relation to informing carers of their right to an assessment and the requirement contained in Patient Focus and Public Involvement Action Plans to have a Strategy that meets the information needs of patients, relatives and carers
- a principle of accessibility, ensuring that information is provided to carers in a wide range of formats and languages, enabling all carers to access information irrespective of their age, disability, ethnicity or other specific needs
- a statement of commitment to ensuring that information and support is available and accessible to carers from black and minority ethnic communities, as required under the Race Relations (Amendment) Act 2000 and *Fair for All*
- a statement of commitment to the principles of equality and diversity

## 10. Carer Referral

This guidance also makes a **best practice recommendation** that:

- where a carer appears to the Board to have a significant caring role, NHS staff formally refer such carers on to appropriate sources of support, ie local carer support agencies.

## **NHS Carer Information Strategies: Guidance**

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**Section 6 - Carers' Information Needs**

## **1. SECTION 1 – PURPOSE AND BACKGROUND**

### **1.1 Purpose**

1.1.1 This guidance is designed as a tool for NHS Boards to enable them to implement the requirement by Scottish Executive Ministers that they develop and put in place an NHS Carer Information Strategy.

1.1.2. This guidance should be read in conjunction with Scottish Executive Circular CCD2/2003: *The Community Care and Health (Scotland) Act 2002: Carers – Guidance on Sections 8-12*. CCD2/2003 can be found at [www.show.scot.nhs.uk/sehd/ccd.asp](http://www.show.scot.nhs.uk/sehd/ccd.asp).

1.1.3 Its 6 sections set out:

- the background and purpose of the guidance
- the legislative and policy context which underpins and informs the requirement to develop an NHS Carer Information Strategy
- the format and content that an NHS Carer Information Strategy should take, including minimum requirements, a timetable for delivery and monitoring arrangements
- the existing legal definition of a carer
- guidance interpreting ‘regular and substantial’ care which helps to underpin the legal definition of a carer
- a checklist of carers’ information needs

### **1.2 Background to the Guidance**

1.2.1 Initially prepared by an Executive led stakeholder working group, draft guidance was issued for consultation in August 2004. Responses (78 in total) were received from local authorities, NHS Boards, health professional bodies, carer organisations and the wider voluntary sector as well as from individuals. Many of the comments made have been taken on board in producing this final guidance.

### **1.3 Who are Carers?**

1.3.1 A carer is:

- a person of any age, who looks after family, partners or friends in need of help because they are ill, frail or have a disability and need support to live independently.
- someone who provides unpaid care.

1.3.2 Carers can be:

- adults supporting adults
- young carers caring for adults or another young person, or
- carers of children with disabilities, whether the carer is a parent or not.

1.3.3 The support a carer provides may include:

- moving and handling
- help with feeding
- personal hygiene
- administering medication
- emotional support
- assistance with life-skills
- acting as an advocate or guardian for the cared-for person
- helping someone to access leisure and recreation.

1.3.4 Carers are defined in legislation (see Section 4) as people providing a substantial amount of carer on a regular basis. The application of ‘regular and substantial’ is designed to ensure that only carers with substantial caring roles have the right to a ‘carers assessment’, as a gateway to securing practical support from the statutory agencies. ‘Regular and substantial’ has never been defined legislatively. Interpretation of ‘regular and substantial’ has been left to professionals on the ground to decide, based on the individual circumstances in each case and taking into account a wide range of factors. This inevitably requires some form of preliminary screening to explore the caring role and the impact of that on the carer.

1.3.5 Professional carers and family members looking after children without disabilities or long-term health conditions are not included in the definition of carer, as used in this guidance.

## **1.4 Carer Statistics**

1.4.1 The 2001 Census identified 480,000 carers in Scotland of a total population of 5,000,000 - approximately 12% of the adult population. Most are aged between 45 and 64. 62% are women and 7% are parent carers. Approximately 50% look after someone over 75. 49% combine caring and employment (either full or part-time). 26% are retired and a further 25% are not in paid employment. In Scotland 63% of carers (310,000 people) care for up to 19 hours a week; 12.5% of carers (60,000 people) care for 20-49 hours per week; and 24% of carers (115,000 people) care for over 50 hours per week.

1.4.2 The National Census of 2001 identified in Scotland over 16,000 young carers under the age of 18 who are providing care at home. It is thought this figure could be higher, as it is unlikely that the Census identified young carers who care for others as a result of drug/alcohol misuse in the family or those who care for parents with mental health problems. A recent survey in the Highlands, for example, found that 10% of secondary school children provide care at home to a relative.

1.4.3 The 2001 Census recorded a minority ethnic carer population of 6,800, but local data suggests a significant under-enumeration of minority ethnic carers. Language and concepts around unpaid care may not be well understood within minority communities. It may also be more difficult to identify carers because of these communities' relative dispersal, the under-development of community services/networks and a lack of engagement with mainstream services and service planners. Little is also known about carers from white minority communities such as Eastern Europeans and Italians as well as carers within Scottish gypsy traveller communities who are also likely to face barriers to identification and support.

## **1.5 Demographic Trends**

1.5.1 Scotland's population is becoming healthier and people are living longer healthier lives. Despite that and continued progress in health technology and treatment, the next 10-20 years will inevitably bring a sizeable increase in the numbers of older people requiring care at home and in the community. This will mean a rise in the overall number of unpaid carers and in the number of carers who are themselves elderly. Research by Carers UK estimates a 60% increase in the number of carers across the UK by 2037, resulting from an increasingly older population. The Care 21 Report: *The future of unpaid care in Scotland, Delivering for Health and Changing Lives*, the findings of the Executive's 21<sup>st</sup> Century Social Work Review, all acknowledge the increasing importance of unpaid care in the years to come as a means of supporting self care and self management of people with support needs.

## **1.6 Impact of Caring**

1.6.1 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. Carers in Scotland providing high levels of care are a third more likely to suffer ill health than non-carers. Nearly 60,000 carers in Scotland say they are in poor health (Carers UK, 2004). Young carers are twice as likely as their peers to have mental health issues. 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 a long periods. Without additional support, severe strain is often placed on the wider family, impacting on the development of other siblings. Often children with complex needs are looked after by a single parent, as a result of a marital or partnership breakdown.

1.6.2 Research and recent policy developments acknowledge the occupational hazards of caring, particularly for those family carers providing over 20 hours of care a week. 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. The need to support carers was recognised by the Executive in its guidance to statutory agencies, on the carers' legislation in Scottish Executive Circular CCD/2003: *Community Care and Health (Scotland) Act 2002: Carers – Guidance Sections 8-12*. Providing carers with appropriate information and support early in their caring role requires early identification, particularly through local health agencies.

## 2. SECTION 2 – POLICY CONTEXT

### 2.1 Aims

2.1.1 This Section sets out the legislative background to the introduction of NHS Carer Information Strategies and highlights key policy drivers related to improving carer support. Supporting carers and involving them in the partnership of care is a key element of the Scottish Executive's health and social care agenda. It is also in line with the Executive's priorities of social inclusion, reducing health inequalities and building better communities.

