

CONSULTATION RESPONSE

Carers Scotland response to Mental Health Strategy for Scotland 2011-15

Carers Scotland is a charity set up to support the thousands of people in Scotland who care for an elderly partner, sick friend or disabled family member. Caring is part of life. Three in five of us will provide unpaid care for someone at some point in our lives. However, without the right support the personal cost of caring can be high with many carers experiencing poor health, poverty and disadvantage. Carers Scotland helps carers and campaigns to make their lives better.

Carers are key partners in care and contribute significantly to society, health services and social care, saving the economy an estimated £10.3 billion each year¹. There are more than 657,000 carers in Scotland, with more than 110,000 providing 50 hours or more of care each week. It is estimated that by 2037 there will be 1 million carers in Scotland.²

Carers Scotland welcomes the opportunity to comment on the Mental Health Strategy for Scotland and would make the following response. We have focused this response on some key areas for consideration.

In the first instance, whilst the Strategy includes a section on carers, we believe that Strategy as a whole would be strengthened by having a consistent thread running throughout the it emphasising caring so that is not seen in isolation. It is important to ensure that carers' role as key partners in the provision of care is fully recognised and the needs, experience and contribution of carers are built into all elements of the Strategy, particularly around issues such as:

¹ Valuing Carers, Carers UK (2011)

² ibid

- confidentiality and information sharing with both adult and young carers
- supporting the emotional wellbeing of carers
- training around managing their caring role
- training for staff at all levels in hospital based, community and general practice about the role of carers and working effectively with them as key partners.
- carer involvement in supporting self management and planning services

The following paragraphs within our response expand upon some of these issues.

Caring, consent and confidentiality

Carers, particularly those caring for someone with mental ill health, often report that they are not involved in discussions about the care of the person they look after and find it difficult to obtain the information they need to provide appropriate support to the person they care for.

“I need to know what you are trying to achieve for my son and how you are planning to do it. I need to understand the treatment that he is receiving so that I can play my part in his recovery programme. What I do not need to know are the personal details of what takes place between him and the professionals concerned.” (carer³)

This lack of involvement of carers and of sharing appropriate information fails to recognise carers' role as key partners in care nor does it take advantage of the wealth of knowledge and experience the carer has about caring and the person they care for. Whilst we recognise the importance of patient confidentiality, the carer is likely to be the principle source of support for the individual in the community and be required to, where necessary, respond to an immediate crisis. “Confidentiality” often creates a significant barrier, even where an individual has already agreed to information sharing and/or involvement of their carer.

Guidance on developing services for carers and families of people with mental illness by the Department of Health⁴ notes:

³ “Carers and confidentiality in mental health” Royal College of Psychiatrists and the Princess Royal Trust for Carers

⁴ 2002

"The carer and the person cared for have the right to expect that information either provides will not be shared with other people without their consent. But issues around 'confidentiality' should not be used as a reason for not listening to carers, nor for not discussing fully with service users the need for carers to receive information so that they can continue to support them. Carers should be given sufficient information, in a way they can readily understand, to help them provide care effectively."

Carers Scotland therefore recommends the development of practical guidance for staff on appropriate information sharing and on obtaining consent for sharing of more detailed information. This could be developed in line with that described within guidance on NHS Carer Information Strategies⁵ on the provision of information for all care groups. This recommended guidance should be developed to also reflect the requirements of effectively supporting young carers in their caring role.

Promoting carers' emotional wellbeing

The Strategy would be strengthened by prioritising the emotional wellbeing of carers within local and national developments. Research⁶ has consistently shown the high emotional costs of caring with more than half of adult carers reporting depression and most experiencing stress and anxiety. In Carers Scotland's most recent research, 79% of carers reported that they experienced mental ill health as a consequence of caring.⁷ In research⁸ with young carers in Edinburgh, 60% had problems sleeping and over 30% had self harmed or had suicidal thoughts.

