



Department of

**Health, Social Services
and Public Safety**

An Roinn

**Sláinte, Seirbhísí Sóisialta
agus Sábháilteachta Poiblí**

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**PRIMARY AND COMMUNITY CARE DIRECTORATE
Elderly & Community Care Unit**

Circular HSS (ECCU) 4/2006

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To: Chief Executives of HSS Boards and Trusts
Chief Officers of HSS Councils
General Practitioners

For information – Regulation and Quality Improvement Authority

IMPLEMENTATION OF THE CARERS STRATEGY

Introduction

1. In 2002, after an extensive period of consultation with carers, the then Minister Bairbre de Brun, issued 'Valuing Carers' a report containing 19 key recommendations for the development of practical support for carers. Since then, work has been ongoing to deliver on those recommendations. In January 2006, the Department published 'Caring for Carers', a strategy specifically designed to recognise, value and support the caring role. It represents a long term plan of action to deliver on the recommendations originally set out in 'Valuing Carers'
2. A carer is a person who, without payment, provides help and support to a family member or a friend who may not be able to manage without this help because of frailty, illness or disability. Carers can be adults caring for other adults, parents caring for ill or disabled children, or young people who care for another family member. The Department recognises that the role played by carers enables many thousands of vulnerable people, who need support, to continue to lead independent lives in their local communities. This represents a significant contribution to the overall range of services provided by the Health and Personal Social Services and other agencies. It is therefore right and sensible that carers should be provided with the support they need in order to enable them to continue in their caring role. In addition, these services must recognise carers both as partners in the management of care and as individuals in their own right.
3. Figures from the latest census (Northern Ireland Census of Population 2001) indicate that there are approximately 185,000 people providing



informal care in Northern Ireland. The support that carers need varies widely from information, independent advocacy, emotional support and practical advice, through social security benefits to flexible and responsive support services. It is important that the services provided by the Health and Personal Social Services and commissioned from other non-statutory organisations reflect the full spectrum of that need.

4. This circular is the first in a series designed to provide practical advice for the HPSS on delivering the key elements of the strategy.

Legislative Background

5. In 2003 the Northern Ireland Assembly brought into force the Carers and Direct Payments Act, which imposes a legal requirement upon the Health and Personal Social Services (HPSS) to advise carers of their right to an assessment and if requested to carry out an assessment. In response to assessment, HPSS bodies are empowered to provide a range of services within local priorities and available resources. The legislation also brought carers within the scope of Direct Payments, which can be made in lieu of service provision to meet an assessed care need. The Department has issued guidance to the HPSS on the implementation of the legislation. Revised guidance on assessment and the provision of information to carers was issued in April 2005.

Quality Standards for Health and Social Care

6. In March 2006, the Department issued the Quality Standards for Health and Social Care. These Standards recognise the importance of carers' views and experiences in the planning, delivery, evaluation and review of services. The Regulation & Quality Improvement Authority will be reviewing the quality of HPSS services later this year and will be looking for evidence that the role of carers is recognised in the way that organisations commission or provide care.

Identification of Carers

7. Many people who carry out a caring role do not identify themselves as carers and are not aware of the support services available to them. It is imperative they get the right information at the right time and in order to ensure this is achieved, more work must be carried out by the HPSS to identify carers. Many health and social care professionals are well placed to identify the presence of an informal carer and, once this is done, they can then be directed towards appropriate services. The Quality and Outcomes Framework (QOF), Practice Management Indicator 9 states that General Practitioners should have a protocol for the identification of carers and a mechanism for the referral of carers for health and social services

assessment. Evidence from the 'Valuing Carers' consultation process pointed to the need for health and social care professionals to be particularly proactive in seeking out the presence of older and younger carers because they may be less likely to come forward but may be more likely to need specific support to deal with their caring responsibilities.

8. It is essential that the existence of a carer is recorded on all patient and client records, both paper and electronic. Carers must be kept informed of any change in the management plan in relation to the person they care for as this will generally have an impact on their role also. In addition, changes to the health and social care status of a carer will often have a significant impact on the life of the person they are caring for, and health and social care professionals need to be aware of this in order to put in place any necessary support mechanisms.
9. Trusts are required to have specific protocols for the discharge of patients from hospital to a community setting. Those protocols must include the identification of carers and their full engagement in the planning of arrangements for discharge.

Consent to share patient/client information

10. The Department recognises the need for carers to be provided with information on the current and future health and social care needs of the person they are caring for. This information is necessary to enable carers to make an informed decision about their future caring role, and will help to support them in their day to day caring role.
11. General Practitioners, other clinicians and all professionals should actively encourage and seek patients' and clients' consent to share information about their illness or disability, medication and symptoms with the carer. They should stress the importance and benefits of sharing this information with the carer, and how it will help to improve their future care. This and any decision not to give consent must be recorded in the patient's/client's notes.
12. In a small number of cases, patients may refuse to give their consent to any information being shared with their carer. There are some circumstances where, even without consent being given, it will be necessary to provide the carer with information relating to the client's needs. This may be given in the interests of maintaining the carers own safety or that of other members of the public; such decisions must be made on a case by case basis and the best interests of both the patient and the carer must be borne in mind.
13. In exceptional circumstances, when consent is not forthcoming, GPs, clinicians and all professionals should refer to paragraphs 5.6 and 5.7 of

"The Protection and Use of Patient and Client Information" (HPSS Guidance 1999) [See Annex 1]. This Guidance is currently under review and it is anticipated that revised Guidance will be issued in mid 2007. Health and social care professionals must also recognise that patients/clients have the right to change their minds on whether to give consent and they should review the decision regularly with the patient/client as the issue arises.