2.1.2 The unpaid care workforce is the single largest provider of care to people with support needs in our communities. The Executive acknowledges that without their contribution, statutory agencies would face considerable, and perhaps unmanageable, pressures. Scotland is in many ways leading the UK in its policies to support carers, as recognised by the 2005 Care 21 Report *The future of unpaid care in Scotland*, particularly with the Executive's recognition that carers are key partners in the provision of care. The report however found a sizeable gap between policy and delivery of support, which will need to be addressed.

2.1.3 *Delivering for Health*, the Executive's response to Professor Kerr's report *Building a Health Service Fit for the Future*, sets out a programme of action for the NHS to shift the balance of care and to secure health improvement by prioritising preventive and proactive care. The report recognises the role of carers in supporting the health and welfare of those they care for. In addition to providing health care, carers help to promote independence, prevent or delay admissions to hospital or care homes and facilitate early and effective discharge from hospital.

2.1.4 *Building a Health Service Fit for the Future* and *The Future of Unpaid Care in Scotland* both recognise the growing evidence that caring can affect carers' own health and that the health of a carer is increasingly at risk as their caring responsibilities increase. Female carers with the greatest responsibilities have a 60% higher chance of experiencing distress than non-carers, with the risk increasing with the intensity of caring (Hirst, 2004). Carers in Scotland providing high levels of care are a third more likely to suffer ill health than non-carers. Nearly 60,000 in Scotland say they are in poor health (Carers UK, 2004).

2.1.5 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 support carers to access leisure opportunities and breaks from caring. The provision of free flu jabs for carers in Scotland is an example of a public health initiative being taken to support carers' health. The impact of caring on the health of young carers and carers from minority ethnic communities require specific consideration to ensure appropriate health-promoting initiatives which are sensitive to age, culture and family circumstances.

The Executive's vision for carers is to:

- Facilitate early identification of carers by health and social work agencies. Thereby improving access by carers to the information and services that they need to help them to care, in order to protect their own mental and physical health. This needs to be done across adult and children's services.
- Ensure that carers receive earlier and more planned support, through local partnerships involving local authorities, the NHS, the voluntary sector and the private sector.
- Create cultural change so that carers are empowered in the decision making processes around care management and at a strategic level in service planning and delivery.
- Ensure that carers' issues are mainstreamed into the everyday working practices of social work and NHS staff, to ensure that staff work with carers in effective partnership both to support the carer but also to maximise patient/user care.

## 2.2 Key Principles

2.2.1 The following 2 key principles lie at the heart of Executive policies to support carers and the people they care for. They are set out below in an NHS context and should underpin the development and implementation of all NHS Carer Information Strategies.

### 2.3 Partnership

2.3.1 The Scottish Executive recognises carers as key partners in the provision of care. This principle was most recently set out in November 2005 in *Delivering for Health* which commits NHS Scotland to developing systematic support for patients and their carers to facilitate self-care.

### 2.4 Prevention

2.4.1 Prevention of ill-health and the development of self-care management are essential strategic components to shifting the balance of care, preventing hospital admission and improving quality of life. Carers are vital partners in achieving these objectives. Physical health, emotional well-being and appropriate support are all important for carers to cope with the caring task, with direct benefits for the quality of care and the health of the cared-for person.

## 2.5 *Strategy for Carers in Scotland*

2.5.1 Supporting carers has been a key priority for the Executive since its *Strategy for Carers in Scotland* ('Carers Strategy') was published in November 1999. The Carers Strategy continues to provide a national framework for delivering improved support to carers,

predominantly through the development of local support services and the provision of improved information to carers.

2.5.2 The Carers Strategy has helped to deliver change through the development of local carer strategies, developed and implemented in partnership by local authorities, NHS Boards, and carer organisations/groups. Outcomes include improved local infrastructures for carer support, and improved joint partnerships with carers, and carer organisations, on care management and service planning.

## **2.6 *Community Care and Health (Scotland) Act 2002***

2.6.1 The commitment in the Carers Strategy for new legislation was fulfilled when Sections 8-12 of the *Community Care and Health (Scotland) Act 2002* ('the 2002 Act') came into force in September 2002. The 2002 Act enhanced existing legislative duties to:

- Give 'substantial and regular' carers an independent right to have their support needs as carers assessed by local authorities, or other agencies under Single Shared Assessment, irrespective of whether or not the cared-for person chooses to be assessed. (See Section 5 for guidance on the way that 'substantial and regular' is interpreted).
- Extend this right to an independent assessment to young carers, aged under 18.
- Require local authorities to notify those carers they encounter in their day-to-day duties of their right to an assessment.
- Require local authorities to take account of a carer's contribution and views before deciding what services to provide to the cared-for person.
- Provide Scottish Executive Ministers with the power to require NHS Boards to put in place an NHS Carer Information Strategy.

## **2.7 *Partnership for Care***

2.7.1 *Partnership for Care*, the Scottish Executive's White Paper on Health, published in February 2003, reaffirmed the need to work in partnership with carers at all levels within the NHS. It stressed that "the vital role of carers as major care providers must be recognised at all levels in the NHS and staff must work closely with carers as partners in providing care".

2.7.2 *Partnership for Care* recognised the importance of carers having appropriate and targeted information about sources of support and advice. It stressed too the need for information to help carers deal with the condition/treatment of the person they care for, whilst respecting patient confidentiality. The importance of such information to carers of people with mental health problems has already been recognised in the Mental Health (Care and Treatment) (Scotland) Act 2003.

## **2.8 *Delivering for Health***

2.8.1 Professor Kerr's report *Building a Health Service Fit for the Future*, published in May 2005, and the Executive's response *Delivering for Health*, November 2005, recognise the important relationship between Scotland's NHS and unpaid carers. Both stress the need for better carer support to achieve shared national objectives: better health and care provision in the community, increasing emphasis on self care, and reduced NHS and social care intervention.

2.8.2 *Building a Health Service Fit for the Future: Chapter 5: Self-care, carers, volunteering and the voluntary sector* sets out that the NHS should take the following steps to support carers:

- Make carers' health a public health issue
- Implement fully NHS carer information strategies
- Encourage carer participation and partnership involvement in planning
- Develop and provide carer training ('expert carer training')
- Build carer awareness into professional training

2.8.3 The impact of these commitments on the development of local NHS Carer Information Strategies is addressed in Section 3 of this Guidance.

## **2.9 *Care 21 Report: The future of unpaid care in Scotland***

2.9.1 The Care 21 Report *The future of unpaid care in Scotland*, (September 2005), endorses the principals of NHS Carer Information Strategies, and recommends their full implementation as soon as possible (Recommendation 6). It also contains recommendations that would be delivered in part through the objectives set out in this guidance:

- the creation of a national expert carer training programme (Recommendation 4)
- frontline staff to advise carers about their rights as well as sources of support (Recommendation 5)
- training for health and social care staff to include carer awareness elements (Recommendation 7)
- Scottish Executive, local authorities, NHSScotland and partner agencies to focus on the health of unpaid carers (Recommendation 16)
- a call for the recommendations of the report to be incorporated into providers' performance management systems and progress monitored by the Executive (Recommendation 21)

2.9.2 The Report contains 22 recommendations aimed at the Scottish Executive, the UK Government, local authorities, the NHS and the voluntary sector, which are designed to deliver improved carer support over the next 10 years. The Executive will respond to the report in spring 2006.