"I gave up working to care for an elderly relative and receive no financial help or support. I feel like a nobody. I feel very lonely and depressed most of the time."⁹

⁵ HDL (2006) 22, Section 3.4, "NHS Carer Information Strategies: Minimum requirements and guidance on implementation", Scottish Government (2006)

⁶ For example, "Hearts & Minds: the health effects of caring", M. Hirst published by Carers UK (2004), "Carer distress: A prospective, population-based study, *Social Science & Medicine*, Volume 61, Issue 3, Pages 697-708, Michael Hirst; "In Poor Health: the impact of caring on health", Carers UK, 2006; SCIE research briefing 11: The health and well-being of young carers (2005), Carers Week Survey 2006

⁷ "The Cost of Caring", Carers UK & Carers Scotland (2011)

⁸ V. E. Cree "Worries and Problems of Young Carers; Issues for Mental Health" in *Child and Family Social Work* (2003) 8, pp 301-309

⁹ Carer in "The Cost of Caring", Carers UK & Carers Scotland (2011)

This impact on emotional health has been recognised within the Government's recent carers' strategies, Caring Together and Getting it Right for Young Carers which make a number of recommendations to promote and improve the emotional wellbeing of carers, including increasing access to psychological therapies and to child and adolescent mental health services.

Carers Scotland recommends that a particular target or outcome is developed within this Mental Health Strategy to seek to improve the emotional wellbeing of carers and young carers. This should incorporate increased access to psychological therapies and counselling for both adult and young carers and the promotion of practical and emotional support services and training available from the NHS, carer and condition specific organisations, advocacy and social work services.

In addition, with more than 100,000 carers aged 65 or over, activities to promote better mental health in later life should also recognise the need to support the emotional wellbeing of older carers.

Measures should also include increasing the availability of bereavement support for carers at the end of their caring journey. Bass and Bowman (1990) suggest that "*the greater the caregiving strain on an individual prior to bereavement then the greater the strain on the individual post bereavement.*"¹⁰ Mixed forms of support should be developed including counselling, support groups and information. For example, Tudiver et al (1995) identifies that emotional support through regular support group meetings and incorporating health promotion fills many of the bereaved individual's needs¹¹. The role of GPs and other frontline primary healthcare workers is pivotal in identifying carers who require this support and referring them to appropriate services and support. Carers Scotland would also recommend building on the knowledge and expertise of local carers and voluntary organisations by, for example, encouraging the development (where not already available) of specific support for carers on bereavement and moving on from caring. This may involve, for example, investment in dedicated staff or alternatively in providing appropriately qualified staff to deliver support hosted by organisations.

¹⁰ Literature Review of Bereavement and Bereavement Care, The Joanna Briggs Institute & Faculty of Health and Social Care, Robert Gordon University (2006)

¹¹ *ibid*

Furthermore, employers also have a role to play in supporting carer employees on their return to work for bereavement. Russell (1998)¹² suggests that employers have a “*structure and system in place*” to support staff who are bereaved. This approach makes sense for employers to maintain a healthy workplace for all employees, not solely carers and may prevent further impact on an individual's emotional wellbeing. Activity with employers should remain a key part of work to reduce stigma, raise awareness of the support available and enable carers and individuals to remain in employment.

Training for carers

Training for carers should be an integral element of the Strategy. As equal partners in the provision of care, carers should have the same access to training as the paid workforce. Caring Together highlighted that carers who have the opportunity to undertake training report feeling more supported and confident in managing their caring role. This supports carers' emotional and physical wellbeing and in turn can reduce the likelihood of a breakdown of care and more costly interventions by statutory services. For example, a trial¹³ into providing training to carers of individuals who had had a stroke, showed a range of positive outcomes for carers and patients including improved quality of life and reduced anxiety and depression. Further evaluation¹⁴ showed greatly reduced costs for care.

As noted within our contribution on emotional support, many local and national carer and voluntary organisations provide training and activities to support carers' emotional wellbeing. This includes topics such as managing stress and changing relationships alongside, for example, moving and handling, first aid and managing medications.

Carers should also be offered training to enable them to effectively support the person they care for in managing their condition. A number of local carer organisations have received funding through NHS Carer Information Strategies and the national carer organisations training grants to support the development and delivery of training on caring for someone with, for example, dementia, mental health, MS and stroke. Other voluntary organisations also provide training for carers including, for example, Alzheimer's Scotland's and Diabetes UK Scotland.