Recognition of the caring role

14. During the course of the initial consultation process, carers told us that a clearly identified carers' co-ordinator in each Trust would provide a focal point for dealing with issues affecting carers. Carer's co-ordinators are already operating in some Trusts, with both carers and the Trusts reporting the benefits of the role. The primary functions of this post should involve:
 - Proactively raising awareness of carers issues within the Trust and ensuring that they are explicitly addressed in service planning arrangements;
 - Establishing and supporting a carers reference group in each Trust area which will promote and cultivate carers networks across all programmes of care;
 - Facilitating links between carers, carer organisations and the Trust by providing a focal point for practical support such as access to premises;
 - Co-ordinating the development of an information pack on local services for carers; and
 - Developing sustainable partnerships with the voluntary and community sector.

All HSS Trusts, that have not already done so in response to the original Valuing Carers recommendation, should now take steps formally to designate a clearly identified carers' co-ordinator to ensure that all support services are brought under coherent leadership.

15. To support the role of the carers' co-ordinator and to ensure that carers are afforded appropriate priority within the organisation as a whole, all HPSS bodies should nominate a board member with specific lead responsibility for issues relating to carers.
16. It is also vital that carers have the opportunity to become fully engaged in the planning, delivery and evaluation of services not only for themselves but also for the people for whom they care. HSS Trusts should therefore support the establishment of a carers' forum within their area, working as appropriate with voluntary and community organisations to build local support networks. Service commissioners will need to establish

appropriate channels of communication to ensure that the views of reference groups are taken into account in their commissioning plans.

Statistical Information

17. The Carers and Direct Payments Act (Northern Ireland) 2002 places a legal obligation upon the HPSS to assess the needs of carers. It is absolutely vital that the HPSS is in a position to report accurately on the extent to which this obligation is being met. The Department's Information and Analysis Directorate is currently trialling an information system that will report on assessments undertaken and services in place for carers. HSS Trusts must cooperate fully in the development of the necessary information systems.
18. Commissioners should also ensure that information on need collated from carers' assessments is taken into account in reaching commissioning decisions.

Funding

19. Resources are not available to deliver on every aspect of the strategy immediately. The initial focus for additional investment, and a clear priority identified by carers themselves, is the expansion of flexible and responsive respite services. The Department has recently allocated £400,000 recurrently to the HPSS for that purpose. In addition, the Department directly funds the voluntary group Carers NI, which works for and with carers across Northern Ireland by providing information, support and training. In conjunction with others, the Department has also funded specific developments such as a regional carers' information network and a training DVD about young carers.
20. The voluntary and community sector is already well placed to deliver the type of flexible and responsive support services that will enable carers to continue caring and to give them as much access as possible to the same opportunities that others enjoy. It is therefore important that the sector be given every opportunity to engage fully in the development and provision of these services. Contractual relationships with the voluntary and community sector must be based on sustainability and the true cost of providing care.

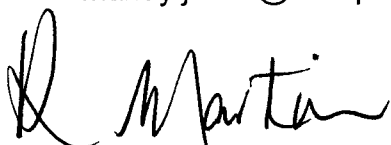
Summary of actions required:

- **The presence of a carer should be recorded on all relevant patient/client and carer records;**
- **Health and social care professionals should be particularly proactive in identifying the presence of older or younger carers;**

- **Health and social care professionals should ensure they are fully aware of guidance relating to seeking consent to share information;**
- **HSS Trusts should have a formally identified Carers' Co-ordinator;**
- **HSS Trusts should support the establishment of a carers' reference group within their areas;**
- **HSS Commissioners, Trusts and Councils should identify a board member with overall responsibility for carers' issues across their organisations;**
- **HSS Trusts should cooperate fully in the development of the necessary information systems**
- **HSS Trusts must engage directly with the voluntary and community sector about the development and delivery of sustainable carer support initiatives.**

Further Information

21. If you require further information on any of the details contained within this circular, please contact Mandy Jones on 02890 522930 or mandy.jones@dhsspsni.gov.uk.



RAY MARTIN
Elderly and Community Care

**Paragraphs 5.6 and 5.7 of “ The Protection and Use of Patient and Client Information”
(HPSS Guidance 1999)**

Release of information to protect the public

5.6 It may sometimes be justifiable to pass on patient or client information without consent or statutory authority. Disclosures for the “discovery of iniquity” are traditionally cited. Most commonly these involve the prevention and detection of serious crime, but can extend to other dangers to the general public, such as a public health risk or risk of violence, where, as, already noted, essential information may need to be shared with other agencies.

5.7 Each case must be considered on its merits, the main criterion being whether the release of information to protect the public should prevail over the duty of confidence to the patient or client. The possible consequences for the patient or client must be considered whatever the outcome. Decisions will sometimes be finely balanced and may concern matters on which HPSS staff find it difficult to make a judgement. Therefore it may be necessary to seek legal or other specialist advice or to await or seek a court order. It is important not to equate “the public interest” with what may be “of interest” to the public.