## **2.10 *Changing Lives: Scottish Executive's 21<sup>st</sup> Century Social Work Review***

2.10.1 *Changing Lives* the report of Scottish Executive commissioned 21<sup>st</sup> Century Social Work Review, and the Executive's response to the report, mirror many of the messages in *Delivering for Health* around self-care, early intervention and the need for increased recognition of the role of unpaid carers. This creates substantial potential for synergy around improving support for carers within both these policy frameworks.

## **2.11 *Children's Services***

2.11.1 Ministers have embarked on an ambitious agenda to improve the integration and quality of services so that children and young people get the help they need when they need it. This agenda is being driven forward by the Cabinet Delivery Group for Children and Young People. The key components are to improve delivery (eg through integrated children's

services planning, reducing bureaucracy and encouraging joint working); a new Quality Improvement Framework; joint inspections of children's services; improved assessment of children's needs and information sharing; and developing the children's services workforce. Delivery of this agenda will be further strengthened through implementing *Getting it Right for Every Child* which proposes a unified and child-centred approach to children's services, requiring a single assessment of a child's needs, one plan of action and a lead professional to ensure that the plan is delivered and that progress is monitored. Development of integrated support for young carers under the Executive's Carers Strategy will need to sit alongside these components.

## **2.12 Equality/Diversity**

2.12.1 The Executive's Carers Strategy placed an expectation on statutory agencies to consider the needs of minority ethnic carers in the development of services, in accordance with statutory obligations under the Race Relations Act 1976. Scottish Executive Circular CCD2/2003 requires statutory agencies to take into account the different cultural backgrounds of carers, the provision of information in appropriate formats, the need for language and communication support and culturally competent assessments. It also refers to the need to provide accessible services, to promote race equality and to monitor policies and services in line with the Race Relations (Amendment) Act 2000.

2.12.2 *Fair for All* (Scottish Executive 2002) requires NHS Boards to develop support for minority ethnic carers. An integrated equality and diversity approach is currently being developed by the Scottish Executive to build on the work of *Fair for All* and to ensure that individuals are able to access health services irrespective of their race, religion/faith, sexual orientation, age, disability or gender.

### **3. SECTION 3 – NHS CARER INFORMATION STRATEGIES : FORMAT AND CONTENT**

#### **3.1 Content**

3.1.1 This Section of the Guidance includes references to the minimum requirements of an NHS Carer Information Strategy, and suggested best practice recommendations, which are currently listed for ease of reference in Annex A to the HDL. The reason for repeating them here is so that they can be explained in context of the relevant policy background and to explain more fully in this guidance why these requirements and best practice recommendations have been made and how delivering them might best be achieved. This Section also gives the timescale for submitting Strategies to the Scottish Executive and details the monitoring arrangements that NHS Boards must follow. It sets out requirements in specific areas of NHS activity as well as providing strategic objectives.

#### **3.2 NHS Role In Supporting Carers**

3.2.1 The vital role of the NHS in identifying carers, offering them information and signposting or referring them to sources of advice and support is widely documented in research, publications and current NHS policy drivers, such as *Delivering for Health*. Research shows that for 4 out of 5 carers, their first point of contact with any statutory agency is with a community-based health service. Research also shows that this first point of contact is generally within a primary care setting, either at a health centre, GP practice or at home. Identifying all carers and providing them with information at the earliest point of contact is central to the aim of creating effective NHS Carer Information Strategies. Information provision is not a one-off exercise, however. 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. The Ministerial power to require the development of NHS Carer Information Strategies seeks to deliver systematic carer identification and provision of information to carers, based on existing good practice.

3.2.2 Recent health care policy has identified new responsibilities for NHS Boards, Community Health Partnerships and local NHS services to support unpaid carers, in partnership with their local authority and voluntary sector partners. Traditional NHS responsibility to work with local authorities to plan, develop and fund local respite services has been enhanced by new joint planning structures and integrated partnership working which include(s) carers and carer-led organisations as key partners. NHS lead responsibilities include carer identification through primary care practice teams, single shared assessment of users and carers and involvement of carers in hospital discharge protocols. Under Joint Future, the NHS is involved with local authorities in a range of joint activities such as Single Shared Assessment and joint services, including those for carers. They engage with carers individually and collectively.

### 3.3 Scope of NHS Carer Information Strategies

3.3.1 Section 12 of the 2002 Act is aimed at 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. This requires NHS staff to make a judgement on whether the caring role is regular and substantial, in line with Scottish Executive Circular CCD/2003. NHS representatives involved in developing this guidance felt that this was impracticable for many NHS staff, unless the Board designated specific staff to facilitate carer support (see practice model outlined in para 3.3.4).

3.3.2 It is recognised that carers who are given information on their rights and on avenues of support early on in their caring role feel better equipped to cope with the pressures of caring, even if they do not have or invoke those rights until later. In order to create a preventative approach in line with Delivering for Health and in order to minimise the requirement on NHS staff to assess whether a caring role is regular and substantial this guidance suggests that Boards extend their NHS Carer Information Strategy to all carers that they come across in their day to day duties, in particular the provision of information to help support the carer in their caring role, advising carers of their potential right to a carers assessment and signposting carers on to sources of support and advice. Such an approach would dovetail with existing information requirements under the Patient, Focus and Public Involvement agenda and would also be in line with a similar duty placed on local authorities by Sections 9 and 11 of the Community Care and Health (Scotland) Act 2002. This approach is already being adopted by some Boards. It also offers a systematic and cost effective approach to implementing NHS Carer Information Strategies.

3.3.3 The scope of this guidance might appear to go beyond the provision of information by requiring training of NHS staff on carer awareness. However, staff training on carer-related issues is fundamental to ensuring that information provision is mainstreamed into the day to day activities of NHS professionals and staff at all levels. The guidance also requires NHS Boards to consider, with local partners, the training needs of carers. Training is viewed as a means of providing valuable information that will support carers in their caring role.

NHS Greater Glasgow have already introduced innovative ways of raising staff awareness of carers, providing carer information and monitoring NHS performance in this area. Staff have had carer training in the workplace, have been provided with carer support cards and booklets, community-based staff have been provided with bookmarks with carer contact numbers on them. Dedicated carer notice boards are also in use in key sites including health centres, clinics, mental health resource centres, GP practices and hospitals. Regular emails have also been sent to staff reminding them of the importance of identifying and signposting carers. NHS Greater Glasgow also have experience of delivering this activity in partnership with several local authorities.

3.3.4 Where a carer appears to the Board to have a significant caring role, best practice would involve NHS staff formally referring such carers on to appropriate sources of support, ie local carer support agencies. This would build on existing good practice in some NHS Boards (see below) and across the majority of GP practices across Scotland, 80% of which

have carer identification and referral protocols in place under the GMS contract Quality and Outcomes Framework, Practice Management Indicator 9. Under the incentives provided in the Direct Enhanced Services Directions 2006, practices are also rewarded for setting up carer registers.

