

CONSULTATION RESPONSE

Carers Scotland response to Better Health, Better Care: A discussion document

We welcome the Scottish Government's continuing commitment to sustaining and improving health and the development of the discussion document "Better Health, Better Care". Overall we agree with the content and focus of the document, in particular building on the work of "Building a Health Service Fit for the Future" and its development of a new model of health care delivery where carers are supported as partners.

We welcome the continued message that carers are key partners in the delivery of care. However, there is still significant work to be done to change this from a principle and aspiration to an issue that informs practice by health and social care practitioners.

However, we offer the following observations on the document.

Chapter 1: Improving Your Experience of Care

(a) Involvement

Involvement of carers in the design, development and delivery of services is too often tokenistic. A number of activities could improve carer involvement:

- the provision as standard of replacement care or funding for carers to arrange replacement care.
- meetings held at times that ensure that carers can attend. Planning for involvement needs to take account of the times care services are delivered and other responsibilities carers may have, for example, childcare or employment.
- the provision of transport to enable carers from areas with poor public transport to attend.
- improved publicity of opportunities to get involved
- the provision of training for carers to support them in becoming involved, for example, negotiation or assertiveness skills.

Moreover, there is a need to see carers as a distinct group with differing, yet often complementary, needs and aspirations to that of patients. Involvement should include both

patients and carers not simply a homogenous “patient/carer” or “user/carer” representative.

(b) Transport

At present, transport is a significant barrier to carers and the person they care for accessing health care services. In particular, for rural carers, transport is often infrequent, not available or not arranged in a way that meets their needs and, is often too expensive in relation to many carers limited finances.

- Health appointments arranged at a time that suits carers and patients.
- Dial a Bus and other similar schemes extended to support both health appointments and hospital visiting. This could include vouchers for taxis for those who cannot use public transport.
- Scottish Ambulance Service Patient Transport services encouraging carers to attend health appointments with patients. This includes ensuring that GPs and others booking transport are aware of the need to book space for a carer to attend with the patient.
- Reliable public transport to health appointments which should form part of a wider transport strategy.
- Reimbursement of travel costs for carers to visit the person they care for in hospital.

(c) Making health care available out of hours

The extension of health care to provide out of hours service could be beneficial to carers, in particular carers who are employed. These carers face the same difficulties as other employed individuals in accessing health appointments. However, they experience additional difficulties in arranging health appointments that fit in with alternative care services.

(d) Improving the patient and carer experience

It is essential that the key role that carers play in reducing emergency admission and supporting self-care and the management of long term conditions is fully recognised. Carers are key partners in the provision of care and, as such, need information, training and support to enable them to support the health care of the person they care for. Many of these issues have been addressed through the development of NHS Carer Information Strategies. However, it is essential that NHS Boards have a real commitment to their implementation, for example, by providing carer awareness training to all staff.

Alongside these issues, there is a need to ensure that hospital discharge is more effective. Often discharge is arranged without care services and sufficient support and information in place. This places a significant burden on carers.

Awareness of the issues faced by carers is essential. This includes appointments made at a time that suit carers, for example, at a time when care services are available and when appropriate transport is available. Effective partnership with social care services in this and indeed all instances is essential. A carer may not be able to attend a health care appointment or have investigations or treatment without the provision of replacement care. This includes respite care to allow a carer appropriate convalescence following an operation or period of ill health. However this needs a coordinated approach. It should not be assumed that carers are already in contact with social services. Recent research found

that 41% were supporting someone who was not receiving any services at all.¹ Planning to ensure carers can attend health services is essential,

Chapter 2. Best Value

Carers Scotland welcomes initiatives to ensure best value in the delivery of NHS services. We support the aspiration of improved standards and ensuring equality of service and treatment throughout Scotland and for improved joint working and activities between health, social care, the voluntary sector and other local authority services such as, for example, housing. More services available locally can benefit both carers and patients but carers must have confidence that quality is not sacrificed for accessibility.

We would welcome a target for the maintenance and improvement of carers health as an operational target for NHS Scotland.

