

# Caring Conversations

## Carers and Dementia – Meeting the Challenge

**Caring Conversations** is a series of discussion papers by the Association of Directors of Adult Social Services (ADASS) supporting the refreshed 2010 national strategy for carers [4]. For the first time, Alzheimer’s Society, Carers Trust and ourselves have come together to say something about improving responsiveness to and outcomes for carers of people with dementia living at home.

The term *dementia* covers a range of symptoms such as memory loss, mood and behavioural changes, and difficulties with communication and reasoning. Dementia is not a natural part of growing old. It is caused by progressive and degenerative diseases of the brain. Care and support for increasing numbers of older people is a growing challenge for us all.

### Dementia – What it means [1] [2] [3] [7]

<p><b>Demography – how many now</b></p> <ul style="list-style-type: none"> <li>• Some 650,00 people in England</li> <li>• 1 in 3 people will die with it</li> <li>• Likelihood increases with age:             <ul style="list-style-type: none"> <li>○ 1 in 100 of those aged 65-69</li> <li>○ 1 in 25 of those aged 75-79</li> <li>○ 1 in 6 of those aged over 80</li> </ul> </li> <li>• Two thirds will be women</li> </ul> <p><b>Demography – how many in future</b></p> <ul style="list-style-type: none"> <li>• 25% increase by 2021 on 2012</li> <li>• Set to double in the next 40 years</li> </ul> <p><b>Diagnosis &amp; Assessment</b></p> <ul style="list-style-type: none"> <li>• Under half receive a formal diagnosis</li> <li>• Over a third of families, carers or friends wait over a year after symptoms start before going to the GP - 1 in 10 never go</li> <li>• Often carers do not have a carer’s assessment of their needs</li> <li>• Only around a third of carers receive services following an assessment</li> <li>• Around a third of carers say they have not received enough information</li> <li>• Non-cognitive symptoms are often the most stressful for carers</li> </ul>	<p><b>Impacts of Dementia</b></p> <ul style="list-style-type: none"> <li>• Needs for support increase greatly as dementia progresses</li> <li>• In time, inability to carry out simple every day and familiar tasks</li> <li>• Not all about memory loss</li> <li>• Communication problems</li> <li>• Anxiety and depression as well as unusual and ‘challenging’ behaviours</li> <li>• Levels of stress, physical and emotional impacts on carers.</li> <li>• Social exclusion or community isolation</li> </ul> <p><b>Support &amp; Care to Stay at Home</b></p> <ul style="list-style-type: none"> <li>• Around 4 in 5 people with dementia said they valued living at home</li> <li>• The same proportion lived with a carer</li> <li>• Around half of people supported by carers are over 80</li> <li>• A third of carers say the person they support has lived at home for 7 years</li> <li>• Having independence was important</li> <li>• Many felt their carer did not always get the support they need to carry on caring</li> <li>• Access to respite care and breaks is not always available</li> <li>• Negative impacts on carer health and well being were a concern</li> </ul>
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### This is about all of us!

At some point in our lives many of us may be called upon 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 the supported person. Each caring situation will be unique and derive from the care needs of the person with dementia. It brings challenges and rewards. There will be particular pressure points along the caring journey such as early days, diagnosis, breaks, loss, going into or coming out of hospital, money and end of life. Caring for someone with dementia can be physically and emotionally tiring and fulfilling in turn.

## **Carers Speaking**

Feedback can generate a rich resource for commissioning and provision of support. Here is what some carers have said about their experience that illustrates policy and practice challenges:

### **COPING WITH CARING**

*I get depressed about the future as my dear husband gets worse and worse Alzheimer's. I worry and feel anxious and sad for him.* [3]

*Difficult coming to terms with my husband's dementia. I lost my patience easily. I felt very resentful with the situation.* [3]

*I was shocked at how mum had changed ... I was in denial before – now I know something is wrong.* [5]

*I have lost my husband and now have to look after a complete stranger.* [3]

### **SHARING AND UNDERSTANDING**

*Is it the same for everyone? How can things be so, so difficult, always?* [5]

*We all came away with much better insight into how dementia is affecting our loved ones and how we can improve both their lives and our own.* [6]

*The opportunity to share in a... forum ... to realise how similar are the doubts, fears and guilt of others is so helpful. Also thinking about solutions... in a group in a structured way* [6]

*What and who do I go to for help - I am new to this site and it is nice to feel you can discuss things and get thoughts from other people going through the same thing.* [5]

### **GETTING HELP AND INFORMATION**

*Help needed as we are getting out of our depth....Aunty finds it difficult to cope and just turns off... Uncle gets in a pickle... and confused, repeating things over and over again.* [5]

*I have all the information I need... but sometimes you just need to phone somebody.* [3]

*It's so hard to know what to do for the best not only at the start of your journey but throughout, as the goalposts do keep moving.* [5]

*I happen to know someone... and she said...there's a number you can ring and as soon as I rang... it was all put into place.* [3]

### **ACCESSING CARE AND SUPPORT**

*If you've got a good GP they will help. We have been very lucky.* [3]

*The hospital... said she can't have... a physiotherapist as she won't be able to remember the exercises. I will ask again... at next week's outpatient appointment.* [5]

*[Personal budgets] – It's very difficult to get a carer for xx an hour, so I just fudge it.* [3]

*I now have this awful form to fill in care/support plan and I haven't got a clue what I'm doing, so that's my next task get to grips with what dad can and can't have in the way of help.* [5]

## **Carers and Dementia – Challenges for Agencies and Communities**

Research by the Carers Trust in 2011 and Alzheimer's Society for the **Dementia Challenge** report of 2012 highlighted the challenges carers and people with dementia may encounter. Some of the issues agencies need to focus on as commissioners and arrangers of care and support are:

- **Public understanding and awareness:** raising this to improve recognition and support

- **Information, advice and advocacy:** services are accessible locally or nationally
- **Individual awareness or understanding:** knowing what dementia is or what may happen.
- **Having personal choice and control:** access to personal budgets, being partners in care
- **Ensuring dignity and respect:** both for the person with dementia and carers seeking help
- **Diagnosis:** a key barrier is the time between symptoms and getting professional advice [7]
- **Opportunities for a break:** having respite and support in ways that help to stay at home
- **Voices not being heard:** building experience into commissioning or provision of support and at critical points such as assessment and hospital admission, stays and discharges.
- **Skilled professionals:** consistency, confidence, sensitivity and awareness in working with people with dementia and their carers
- **Stigma of dementia:** risks of social isolation resulting from caring role
- **Carer stress or risk of harm:** understanding pressures and reducing impacts on carers.

### Meeting the Challenges - Some Local Conversation Points

A key quality outcome for people with dementia [Department of Health, 2010] is that ***“those around me and looking after me are well supported”***. Carers provide the vast majority of care for people with dementia. They have diverse needs. Do talk about what works well and whether you have good practice or improved outcomes to share with others. Think about the local challenges as well and the opportunities for conversations around:

#### EARLY INTERVENTION & INFORMATION

- How do we improve awareness, understanding and the contribution of early help?
- Have we got accessible, timely and good quality local information, advice and support?
- What do we know about the practical problems people face? What do they say would help?

#### DIAGNOSIS AND ASSESSMENT

- What can we do to unlock diagnosis of people with dementia and assessments for carers?
- Are our local arrangements culturally appropriate and language matched?

#### CHOICE AND CONTROL

- How do we ensure people have sense of personal choice and control over their lives?
- Are personal budgets designed around needs and wish to stay at home? Are there barriers?
- How are people supported through breaks? Do they have a real say over what is provided?
- How do we build dementia friendly communities; including, local shops and services?

#### CARERS AS PARTNERS

- Are care and support needs being mapped into the Joint Strategic Needs Assessment?
- Are carers real partners in caring and partners in strategic and service development?

## Building on what works – Some Examples

Many examples are available on the **Carers Hub**. <http://www.carershub.org/>. Good practice examples on supporting choice and control are being collated by Alzheimer's Society. Other examples include:

Information and support services are becoming more widely available including Dementia Advisers and information programmes for carers. Pilots started in 2009. Examples include: [http://www.linknorthtyneside.org.uk/Files/Project%20Space/DementiaAdviserPilotreport\\_May11](http://www.linknorthtyneside.org.uk/Files/Project%20Space/DementiaAdviserPilotreport_May11).  
<http://www.ageuk.org.uk/camden/Our-services/Dementia-adviser-service/>

**Talking Point** is an on-line forum run by Alzheimer's Society. It offers peer support which many carers find helpful. We used it to provide material for the carers' speaking part of this paper: <http://forum.alzheimers.org.uk/forumdisplay.php?25-Support-for-people-with-dementia-and-their-carers>

**Worried about your memory?** Is an initiative by Alzheimer's Society designed to help people who feel their memory or that of someone they support is getting worse and whether this may be a sign of dementia. <http://alzheimers.org.uk/site/scripts/documents.php?categoryID=200344>

**HomeShare**, is run by Crossroads Care. It provides respite for carers who face difficulties accessing mainstream day care provision. Groups meet in the HomeSharer's own home. <http://www.carershub.org/content/care-staff-open-their-homes-people-dementia>

**The City Bridge Trust Dementia Project, Crossroads Care Bexley** offers personalised support for BME dementia carers. It also tries to identify gaps in provision and barriers people may face when accessing services. <http://www.carershub.org/content/personalised-support-packages-bme-dementia-carers-further-details>

## Where we got some of our information from:

We have drawn on a wide range of information, knowledge and experience and in particular:

- [1] Alzheimer's Society, **Dementia 2012 Infographic** <http://www.alzheimers.org.uk/2012>
- [2] Alzheimer's Society, **Support. Stay. Save** - Care and Support of people with dementia in their own homes, 2011.
- [3] Princess Royal Trust for Carers, **Always on Call, Always Concerned** – A survey of the experiences of Older People, 2011. [http://www.carers.org/sites/default/files/always\\_on\\_call\\_always\\_concerned.pdf](http://www.carers.org/sites/default/files/always_on_call_always_concerned.pdf)
- [4] Department of Health, **Recognised, Valued and Supported: next steps for the Carers Strategy**, 2010.
- [5] Alzheimer's Society, **Talking Point** [for reference – see above]
- [6] Alzheimer's Society, Respondents to evaluation of Carers Information and Support Programme.
- [7] All Party Parliamentary Group on Dementia – **Unlocking Diagnosis –The key to improving lives of people with Dementia**, July 2012, [http://alzheimers.org.uk/site/scripts/download\\_info.php?fileID=1457](http://alzheimers.org.uk/site/scripts/download_info.php?fileID=1457)

## More Information - Contacts:

**Carers Trust 2012** - Carers Trust is a registered charity in England and Wales (1145181) and in Scotland (SC042870). Registered as a company limited by guarantee in England and Wales No. 7697170. Registered office: 32–36 Loman Street, London, SE1 0EH <http://www.carers.org/> E-Mail: [info@carers.org](mailto:info@carers.org)

**Alzheimer's Society**, Registered charity No: 296645. A company limited by guarantee and registered in England No: 2115499 and operating in England Wales and Northern Ireland. Registered office: Devon House, 58 St. Katharine's Way, London E1W 1LB. [www.alzheimers.org.uk](http://www.alzheimers.org.uk) National Dementia Helpline 0300 222 1122

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