

<b>Section A: NICE to complete</b>	
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<b>Guidance title:</b>	Interventions to support older carers
<b>Committee:</b>	
<b>Subject of expert testimony:</b>	Carers
<b>Evidence gaps or uncertainties:</b>	[Please list the research questions or evidence uncertainties that the testimony should address]
<ul style="list-style-type: none"> <li>- Effective interventions to support the independence and mental wellbeing of older carers</li> <li>- Benefits of interventions to older carers and to those for whom they care</li> <li>- Effective means of identifying older carers</li> <li>- Barriers and facilitators to delivering effective interventions to older carers</li> <li>- Data on the cost effectiveness of interventions in this area</li> </ul>	
<b>Section B: Expert to complete</b>	
<b>Summary testimony:</b>	[Please use the space below to summarise your testimony in 250 – 1000 words – continue over page if necessary ]
<p>Carers Trust is the largest charity in the UK for carers, with our Network Partners (local carer services) we support over half a million carers which includes young carers.</p> <p><b>Issues Faced by Older Carers</b></p> <p>There are 1.3 million people over the age of 65 with caring responsibilities and 670,000 carers of people with dementia the vast majority of whom are over the age of 60.</p> <p>Carers Trust has undertaken a number of pieces of research looking at the issues faced by older carers <sup>1 2</sup> this research highlighted a number of issues and challenges faced by older carers. These include:</p> <p>Four in ten older carers stated their mental wellbeing had deteriorated in the last year.</p> <p>69% said that caring had a negative impact on their mental health.</p> <p>Many carers felt that there was a lack of choice for the future for both them and the person they care for.</p> <p><i>“I feel trapped by my husband’s dependency on me; I am unable to envisage a happy future for either or both of us, given the inevitable deterioration in his neurological</i></p>	

<sup>1</sup> Always on Call, Always Concerned, The Princess Royal Trust for Carers, 2011.

<sup>2</sup> A Road Less Rocky – Supporting Carers of People with Dementia, Newbronner, Chamberlain, Borthwick, Baxter, Glendinning, Carers Trust, 2013

*condition. I am often overwhelmed by a feeling that life is hopeless and lacking in joy.” - Carer*

Many older carers felt that their needs as carers were not considered by professionals.

It should be noted that as the age of the carer increased so did their belief that their physical and mental health had been affected by their caring role.

A lack of access to a carer break or respite was cited as contributing to the strain of caring.

Most support for carers was provided by carers' organisation yet for many carers the lack of an “offer” of a referral to carer support services was a problem. It should be noted that as many carers do not prioritise their own health needs, signposting to services is insufficient.

*“Although I had the contact details for Carers Trust it took me a long time to finally admit that I was not coping as well as I thought I was. My feeling is that a more proactive attitude from my GP would have been useful. Carers do not think we are carers until we are in over our heads.” - Carer*

The impact on older carers has an impact on both their mental and physical wellbeing, it was identified that those caring for someone with dementia experienced significant additional challenges.

In addition to the issues presented by their caring role it should be noted that the complexities of being an older carer are many these include:

Two people with complex and serious medical conditions caring for one another

Older carers often caring for more than one person.

The challenges of an ageing population of people with serious learning and mental disabilities who must then care for an elderly parent and vice versa – commonly known as “mutual caring”.

### **Means of Carer Identification and Support**

Carers Trust has a number of initiatives that work directly with health professionals to raise awareness of carers needs and improve the identification and support provided to them.

These include:

- Carers Trust Pharmacy Pilot – working directly with pharmacists to identify and refer carers to local support and their GP.
- Carers Trust Triangle of Care<sup>3</sup> initiative working with mental health trusts (but also developed for dementia in general hospitals) for practitioners to identify, include and support carers more consistently.
- Local initiatives including: carer prescription – GP referral to local carer services through a prescription system. Similar system for prescribing a break for a carer.

In addition Carers Trust's Improving Health Outcomes Programme which provides grant funding to Network Partners focussing on needs of older carers; respite and impact on mental health of the caring role both identified as issues to focus on.

A huge range of services offered: carer break prescriptions, counselling courses, holistic therapies, mindfulness, caring skills workshops, social activities, carer

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<sup>3</sup> The Triangle of Care, Carers Included: Good Practice in Dementia Care, Carers Trust, Royal College of Nursing, 2013

support worker interventions – all carers involved cited improved mental wellbeing some of up to 98% attendance.

Some of the challenges faced by carers and carers services when engaging with health professionals include the model of patient-focussed care which often excludes carers. A move to a family-centred model of care would benefit all involved.

### **Measuring Effectiveness & Cost-Effectiveness of Carer Support**

The effectiveness of Carer Support often cites provision of consistent, varied and appropriate support through the length of the carer journey.

Linking NHS, Social Care and third sector together – crucial that carers are identified, included and supported as early as possible on the carer journey.

Skills, knowledge, respite, support (emotional and physical), peer support, advice and information all cited as valuable for carers with identified positive impacts for carers.

Carers Trust Social Return on Investment study shows value of sometimes complex impact measurement of a service for carers. 2011 analysis of value of five carer services was for an investment of £5 million SROI benefit was £73 million.

### **Conclusion & Next Steps**

Carers Trust welcomed the opportunity to provide evidence on the impact of older carers' mental wellbeing. Older carers are a growing population however, the impact of caring and the benefits of providing clear information, advice and support to them requires further more dedicated research.