NHS Lothian employs a designated Carer and Support Development Worker within the Primary and Community Division. The worker is an integral member of the Primary Care Health Trust. The role involves signposting, and more proactively referring, carers to appropriate sources of support and advice as well as the provision of support directly to carers. It also involves raising awareness of carer issues amongst health care professionals within the Board. Dedicated carer support posts are also designated at a LHCC level in Edinburgh.

### **3.4 Purpose of an NHS Carer Information Strategy**

3.4.1 The purpose of an NHS Carer Information Strategy is to ensure that NHS Boards create a strategic framework within which the objectives set out below will be delivered. Scottish Executive Ministers expect a Strategy to clearly demonstrate how these objectives will be met and monitored. How this is achieved is a matter for the local discretion of each NHS Board, working in partnership with carers, patients, NHS staff, local authorities, the voluntary sector and the private sector. NHS Boards, in partnership with these key stakeholders, must determine which other relevant groups they need to work with to develop and implement their Strategy.

3.4.2 The overall objectives of an NHS Carer Information Strategy are to ensure that NHS Boards work in partnership with carers, patients, NHS staff, local authorities, the voluntary sector and other relevant groups to ensure:

- the identification of carers by staff and professionals at all levels within the NHS; and
- the effective provision of targeted information to carers at every point of their journey through the NHS. Information provision is an ongoing process throughout the patient/carer journey and information should be provided at key stages. These will include diagnosis, discharge, the start of treatment programmes and significant changes to treatment or medication. For the types of information that carers need see Section 6.
- carers are informed of their potential legislative right to an independent assessment of their support needs as a carer
- 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.
- that 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.
- that where patients are unable to consent through 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.
  - that the Strategy dovetails with the requirements in the Mental Health (Care and Treatment) (Scotland) Act 2003 around the provision of information to carers. It should also be in line with Standard 7 in the NHS QiS Clinical Standards for Schizophrenia which requires that carers are informed about the illness and acknowledges the particular needs of mental health carers for information. The Strategy should also include protocols to deal with the potential conflict of providing information to carers when they are not a named person under the 2003 Act.
  - that NHS staff as a minimum are able to signpost carers that they come across on their day to day duties to a local carer support agency and, if patient confidentiality allows, to appropriate national organisations supporting patients, users and carers for specific conditions. For example: Alzheimer Scotland, National Schizophrenia Fellowship (Scotland), MS Society (Scotland), Parkinson’s Society (Scotland).
  - that young carers are recognised as a distinct group with specific needs, but are recognised first and foremost as children and young people.
  - that carer awareness is mainstreamed as part of the day-to-day activities of NHS staff at all levels, whether employed by or contracted to the NHS.
  - that clear, measurable outcomes are delivered for carers in terms of being better informed of how to access appropriate support as a result of targeted NHS information.

### **3.5 Content of an NHS Carer Information Strategy**

3.5.1 NHS Boards, working in partnership with carers, patients, NHS staff, local authorities, the voluntary sector, the private sector and other relevant groups, will be expected to demonstrate, as a minimum requirement, within their Carer Information Strategy, how they will deliver the minimum requirements set out in Action Boxes within this Section of the guidance and listed for ease of reference in Annex A to the HDL. They should also demonstrate how the Strategy will deliver the overall objectives listed above. The following paragraphs make explicit the need for NHS action in key areas of service delivery. They also set out requirements for action in areas such as training, accountability and community involvement.

## 3.6 Culture

3.6.1 An NHS Carer Information Strategy must operate in a culture based on partnership-working, team-working, information-sharing and service integration across all levels of the NHS. It must function in partnership with carers, patients, NHS staff, local authorities, the voluntary sector, the private sector and other relevant groups. Such partnership working is not new. An NHS Carer Information Strategy must be built upon the existing partnerships and working practices already created through implementation of Patient Focus and Public Involvement, delivery of the Joint Future Agenda, Joint Health Improvement Plans, Local Health Plans, Local Partnership Agreements and Community Planning, as well as Community Health Partnerships. The success of an effective NHS Carer Information Strategy will depend greatly on the quality of these partnerships as well as effective communication and joint-working between all partners, including carers and the voluntary sector. It will also depend on open and robust accountability within statutory and independent agencies.

3.6.2 The introduction of single shared assessments (SSAs) for all community care client groups and for carers and the increasing role of health practitioners in conducting SSAs is already leading to new ways of working across health and social care teams. Joint working and joint information-sharing is at the centre of SSA and requires that agreed information-sharing protocols are in place for communicating and consulting with all key stakeholders, including carers.

3.6.3 NHS Carer Information Strategies should sit within local carer strategies, which have generally been jointly developed by local authorities in partnership with NHS Boards. As well as providing the development framework for services to support carers, local carer strategies generally address issues such as carer identification and the provision of targeted information to carers.

3.6.4 Strategies should also make linkages with local Child Protection Protocols, so that young carers who appear to NHS staff to be vulnerable or at risk **for any reason, but especially** because of their caring role, are identified by NHS staff and the appropriate agencies brought together in line with the protocol. NHS staff should be aware that many young carers exist in family situations where there is substance misuse or where a parent has mental health issues. **In all matters the welfare of the child is paramount, especially when there are conflicts of interest.**

**As a minimum an NHS Carer Information Strategy must:**

- demonstrate how NHS Boards have identified, in discussion with carers, carer organisations, the wider voluntary sector and local authority partners:
  - the information carers need;
  - how it will be provided; and
  - by which lead agency.
- ensure that NHS staff as a minimum are able to signpost carers that they come across on their day to day duties to a local carer support agency and, if patient confidentiality allows, to appropriate national organisations supporting patients, users and carers for specific conditions. For example: Alzheimer Scotland, National Schizophrenia Fellowship (Scotland), MS Society (Scotland), Parkinson’s Society (Scotland).

**This guidance makes a best practice recommendation that:**

- where a carer appears to the Board to have a significant caring role, NHS staff formally refer such carers on to appropriate sources of support, ie local carer support agencies.

**This guidance makes a best practice recommendation that an NHS Carer Information Strategy should set itself in context with other policies by including:**

- a description of how the Strategy sits alongside other key policies such as Patient Focus and Public Involvement, Delivering for Health, Joint Future, Partnership for Care, Community Health Partnerships, Health Improvement and the new Quality Improvement Framework for Children’s Services.
- a description of how the Strategy sits within jointly-developed local carers strategies, including young carer strategies
- a description of the mechanisms in place that would initiate joint action with partner agencies when the Strategy identifies young carers who may appear to NHS staff to be at risk because of their caring role, or other associated factors.
- a description of how local joint agreements on issues of consent have been reviewed in order to ensure that they adopt the principles set out in the NHS Carer Information Strategy and facilitate the proactive provision of information to carers.
- a description of how the Strategy ensures that it supports equality responsibilities including Fair for All and requirements to implement Race Equality Schemes

### 3.7 Engaging Carers, Partners and Communities

3.7.1 An NHS Carer Information Strategy should be developed using a bottom-up approach in partnership with key stakeholders. NHS Boards have legal responsibility for implementing this guidance and therefore for developing the Strategy. In doing so Boards should maintain an effective, formal dialogue with local carers, carer organisations and the wider voluntary sector to ensure that the Strategy is fully developed, working effectively and providing carers with the information they need. This reflects the existing duty on NHS Boards to involve and consult the public on service delivery and the wider public involvement agenda which aims to make public services more responsive and accountable to citizens and local communities. NHS Boards should report to their local communities, through existing networks of patient/user and carer groups and community care forums, on how their views are taken into account in the development of an NHS Carer Information Strategy.

