

Caring Conversations

Older Carers and health – promoting wellbeing

Caring Conversations is a new series of resource papers by the Association of Directors of Adult Social Services [ADASS] in support of implementation of the refreshed national strategy for carers published by the Coalition Government in November 2010. The underpinning rationale of the *Conversations* series is that we can better learn from experience and build on what works well if we talk about it in the context of doing something in response. This paper is about impacts on older carers [65 and over] caring for a partner or near relative of a similar age and the particular issues the hospital discharge process can raise for them.

Some messages

Earlier in 2011, The Princess Royal Trust for Carers published *Always on Call, Always Concerned – A Survey of the Experiences of Older Carers*. [1] This highlighted that many older carers:

- found it difficult to cope with the physical demands of caring
- faced loss and change in relationships that were hard to adjust to
- were at risk of poor physical and mental health, particularly depression
- felt frustrated when care professionals did not involve them as partners in care
- had experienced a deterioration in their own health and wellbeing
- rarely got a break from their caring role
- worried about what the future held for them and the person they cared for.

Prior to this both the ADASS and The Trust had published papers about carers and hospital discharge. Many of the carers involved were likely to have been older carers. The key messages were similar:

- raising recognition and support of carers within discharge policies
- improving self-identification of carers and take up of assessments
- providing accessible and timely information for carers
- embedding carers issues in staff training and development
- changing professional attitudes and cultures and their impact on carers
- ensuring discharge pathways understand potential impacts on carers
- responding to particular pressure points around caring for those with dementia
- growing operational cultures to support carers as partners in caring.

Remember, it's about all of us

At some point in our lives most of us are likely to assume responsibility for helping to care or support someone close to us. We become carers when our caring responsibilities exceed normal expectations for a relationship due to the illness or chronic condition of someone close to us. There will be particular pressure points along the care and support pathway, such as, going into or coming out of hospital, breaks, money and endings.

Older carers – some figures

Of the UK's estimated six million carers around half are over 50. This paper is concerned with carers aged 65 and over and draws on material from *Always on Call, Always Concerned*, the 2001 Census and materials published by carers organisations [2] [3]. The following tables summarise data for England from the Carers Factsheets on the Department of Health website:



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Table one: England, older carers and number of hours caring, men and women [2001] [4]

All carers	Men			Women		
	1–19hrs	20–49hrs	50+hrs	1–19hrs	20–49hrs	50+hrs
Age						
65–74	161,610	28,319	80,746	177,386	32,478	101,658
75–84	59,256	16,318	58,060	60,251	13,177	54,179
85+	7,182	2,596	11,156	7,359	1,927	8,044
Total	228,048	47,233	149,962	244,996	47,582	163,881

Table two: England, older carers in poor health and number of hours caring, men and women [2001]

Carers in poor health	Men			Women		
	1–19hrs	20–49hrs	50+hrs	1–19hrs	20–49hrs	50+hrs
Age						
65–74	19,697	5,805	20,817	21,206	6,604	23,695
75–84	9,564	3,879	16,963	10,449	3,775	17,072
85+	1,510	666	3,652	1,882	677	3,051
Total	30,771	10,350	41,432	33,537	11,056	43,818

While these data are ten years old, the messages they contain are still relevant:

- There were nearly 900,000 older carers of whom a fifth said they were in poor health.
- Just over a third of older carers gave 50 or more hours of care.
- The likelihood of the carer being in poor health increased steadily with age.
- Just over a third of older carers were aged 75–84.
- The proportion of male carers rises gradually with age.
- Carers aged 85 and over are more likely to provide more hours of care a week.
- One in ten carers are in poor health.

Other material shows:

- Male carers were usually living with a partner.
- Regional variations in the proportion of older carers in poor health, often reflecting geographic patterns of life expectancy, poor health and socio-economic disadvantage.
- Fewer carers, reflecting population profiles in 2001, were from black, Asian and minority ethnic groups.
- Experience of financial difficulties linked to caring.
- Declining physical and mental health and wellbeing during the time of being a carer.
- A third of older carers report cancelling medical treatment due to caring responsibilities.
- Some eight out of ten older carers have worries about the future and the person they support.
- Nearly four in ten carers are unable to get breaks away from caring.