Chapter 3. Taking Responsibility

Carers Scotland agree with most aspects of this approach. However, for carers a number of issues must be considered:

- **the inclusion of carers in health promotion strategies:** Carers have a significantly increased likelihood of poor health and strategies must be put in place to address this (this is discussed further in our response to Chapter 4: Tackling Health Inequalities) For example, a survey of 5000 carers in 2006² found that 73% of carers said that health problems affected their own ability to care, with 59% saying their health problems affected the person they cared for. The most common complaints, stress/worry (91%), depression (58%) stem from the emotional impact of caring, while backache (50%) demonstrated the physical toll on the health of carers. GP registers of carers are a positive first step but we would welcome the inclusion of additional health related criteria – not solely information and referral to appropriate social care services . This could include an annual health check for carers.
- **marketing and public awareness of health issues is important:** We would welcome the consideration of improved public awareness of caring. The NHS has an integral part to play in raising the profile of caring. Often carers do not recognise themselves as “a carer” and see themselves as, for example, a parent, child or spouse. However, this often means that they do not access the services and support available. For example, research by Carers UK during Carers Rights Day 2005 estimated that there is around £70 million of carers benefits unclaimed each year. In addition, every year over 170,000 people become carers, with a similar proportion ceasing to be carers.³ To ensure that those who are new to caring are not missed, we would recommend an annual public information campaign of the role of carers and the need to protect their health – this could be linked with the annual flu immunisation campaign and the need for carers of vulnerable people to be immunised.
- We would encourage the Scottish Government to **extend low level health measures to protect the health of carers.** A positive step was made in introduction flu

¹ Yendell S et al “Stages and Transitions in the Experience of Caring”, University of Leeds and Carers UK, 2007

² Carers Week Survey 2006

³ “In the Know: the importance of information”, Carers UK, 2006

immunisation for carers. However, anecdotal evidence suggests many GPs do not consider carers to be a priority or indeed are unaware of the instruction to include carers in flu immunisation programmes. Other measures could include healthy activities and alternative therapies to reduce stress or annual health checks for carers from the point they are identified. Investing small amounts of resources in carer support could prevent serious deteriorations and crisis in health and wellbeing that might otherwise have costly implications for health and social care.⁴

- We welcome the aspiration to **increase participation in sport and physical activity**. However, for carers this can often be nothing more than an aspiration as the cost, availability or time they need is not available. Ensuring carers can be included in sport and physical activity initiatives could include concession schemes for carers, activities delivered locally in, for example, community facilities such as evening activities in schools and daytime activities in community halls and, the need to consider carers leisure and recreation needs in carer's assessments and the delivery of services to give carers time to take part.
- We welcome the identification of **returning to work as an issue that can positively impact on health and wellbeing**. However, for many carers returning to work will not be possible without effective, flexible alternative care services being available. In recent research, most working carers said they needed at least one service that they were not currently receiving and, very few had access to breaks and less than a quarter access to respite services. Between 40% and 50% said that they felt the lack of flexibility and sensitivity in the delivery of services was hampering them in getting support.⁵

For carers who are currently in employment, we would welcome the extension of campaigns to provide safe and health promoting workplaces. This should include aspects of supporting employees who having caring responsibilities. Work through Carers Scotland's Action for Carers and Employment project and the Employers for Carers Initiative (see www.carerscotland.org/employersforcarers) identified a range of good practice in supporting carers in the workplace and worked with other employers to develop activities. These included carer groups in the workplace, information packs for carers and specific support such as flexible working and access to a telephone to check on the cared-for person.

- **The improvement of health needs to be a wider agenda than simply the activities of NHS Scotland.** Housing is a clear example. The following scenario outlines the impact inappropriate housing can have on patients and carers.

A patient who has had a stroke and now cannot walk needs barrier free housing on one level as he is now wheelchair bound. He should not be discharged without appropriate housing. Whilst an assessment was carried out in the hospital, no services are ready for his discharge. He was discharged to carer (his wife) at home. The Scottish Ambulance Service patient transport service brought him home and lifted him into his house and into bed, which has now been placed in the living room. His house has stairs to the front door and inside. He lives and sleeps downstairs as he cannot get up the stairs. The toilet is upstairs so he has to use a commode downstairs. His wife has to lift him out of bed and onto the commode, as well as washing and dressing him. A stair lift cannot be provided on the type of

⁴ Hirst, Michael "Hearts and Minds: the health effects of caring", University of York Social Policy Research Unit and Carers Scotland, 2004.