3.7.2 An NHS Carer Information Strategy should be tied in to the wider range of public involvement structures and processes already in place to ensure community engagement in care management and service planning. This will require NHS Carer Information Strategies to work with and inform the wider range of community consultation structures which are being developed to take the Community Planning Process forward. These mechanisms will vary across Scotland but might, for example, include citizen's panels and forums, Minority Ethnic Health Forums, area committees, parent groups, community councils and Social Inclusion Partnerships. Public partnership forums, being developed under Community Health Partnerships will also feed into these local involvement mechanisms, particularly in relation to health improvement. These provide a good opportunity for those working in the health arena to discuss with local partners, including the voluntary sector, how best to streamline and improve local involvement processes, building on good practice and joining up activity wherever possible.

**As a minimum an NHS Carer Information Strategy must:**

- specify the arrangements for the involvement of carers, carer organisations, local authorities and other key stakeholders in developing and reviewing the NHS Carer Information Strategy
- identify work already done with local partners to develop a joint information strategy for carers
- specify arrangements for involving young carers, through local organisations/bodies representing young carers, in developing and reviewing the NHS Carer Information Strategy
- specify arrangements for the involvement of carers from minority ethnic groups and other equality groups in developing and reviewing the NHS Carer Information Strategy

### 3.8 General Principles

3.8.1 An NHS Carer Information Strategy should, as best practice, adopt the following fundamental principles in terms of its development and implementation.

**This guidance makes a best practice recommendation that an NHS Carer Information Strategy should contain a statement of general principles to underpin the Strategy, including:**

- statements of principle recognising and treating carers as key partners in the provision of care. These statements should reflect the different position of young carers who must be engaged, consulted with, particularly in terms of developing the Strategy, and supported but not viewed as key care providers
- a statement of commitment that all levels of the NHS will work in partnership with carers in line with *Partnership for Care* and *Delivering for Health*
- a statement which recognises the statutory duty placed on NHS Boards by the 2002 Act in relation to informing carers of their right to an assessment and the requirement contained in Patient Focus and Public Involvement Action Plans to have a Strategy that meets the information needs of patients, relatives and carers
- a principle of accessibility, ensuring that information is provided to carers in a wide range of formats and languages, enabling all carers to access information irrespective of their age, disability, ethnicity or other specific needs
- a statement of commitment to ensuring that information and support is available and accessible to carers from black and minority ethnic communities, as required under the Race Relations (Amendment) Act 2000 and *Fair for All*
- a statement of commitment to the principles of equality and diversity

### 3.9 Delivery In NHS Operating Systems

3.9.1 The NHS is undergoing significant change through the introduction of Single System Working and Community Health Partnerships. NHS Boards will therefore be organised in different ways. There may be geographically-based operational areas (including acute and primary care services); there may be primary care or acute care operating divisions, or other structures in place, together with emerging Community Health Partnerships. NHS Boards should ensure that a General Manager or other Senior Manager is invested with the responsibility of ensuring that all staff in that operational sphere are appropriately informed, trained and equipped to support carers as detailed in the Board's NHS Carer Information Strategy. Frontline service managers in particular have a crucial role to play in this area.

**As a minimum an NHS Carer Information Strategy must:**

- describe the practical steps which will be taken to deliver the NHS Carer Information Strategy objectives systematically throughout the Board area
- describe how each NHS operating sphere/service and joint arrangements with local authorities, the voluntary sector, and private sector will support the objectives of the NHS Carer Information Strategy
- develop strategic proposals to address the identification and information needs of specific carer groups such as young carers and carers from minority ethnic communities

### **3.10 Community Health Services**

3.10.1 A wide range of health services have a crucial role to play in ensuring that carers are identified and provided with information at first point of contact. Where professionals/staff are independently contracted, NHS Boards should take a proactive role regarding carer identification, information and signposting amongst such professionals/staff and should explain within the NHS Carer Information Strategy how this is being taken forward. Key community-based services include:

- GP Practices/Primary Care Teams
- hospital and community-based pharmacists
- community hospitals
- care of the elderly hospitals
- community assessment and rehabilitation
- out patient clinics, particularly those dealing with chronic disease management
- psychiatrists and mental health clinics
- dieticians
- podiatrists
- community child health services
- community health projects funded by NHS Boards
- school nursing

3.10.2 The Strategy should also apply to NHS staff working in partnership with local authorities, as well as the voluntary and private sectors in community-based health/social care services, as part of the Joint Future arrangements being incorporated into Community Health Partnerships. Such services include:

- council home care/day care/housing services/leisure services
- older people's services
- children's services
- community mental health services (including psychology)
- learning disability services
- acquired brain injury services
- services for people with physical/sensory disabilities
- rapid response teams

- drug and alcohol services (addiction services)
- health practitioners working with education authorities

**As a minimum an NHS Carer Information Strategy must:**

- demonstrate how NHS Boards are promoting carer identification and the provision of targeted information to carers by GPs and Primary Care staff  
This should demonstrate the link between practice involvement and the GMS contract Quality and Outcomes Framework, Practice Management Indicator 9 involving carer identification and referral as well as activity to set up carer registers in line with the Direct Enhanced Services Directions 2006.
- set out how NHS Boards are making community-based pharmacists aware of their role in supporting the Strategy.

### 3.11 Acute/Hospital Services

3.11.1 Each hospital directorate/service should be able to fulfil the requirements set out in this Guidance. A carer's first contact with the statutory agencies could be in any of a hospital's departments/directorates. General Managers /Senior Managers and frontline managers should be identified in all sectors, including acute services, to implement the Strategy in their area of responsibility (see 'Accountability').

3.11.2 Scottish Executive Circular CCD9/2003: *Framework for the production of joint hospital discharge protocols* already requires the full involvement, at all times, of patient and carers in decisions about an individual's care. In the case of planned admissions, discharge planning should be initiated prior to admission. This guidance already requires hospital teams to have protocols for involving patients, relatives and carers.

**As a minimum an NHS Carer Information Strategy must:**

- demonstrate how hospital staff ensure that carers are routinely identified and given targeted information and how staff ensure that carers are signposted to appropriate support services and made aware of their potential right to an assessment
- set out how carer identification, the provision of targeted information to carers, carer signposting on to sources of advice and support, and advising carers of their potential right to an assessment is integrated into hospital discharge procedures and admission procedures.