Some older carers speaking [1]

Weight of responsibility:

- I feel so responsible for everything.
- However tired I feel, I still have to care for my husband.
- I worry that I will not cope with caring and that makes me low.
- Worrying about how things turn out – as wife’s condition gets worse.
- So many things to remember, sometimes feel like my head will explode.

Feelings of Loss:

- Being a carer for my husband I find it hard when I see couples having days out together wishing I could do that.

- I have lost my husband and now have to look after a complete stranger.
- It has limited opportunities in my life and upsets me when people speak of their opportunities.
- Feel I am having my life taken away from me ... at 85 I do not have many years left.

Tensions:

- I feel as I get less able I will be able to do less but my husband doesn't think this and expects me to do everything I always have.
- My wife won't go into care or respite and I support this so I worry about [it].
- Although I would like to take a break –I feel guilty if I go out for a couple of hours.
- Unable to have a hip replacement.
- My husband was recently in hospital ... and sent home too quickly.

Impacts – physical health

- Back trouble by so much lifting for years.
- Tiredness and general feeling of fatigue.
- I am much slower and in pain, constantly taking painkillers and lack of sleep.
- I don't really get the sleep I need [up] at least three times a night.

Impacts – mental health

- The strain of constantly looking after someone with advanced Alzheimer's is emotionally and physically draining.
- Get upset watching my husband struggle.
- I am constantly mentally abused by my mother which is totally unfair as I do so much for her.
- My fear is that I too am getting older and I worry about financing ... care.

Worrying about the future

- Always worried about the future – will not be able to keep it up.
- Mainly I worry what would happen if I was to become ill.
- Care for my wife if I should die first

Older carers – local conversations to make a difference

This section of this Conversations paper invites local statutory agencies, patient and carer organisations to use this paper to have local conversations about the experience of older carers and what would improve it for them. While suggesting some conversation points, the most valuable resource will be local experience and feedback. Celebrate what works well, talk about what matters and try to agree on what would make a real difference to outcomes for carers and the person they support in your area.

Planning, commissioning and consultation

- Are the needs of older carers reflected in our Joint Strategic Needs Assessment?
- What is local feedback from older carers telling us about local services and outcomes?
- How is feedback from older carers being used in local commissioning through the Health and Wellbeing Board?
- Is there scope for an Overview and Scrutiny review of improving outcomes for older carers?

Personalised local support and services

- How can personalised care and support, including universal services, secure improved outcomes for older carers?
- Are we able to reduce worries about the future by use of emergency care and support schemes?
- How accessible are breaks for carers locally and is there unmet need?
- What are older carers telling us about their experience of hospital discharge processes?

Health and wellbeing of older carers

- How far is it possible to develop screening of older carers by general practice?
- How can we promote the mental health of older carers and reduce incidence of depression?
- What can we do to reduce risks of injury to older carers arising from lifting and handling?
- How can we make best of the resources in Supporting Carers?[7]

Local progress

- How have we reflected carer awareness within local learning and development activity?
- Do our organisational cultures reflect the commitment to working with carers as partners?
- What has happened locally in terms of taking forward the ideas in Carers and Partners in Hospital Discharge [4], Out of Hospital [5] and Ready to go [6] materials of 2010?

References:

[1] The Princess Royal Trust for Carers, Always on Call, Always Concerned, 2011. [Source all quotes p3].

http://www.carers.org/sites/default/files/always_on_call_always_concerned.pdf

[2] CIRCLE, Regional Factsheets, Department of Health 2009.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113528

[3] Older Carers in the UK and Sheffield Hallam University, Carers UK 2006.

<http://www.carersuk.org/professionals/resources/research-library/item/491-older-carers-in-the-uk>

[4] ADASS, Carers and Partners in Hospital Discharge, ADASS 2010.

<http://static.carers.org/files/hospital-discharge-final-version-4945.pdf>

[5] Acton Shapiro, Out of Hospital Project Report, The Princess Royal Trust for Carers, May 2010.

<http://static.carers.org/files/out-of-hospital-final-report-6-may-2010-5221.pdf>

[6] Department of Health, Ready to Go, 2010.

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalassets/dh_116675.pdf

[7] RCGP and The Princess Royal Trust for Carers, Supporting Carers, An Action Guide for General Practices and their Teams, 2011.

<http://www.rcgp.org.uk/pdf/Supporting%20Carers%20Action%20Guide.pdf>

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