¹² *ibid*

¹³ Training for carers: randomised control trial, Kalra et al., 2004

¹⁴ Training for care givers of stroke patients: an economic evaluation, Patel et al, 2004

Training for the workforce

Carers Scotland welcomes recognition of the importance of training the workforce. We would recommend the extension of this training to include key issues including, as mentioned earlier, consent, capacity and information sharing and to understand and recognise the vital role and contribution of unpaid carers. This understanding of carers' rights and role should be incorporated into all pre and post qualification training for staff and carers should be involved in the development and *delivery* of this training. This training should be extended to staff at all levels, in both community and acute settings and across sectors including the third sector.

This training will be important to effectively identify carers and ensure that they are aware of their rights, of the support available and, where appropriate, referred for a Carer's Assessment. Earlier identification and support can help reduce the impact of caring on a carers' physical and emotional health and prevent a breakdown in care. This is particularly important as many carers often do not recognise themselves as carers. Some carers may take years to identify themselves as such and consequently miss out on financial and practical support. Missing out on critical support can further increase impact on mental health.¹⁵ For those who have not, Within Scotland's carers' strategy, Caring Together, the Scottish Government has clearly recognised this importance of carer identification and committed to a range of actions including:

- working with NHS Boards to ensure that identifying and supporting carers and young carers is embedded in workforce training.¹⁶
- NHS Education Scotland will work with regulatory, professional and national bodies to communicate this importance of identifying and support carers and young carers within workforce training and education.¹⁷
- approaching all relevant national training and qualification accreditation bodies to agree how they could integrate carer identification and awareness into the curriculum by 2013.¹⁸

¹⁵ 83% of carers reported that had experienced mental ill health, missed out on financial support and had not recognised themselves as a carer: "The Cost of Caring", Carers UK & Carers Scotland (2011)

¹⁶ Caring Together, Scottish Government (2010) Action Point 14.5

¹⁷ Ibid Action Point 14.4

¹⁸ Ibid Action 8.2

Implementation and review

Carers Scotland has supported the involvement of carers in the inspection of social work services. The evidence from our partnership with the Social Work Inspection Agency suggests that the involvement of carers as lay inspectors in the inspection of social work services has been both positive and productive. This involvement is continuing under the new Care Inspectorate. Evaluation of the involvement of carer inspectors noted the important part they played in identifying improvements needed.¹⁹

Carers Scotland has continued to promote the need to include carers as inspectors and in the design, development and delivery of services across both health and social care. Carers have unique and expert knowledge, of their own role and of the services and supports that can make greatest impact to carers and people using services. The recent Health and Sport Committee inquiry into the regulation of care for older people noted their belief that *“engaging service users, carers and relatives in the inspection regime is vital. Their engagement helps to ensure that the Care Inspectorate is focusing not just on the inputs into the care service but its outcomes for the service users.”*²⁰

In this respect, we believe that the Strategy should formally incorporate this involvement nationally and locally in both health and social care.

In addition to this activity, in line with carers' role as equal and expert partners in care, carers should be supported to become involved in the design and delivery of local services in their area. This should include the provision of training to support their involvement.

Furthermore, the involvement of the third sector is crucial. They are a significant contributor to the delivery of services and support, with more than 130,000 employees across Scotland²¹. As noted in the ministerial forward to “The Enterprising Third Sector Plan”, *“third sector organisations provide services to some of the most vulnerable people in Scotland and as such have an important role in delivering better outcomes for our communities”*. Greater success can be achieved in implementing the Strategy by sustaining and engaging with the third sector as *full* partners in providing health and social care services in the community. In supporting carers effectively, this includes involving a range of organisations including carer, condition specific and advocacy organisations.

¹⁹ Improving Social Work in Scotland, Social Work Inspection Agency (2009)

²⁰ Health and Sport Committee, 3rd Report, 2011 (Session 4)

²¹ SCVO (2010) Scottish Voluntary sector statistics

Conclusion

Carers Scotland welcomes the proposed Mental Health Strategy for Scotland and supports the proposals to deliver better outcomes for people with mental ill health, dementia and their carers. Carers have a significant part to play in delivering these outcomes. Further action in the areas which we have indicated will better recognise and support carers. We believe that this in turn will strengthen the Strategy and provide better outcomes.

Carers Scotland
30 January 2012

About Carers Scotland

Carers Scotland is an organisation of carers fighting to end the injustice of carer ill health, poverty and discrimination. 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 and specialist 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

The Cottage
21 Pearce Street
Glasgow G51 3UT

Tel: 0141 445 3070
Email: fiona.collie@carerscotland.org
Web: www.carerscotland.org

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