⁵ Yendel, S et al "Managing Caring and Employment", University of Leeds and Carers UK, 2007

stairs they have in the house. Even if they could fit the chair lift it will take at least 3 months. He eventually receives a wheelchair but cannot leave the house as there are four stairs at the front of the house. His wife's caring responsibilities are causing a strain on her physical health and wellbeing and is experiencing back pain and depression. Both he and his wife are deeply unhappy with the situation.

In addition, schemes such as central heating scheme, the Warm Deal and other energy efficiency schemes can improve health through ensuring individuals have warm homes and reduced fuel costs. The NHS has a key role to play in ensuring patients have information on these initiatives and the ways in which they can be accessed.

- **Social work services and the voluntary sector play a key role in ensuring that carers can access both health services and physical activities to improve their health.** This include not only access to primary care but support to enable carers to have the opportunity to take part in activities to improve or maintain their health and wellbeing. As noted earlier, Carer's Assessments should include consideration of the level of support needed to ensure carers can take part in leisure activities and access health services. This may require additional guidance or legislation.

Chapter 4: Tackling Health Inequalities

The suggestions to reduce health inequalities are welcomed. Caring must be seen as a contributory factor to inequality in health and addressed as part of public and local health planning.

Carers Scotland considers the emerging work from the Glasgow Centre for Population Health to be of critical importance. However, we would hope that this work would include the effect of caring as one of its work streams. In Scotland, carers are a third more likely to be in poor health than non-carers. In some areas of Scotland this likelihood of being in poor health is double that of non-carers.⁶ Carers face ill health as a direct consequence of their caring role. Research from the University of York found that carers were 60% more likely to experience emotional distress than non-carers.

Recent research⁷ has identified a number of factors linking inequality of finances, support and opportunity to poor health. Carers who are struggling financially are more likely to be in poor health. Furthermore, carers reported that their frustrations in accessing services, and the limited support they receive, contribute to poor health. There is also a very clear relationship between health, caring and the hours of care given. For both men and women, and for those working full or part-time, self-assessed health deteriorates as weekly hours of caring increase⁸. And, a variety of conditions, including stress-related illnesses are commonly experienced by carers.⁹

Carers also reported¹⁰ putting the health needs to one side, giving priority instead to their caring role, and focusing on the person they care for. As one carer said, despite being diagnosed with skin cancer:

⁶ "In Poor Health", Carers UK, 2004

⁷ Yendell S et al "Diversity in Caring: towards equality for carers", University of Leeds and Carers UK, 2007

⁸ Bucker L & Yendell S "Who cares wins: statistical appendix", Carers UK (2006)

⁹ Mackenzie, CS et al "Cognitive Functioning Under Stress: Evidence from informal carers of palliative patients", Journal of Palliative Medicine (2007)

¹⁰ Yendell S et al "Diversity in Caring: towards equality for carers", University of Leeds and Carers UK, 2007

“In my situation I have to put my caring situation first. (Social services) would just leave you plodding along on a non-functioning level really, and that’s the thing that is really wrong with the system”

With caring affecting 3 in 5 of the population at some time in their lives, the impact of caring as a major cause of health inequality must be explored and action developed for local health partnerships to include this in their work.

Specific planned activities should be considered at meeting the health needs of carers who are additionally disadvantaged by ethnicity, rurality, age and/or sexuality. Furthermore, planning should incorporate specific targets to address to health needs of young carers. (discussed further in “Chapter 6. Best possible start” below).