### 3.12 Training of NHS staff

3.12.1 NHS Boards should build on successful local partnership-working so that frontline staff and professionals are trained in carer awareness issues. This should also include awareness-raising about the issues for young carers, BME carers and for LGBT carers.

3.12.2 Training is already happening in some core curriculum for social work and health graduates/trainees. The Executive will seek to ensure that this is systematic and widespread by improving carer-awareness training in all graduate training curriculum for health and social care professionals.

3.12.3 Training of existing NHS employees, who have had no carer awareness training, should happen in a range of ways, including induction, joint training and, on-going education and communication in relation to health and social care. Joint learning opportunities should be promoted, where practical, to increase the awareness of carers' issues within the NHS and also with local authorities, voluntary organisations and the private sector (where appropriate). The role of the voluntary sector in training provision should be taken into account when developing awareness-raising programmes. The Executive will also work with NHS Education Scotland in this key area and to look at training within continuing professional development.

3.12.4 Training of key staff should be prioritised so as to achieve the greatest benefit for carers and the Strategy should set out clearly what progress will be delivered within the Strategy's lifetime.

3.12.5 Training should be mainstreamed as far as possible into existing training modules, for example Discharge, Single Shared Assessment and Child Protection Training which could provide a vehicle for addressing young carers' issues. Training on carers' issues, should be sufficiently robust to cover the issues in a meaningful and effective way and to enable staff to recognise carers with substantial caring responsibilities, so that they can be signposted or formally referred to sources of advice and support. Training should also make links to protection issues both for vulnerable adults and children in recognition that some caring relationships are abusive. Training mechanisms should be agreed locally and set out clearly in the Strategy.

3.12.6 In recognition of the need for professionals in the mental health field to work in partnership with carers as key partners, the Royal College of Psychiatrists has already agreed to prepare a code of conduct for professionals on issues relating to carers. From 2005, the College has required post-graduate accreditation to have a carer awareness component in the curriculum, with carer-led training.

**As a minimum an NHS Carer Information Strategy must:**

- include detailed action plans for the training of staff over the lifetime of the Strategy, outlining how carer awareness, carer identification, the provision of information to carers, advising carers of their right to an assessment, carer signposting to sources of advice and support and working with carers as key partners are being mainstreamed into NHS practice; specifically through induction programmes, pre-qualification professional training, continuous personnel development and professional training and leadership development
- set priorities for staff training in agreement with local partners, including carers and carer organisations and local authorities
- include in action plans details on training for staff, on culturally-sensitive issues for carers from minority ethnic communities
- include in action plans details on training for staff on issues relating to young carers

### **3.13 Training for Carers**

3.13.1 *Delivering for Health* supports full implementation of NHS Carer Information Strategies, as called for in *Building a Health Service Fit for the Future*. *Building a Health Service Fit for the Future* and the 2005 Care 21 Report *The future of unpaid care in Scotland* both promote the development of ‘expert carers’ in line with the creation of expert patients through a programme of training to promote more self care and self management.

3.13.2 Compelling evidence demonstrates the considerable benefits that can be achieved for patients, carers and the NHS by training and supporting family carers. Improved carer support is cost effective in a range of ways, enabling patients, particularly those with chronic long-term conditions, to be supported longer within the community, and for older people delaying residential care. Better supported carers, particularly those with intensive caring responsibilities are also much less likely to present at GPs with their own health issues.

For Good Practice in supporting carers and the benefits of that to patients, carers and NHS resources see BMJ 2004;328:1099 and 1102 (8 May 2004)

<http://bmj.bmjournals.com/cgi/content/full/328/7448/1085>

This ‘invest to save’ approach within the clinical priority area of stroke rehabilitation demonstrates clearly the impact carer training can have on better patient care, increased self-care capacity, reduced stress levels for carers, a considerable reduction in health professional input throughout the rehabilitation process and a significantly reduced hospital stay (2 weeks earlier discharge on average). This study also provides an economic evaluation with clear resource savings to the NHS.

3.13.3 Carer training is already happening in local partnerships under local Carers Strategies and the introduction of NHS Carer Information Strategies seeks to build on this in a more systematic way.

**As a minimum an NHS Carer Information Strategy must:**

- identify proposals for the development of a strategic approach to ‘expert carer’ training, aimed directly at supporting carers in their caring role and targeted specifically at carers with intensive, or potentially growing, caring responsibilities.
- identify in partnership with local authorities and local carer support agencies what training already exists for carers and how this will be developed and extended over the lifetime of the Strategy.
- demonstrate delivery of person-centred training for carers, covering advice on physical and emotional well-being including demonstrations on moving and handling techniques (if appropriate) and stress management, and advice on specific conditions such as caring for someone with dementia, physical disabilities, mental health problems, special needs, etc
- set priorities for carer training in agreement with local partners, including carers, local carer support agencies and local authority partners. In doing so local training partners should explore the role of further education establishments and existing carer training packages, as well as the delivery of training using IT systems and technology.

### **3.14 Accountability**

3.14.1 NHS Boards are expected to lead the development and maintenance of an effective NHS Carer Information Strategy. This will require significant and sustained organisational and management development with successful leadership. It will be critical to ensure that there is effective leadership at all levels, but particularly at a senior level in the Board, to ensure that staff are appropriately trained and aware of the requirement to identify carers, to provide carers with targeted information, to advise carers of their potential right to an assessment and, to adopt the good practice of signposting carers on to appropriate sources of advice and support.

**As a minimum an NHS Carer Information Strategy must:**

- identify a lead officer at General Manager or Senior Manager level to promote carer identification and information with responsibility to ensure effective development and implementation of the NHS Carer Information Strategy. Links with the Patient Focus and Public Involvement Designated Director should be a priority
- identify specific staff within primary care, acute staff and nursing teams to promote carer identification and to take responsibility for the provision of information to carers
- indicate management and leadership arrangements with front-line staff
- specify functions and services which will be contracted to various key partners, eg, local authorities, voluntary sector organisations and the private sector

### 3.15 Monitoring

3.15.1 This Guidance seeks to ensure that a focus on outcomes for carers is built into each NHS Carer Information Strategy, particularly through the systematic development and implementation of baseline information, performance indicators and meaningful qualitative data against which quality improvements for carers can be measured.

3.15.2 *Delivering for Health* requires that NHS Boards monitor activity to promote and support more self-care. Effective and full delivery of NHS Carer Information Strategies will make an important contribution towards demonstrating this objective.