Chapter 5: Anticipatory Care and Long Term Conditions

Carers Scotland welcomes the focus on anticipatory care and strategies to support the management of long term conditions. We support the recommendations made with additional comments in two areas:

- **Intensive Case Management based on individual care plans is to be welcomed.** However, these plans must ensure effective joint working between health and social care. It is not sensible for good plans to be made by NHS Scotland in managing a long term condition without ensuring that appropriate social care services are available where necessary and that information and support is available to carers supporting health and care. Without taking a holistic approach, issues such as the breakdown of care and inappropriate admission alongside damage to the health and wellbeing of the carer, can arise. Often these issues will have significant cost implications for health services and poor health outcomes for both patient and carer.
- **Improved capacity for cognitive therapies and other psychological therapies for carers is essential.** Often carers in distress are unable to access the counselling services they require as these services are either unavailable or have significant waiting lists. Furthermore, we would recommend additional consideration of the need to provide additional bereavement counselling services. Whilst Cruse Bereavement Care provides an excellent service it is often oversubscribed. One carer was advised that her local Cruse Service had a 6 month waiting list and NHS services were unavailable. She was offered no other options and this left her completely unsupported and in significant distress. Carers Scotland would welcome additional investment in bereavement counselling and general counselling through both the NHS and the voluntary sector including the capacity for local carer support services to have funding to commission professional counselling for carers who approach them.

Chapter 6. The Best Possible Start

Carers Scotland welcomes the recommendations made. However, we would highlight the issues faced by young carers¹¹. Although around 16000 young carers were identified in the Census 2001, it is estimated that there could be around 10 times this many – hidden and

¹¹ Dearden C & Becker, “Young Carers in the UK: the 2004 report”, Carers UK and The Children’s Society, 2004

unsupported. These young carers may be the least likely to access health services and at risk of poor health in the future.

- **A significant proportion of young carers receive no formal support** - one fifth of young carers and their families receive no support other than contact with a dedicated young carer service.
- **Being a young carer affects educational achievement** - 27% of secondary school age young carers missed school and experienced educational difficulties and for primary school age young carers the proportion was 13%. Four in 10 children caring for someone who misuses drugs or alcohol have educational difficulties.
- **Many young carers are caring for a significant number of hours each week** - one third of young carers provide between 10 and 20 hours of care each week, 16% over 20 hours and 2% more than 50 hours.
- **Young carers are carrying out a range of tasks that could impact on their health** - 48% provide general and nursing type care and 18% intimate personal care.

Carers Scotland is aware that the Scottish Government aims to support young carers more effectively and ensure that they are enabled to be children and young people first and foremost. However, it is essential that health services identify their key role in ensuring young carers are able to access health services and activities to promote health and, the opportunities to work in partnership with social services, education and the voluntary sector to positively impact on the lives of young carers.

Chapter 7. Continuous Improvement in Healthcare

Carers Scotland welcomes the recommendations made. We particularly welcome the aspiration to ensure that services respond to individual needs and circumstances. We would recommend the inclusion of carers as a group having specific and differential needs to that of the general population. Furthermore, the provision of local diagnostic facilities would be beneficial to carers and patients. As highlighted earlier, transport to health services can be a significant barrier to both carers and patients. Local services can assist in overcoming this barrier.

About Carers

- There are 660,000 carers in Scotland saving the economy £7.6 billion each year.
- 110,000 carers provide 50 hours of care or more each week.
- 178,000 people become carers every year.
- 3 in 5 of the population will be carers at some point in their lives.
- 250,000 carers juggle their caring responsibilities with employment.
- Carers often face significant poverty with a third in debt and a further third cutting back on food or heating. More than half of carers say that financial worries are affecting their health ¹².
- By 2037 there will be an estimated 1 million carers in Scotland.

¹² "Real Change, Not Short Change", Carers UK, 2007

About Carers Scotland

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

Carers Scotland is an organisation of carers fighting to end this injustice. We will not stop until people recognise the true value of carers' contribution to society and carers get the practical, financial and emotional support they need.

Carers Scotland is here to improve carers' lives.

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

Carers Scotland achieves this by:

- campaigning for the changes that make a real difference for carers.
- providing information and advice to carers about their rights and how to get support
- mobilising carers and supporters to influence decision makers.
- gathering hard evidence about what needs to change.
- transforming the understanding of caring so that carers are valued and not discriminated against.
- providing carer awareness training for staff in health, social care and the voluntary sector
- promoting training for carers to maximise their skills and experience.

CARERS Scotland
the voice of carers

Carers Scotland
91 Mitchell Street
Glasgow
G1 3LN

Tel: 0141 221 9141
Email: fiona.collie@carerscotland.org
Web: www.carerscotland.org