3.15.3 The Executive is already developing a range of outcome measures for carers that are both Performance Indicator related and qualitative. Key outcomes are being mainstreamed, as far as possible, within the Executive's Joint Performance Information and Assessment Framework (JPIAF). Under the Framework local partnerships are already monitoring performance in key areas, including support for carers. Some outcome measures for carers have yet to come on stream and will do so as both JPIAF and partnership IT systems develop. Over time the measures should provide a clearer picture of the support carers across Scotland are receiving in terms of:

- the numbers of carer assessments being conducted and the outcomes of such assessments
- accessibility to support services, including short break services (known also as respite) and in particular access to planned respite
- being treated by health and social care professionals as key partners in the provision of care, both at a strategic level in terms of service planning and delivery and also at an individual level in relation to care management and sharing of information
- whether the legislative provisions for carers contained in the Community Care and Health (Scotland) Act 2002 are being implemented

3.15.4 NHS Boards must take lead responsibility for monitoring, effectively and regularly, the outcomes achieved for carers in terms of their NHS Carer Information Strategy and the requirements of that Strategy, as set out in this guidance. To do so effectively, Boards will want to work in partnership with carers, patients, NHS staff, local authorities, the voluntary sector, and other relevant groups as well as the private sector. Local authorities have similar legal duties placed on them to identify carers and to advise them of their right to assessment. Authorities must also be able to demonstrate compliance with this duty. Local partnerships should therefore consider the development of joint indicators, outcome measures and monitoring systems, as well as effective user and carer evaluation systems.

3.15.5 Under the Patient Focus and Public Involvement agenda, NHS Boards are required to have an Action Plan to meet the information needs of patients, relatives and carers. This arose from an existing requirement set out in generic clinical standards on Patient Focus. Monitoring NHS Carer Information Strategies should, therefore, link to the Action Plan.

3.15.6 Building on existing and developing qualitative and quantitative information systems the measurable outcomes for carers of an effective NHS Carer Information Strategy will be:

- carers are identified early at first point of contact with the NHS
- carers are informed of their potential right to an assessment of their support needs as carer under Section 12AA of the Social Work (Scotland) Act 1968 or in the case of young carers under Section 24 of the Children (Scotland) Act 1995
- carers are well informed of the process and procedures of hospital admission and discharge and are fully involved in the decisions taken at these key stages
- carers are provided with targeted information based on the information needs of local carers. For more detail on the general information needs of carers see Annex D.

**As a minimum an NHS Carer Information Strategy must:**

- provide baseline information against which quality improvements can be measured
- identify joint performance indicators and outcomes for carers
- set out how Boards have worked work in partnership with carers, patients, NHS staff, local authorities, the voluntary sector and other relevant groups to agree indicators/outcomes and monitoring systems.
- demonstrate that NHS staff are aware of the need to identify carers and to signpost them to sources of support/advice
- set out arrangements to monitor and evaluate implementation of this Guidance – setting out auditing and accountability arrangements within the NHS and on a joint basis with local authorities, the voluntary sector and if appropriate the private sector
- set out how monitoring arrangements fit in with accountability for other areas such as Community Health Plans, Patient Focus and Public Involvement Action Plans, Hospital Discharge Guidance, Local Partnership Agreements, etc.
- ensure that effective monitoring arrangements are in place to establish accessibility to information for carers from minority ethnic groups, in line with the requirements of the Race Relations (Amendment) Act 2000 and Boards' Race Equality Schemes.
- set out proposals for reviewing the NHS Carer Information Strategy in consultation with carers and other stakeholders
- ensure annual reports to Scottish Executive Ministers, on how Boards are implementing and evaluating their NHS Carer Information Strategy and setting out progress. Reports must be jointly signed by the NHS Board Chief Executive, the relevant local authority Chief Executive and representatives of the main carer groups/organisations operating within the NHS Board area. Such reports, and the Strategy should be made publicly available, free of charge, to any person requesting them

### **3.16 Submitting NHS Carer Information Strategies.**

3.16.1 NHS Boards are required to submit an NHS Carer Information Strategy for approval to Scottish Ministers. The NHS Carer Information Strategy must cover the whole Board area and be developed in the context of single NHS systems, the development of joint health improvement plans, and local plans to extend Joint Future partnerships and develop Community Health Partnerships.

3.16.2 Each NHS Carer Information Strategy must be jointly signed off by:

- the NHS Board Chief Executive
- the relevant local authority Chief Executive
- representatives acting on behalf of the main local carer groups/organisations operating within the NHS Board area. This should also demonstrate that the Strategy has been developed in consultation with young carers and local minority ethnic communities through the involvement of local organisations representing those groups.

3.16.3 NHS Boards must formally submit their NHS Carer Information Strategy to Scottish Executive Ministers **by 31 October 2006**. Strategies should cover a 3 year period (1 April 2007 - 31 March 2010) and address all the minimum requirements contained within this Guidance. If a Strategy is rejected because there is insufficient detail or a Board has failed to meet the requirements set out in this Guidance, the Strategy will be returned to the Board with a requirement to resubmit it within a specified timescale.

3.16.4 Strategies will be approved by Ministers, with a view to full implementation from **1 April 2007**.

3.16.5 Once NHS Carer Information Strategies have been approved, NHS Boards will generally be able to extend their functions without resubmitting their Strategy for approval by Ministers, as long as such changes are reflected in annual progress reports. However, if an NHS Board wishes to substantially alter the nature of its NHS Carer Information Strategy, a revised Strategy will require Ministerial approval.

## **SECTION 4: LEGAL DEFINITION OF A CARER**

### Background

In legal terms the definition of a “carer” is tied up with the legislative right of a carer to receive an assessment of their ability to provide, or to continue to provide, care for the cared-for person. The term “ability to provide care” is not meant to infer that there is a value judgement to be made by professionals about the carer’s own ability as a carer. It is intended to ensure that professionals, as part of a carer’s assessment, consider a wide range of factors in determining whether a carer is able (due to health or other considerations) and/or willing to provide care at a particular level.

In law only ‘regular and substantial’ carers are entitled to an assessment of their support needs as a carer. These legislative positions on a carer’s right to an assessment are set out in Section 12AA of the Social Work (Scotland) Act 1968 and Section 24 of the Children (Scotland) Act 1995. These Sections are replicated below. The application of ‘regular and substantial’ is designed to ensure that only carers with substantial caring roles have the right to an assessment, as a gateway to securing practical support from the statutory agencies. ‘Regular and substantial’ has never been defined legislatively. Interpretation of ‘regular and substantial’ has been left to professionals on the ground to decide, based on the individual circumstances in each case and taking into account a wide range of factors. This inevitably requires some form of preliminary screening to explore the caring role and the impact of that on the carer. The factors to be taken into consideration in determining “regular and substantial” were set out in Scottish Executive Circular CCD2/2003 which gives local authorities, NHS bodies and the voluntary sector guidance on effective implementation of all the legislative provisions affecting carers contained the 2002 Act. The guidance on defining ‘regular and substantial’ is replicated in Annex C of this guidance, for ease of reference.

The availability of early and targeted information is however important to all carers and not just ‘regular and substantial carers’. Particularly as carers early on in their caring role can benefit in terms of their mental well-being from knowing that support can be available should the caring role become considerable at some later stage. Carers who are not caring on a ‘regular and substantial’ basis may have information needs in terms of moving and handling and generally also require information on medical conditions, etc, to help them provide the appropriate care (See Annex C on Interpretation of Substantial And Regular: Section on Preventative Approach).

### Legislative Definition of Carer

**Section 12 AA of the Social Work (Scotland) Act, as amended by the 2002 Act states that:**

(1) A person (“the carer”) who provides, or intends to provide, a substantial amount of care on a regular basis for another person aged eighteen or over (“the person cared for”) may, whether or not the carer is a child, [8.I.6.39] request a local authority to make an assessment (“the carer’s assessment”) of the carer’s ability to provide or to continue to provide such care for that person.

- (2) The local authority to whom the request is made shall—
- (a) comply with the request, where it appears to them that the person cared for is a person for whom they must or may provide, or secure the provision of, community care services; and
  - (b) if they then or subsequently make an assessment under subsection (1)(a) of section 12A of this Act of the needs of the person cared for, have regard to the results of the carer’s assessment—
    - (i) in the assessment of the person cared for; and
    - (ii) in making their decision under subsection (1)(b) of that section as respects that person.
- (3) Subsection (1) above does not apply as respects a carer who provides, or will provide, the care in question—
- (a) by virtue of a contract of employment or other contract; or
  - (b) as a volunteer for a voluntary organisation.
- (4) Section 8 of the Disabled Persons (Services, Consultation and Representation) Act 1986 (c.33) (duty of local authority to take into account abilities of carer in deciding whether to provide certain services to disabled person) shall not apply in a case where a local authority make an assessment, by virtue of subsection (2)(a) above, in respect of a carer of a disabled person.
- (5) Subsections (4) to (7) of section 12A of this Act apply to a local authority making an assessment by virtue of subsection (2)(a) of this section as they apply to a local authority making an assessment under subsection (1)(a) of that section.
- (6) In this section, “community care services”, “disabled person” and “person” have the same meanings as in section 12A of this Act. [section 8(2)]

**For carers of disabled children similar legislative rights around carers assessments are set out in Section 24 of the Children (Scotland) Act 1995 which states that:**

- (1) Subject to subsection (2) below, a person (“the carer”) who provides, or intends to provide, a substantial amount of care on a regular basis for a disabled child may, whether or not the carer is a child,[9.I.7.33] request a local authority to make an assessment (“the carer’s assessment”) of the carer’s ability to provide or to continue to provide such care for the child.
- (1A) The local authority to whom the request is made shall—
- (a) comply with the request, where it appears to them that the child, or another person in the child’s family, is a person for whom they must or may provide services under section 22(1) of this Act; and
  - (b) if they then or subsequently make an assessment under section 23(3) of this Act to determine the needs of the child, have regard to the results of the carer’s assessment—
    - (i) in the assessment of the child; and
    - (ii) in making a decision as to the discharge by them of any duty they may have as respects the child under section 2(1) of the Chronically Sick and Disabled Persons Act 1970 (c.44) or under section 22(1) of this Act.
- (2) No request may be made under subsection (1) above by a person who provides or will provide the care in question—

- (a) under or by virtue of a contract of employment or other contract; or
- (b) as a volunteer for a voluntary organisation.

(3) Where an assessment of a carer's ability to continue to provide, or as the case may be to provide, care for a child is carried out under subsection (1) above, there shall, as respects the child, be no requirement under section 8 of the [1986 c. 33.] Disabled Persons (Services, Consultation and Representation) Act 1986 (carer's ability to continue to provide care to be considered in any decision as respects provision of certain services for disabled persons) to have regard to that ability.

(4) In this section "person" means a natural person.

## **SECTION 5: INTERPRETATION OF SUBSTANTIAL AND REGULAR CARE**

An interpretation of ‘substantial and regular’ is not defined in legislation but guidance to health and social care practitioners on how to interpret it was set out most recently in Scottish Executive Circular CCD2/2003 (March 2003). The section in the Circular is replicated here for ease of reference.

Extract from CCD2/2003

“The 2002 Act builds on the existing concept in the 1968 Act and the 1995 Act, which establishes that carers who provide “a substantial amount of care on a regular basis” are entitled to an assessment. The 2002 Act does not change these terms. As the terms “regular” and “substantial” are not defined in legislation, it is for local authorities to interpret them in relation to individual cases. This approach allows local authorities, in partnership with other agencies, to reach appropriate individual decisions about whether a carer’s particular circumstances make them eligible for an assessment.

Authorities should make public their approach in interpreting “substantial and regular”, in consultation with local carers’ representatives. Authorities should consider the merits of developing consistent approaches to interpreting “substantial and regular” in discussion with other authorities and carer organisations.

### **In interpreting “substantial and regular” local authorities should -**

- focus on the impact of the caring role on the individual carer and their family
- 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?
- take into account a range of factors, including:
  - the total time spent caring
  - type of caring tasks
  - intensity and pattern of caring
  - cultural background of caring situation
  - distances travelled to and from caring situation
  - number of people being cared for
  - nature of the cared-for person’s needs and their likely duration
  - employment status of carer
  - whether other family members including children are affected by the caring situation
  - age of the carer
  - carer’s physical and mental health

- the history of the caring relationship
- the carer's views
- 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 recur periodically.
- recognise that carers from minority ethnic groups may have different caring patterns, and may be caring in more than one location.
- 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.
- always ensure carers are aware of how the decision on "substantial and regular" has been reached.

#### Caring at a distance

- **In interpreting "substantial and regular" local authorities should -**
- think carefully about the interpretation of "substantial and regular" in the context of carers who -
  - travel significant distances to carry out their caring role, especially where a carer looks after more than one person,
  - are caring for someone who uses or could use services in a different local authority area from the carers' own area.
- work in partnership with the other authorities affected.
- develop local agreements for handling such cases (usually the authority where the cared-for person lives should take the lead in assessing the carer).

## Young carers

### **In interpreting "substantial and regular" local authorities should -**

- not adopt the same approach in interpreting “substantial and regular” for young carers that they would use for an adult carer in a similar role.
- take account of the impact of the young person’s caring responsibilities on their current and future development, as well as their ability to access social, leisure and educational activities.
- take account of the age of the young person and the nature of the caring responsibilities.
- ensure that a child or young person does not have a level of caring responsibility that may undermine their ability to participate in education and leisure and social activities.
- ensure that the cared-for person is receiving sufficient other support so that the young person is not undertaking an inappropriate caring role that might amount to “substantial and regular”.

## Older carers

### **In interpreting "substantial and regular" local authorities should -**

- recognise that caring is likely to demand more of an older carer.
- ensure they focus on the impact of the caring role on the individual.

## Preventive approach.

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 a future breakdown in the caring relationship.

### **In interpreting "substantial and regular" local authorities should -**

- recognise the value of early intervention to sustain carers.

## **SECTION 6: CARERS' INFORMATION NEEDS**

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
- 1<sup>st</sup> treatment
- changes to treatment
- discharge

To be adequately supported in their caring role, carers require information that includes:

- 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 which is best provided by a special benefits adviser or local welfare rights officer, or through trust funds and independent grant-giving bodies.
- 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 (helpful for parent carers of disabled children and carers with Power of Attorney under the Adults With Incapacity (Scotland) Act)
- information on local forums where carers, including young carers, can input on service planning and development

The above list is not comprehensive.