

**ADASS CARERS POLICY NETWORK  
19 November 2012**

***Caring Conversations,  
Carers and Dementia – Meeting the Challenge***

**AFTERNOON WORKSHOP SESSION - SUMMARY**

**Chair: Joe Blott**

Copies of the ADASS ***Caring Conversations*** paper "***Carers and Dementia – Meeting the Challenge***"<sup>i</sup> were sent to all network members on 16 November together with a range of support papers and some materials from the North West Leads workshop on the same issue. There were also practice examples to draw upon from a number of councils. The support materials for the workshop included the recent progress report<sup>ii</sup> on The Prime Minister's Challenge on Dementia<sup>iii</sup> published in March 2012. The key aims of the challenge on dementia were to:

- Drive improvements in health and care
- Create dementia friendly communities that understand how to help
- Better Research

The recent progress report noted strengths and progress but identified challenges around:

- Unacceptably low diagnosis rates
- Poor access to services
- Prolonged hospital stays
- Too early admission to nursing home
- Poor care
- Social Isolation
- Neglect and despair
- Inadequate information, advice and support for carers

Earlier in November, 2012, the President of ADASS, Sarah Pickup, asked all Directors to work together with health partners to deliver improvements and to consider:

- how you provide good information and advice to people and their families both pre and post-diagnosis of dementia and what community based support is available to them in the early and middle stages;
- reviewing your local Dementia Strategy with a particular emphasis on re-ablement and intermediate care access for people with dementia, special accommodation solutions, end of life support and workforce development;
- reviewing your local Carer's Strategy to ensure it contains a focus on assessing families who live with dementia, the support offer to those people, your workforce's ability to have early conversations with people and families about their longer term wishes and the training you provide to family carers to cope with the onset of dementia;

- as a local authority, sign up to the Dementia Care and Support Compact – found in Annex B of the challenge document. Please consider publicising this on your website, stating how you will fulfil this commitment and encourage your local care providers to do the same;
- providing feedback and comments on the Dementia Challenge Website and ask your service user and carers organisations to do the same; and,
- sending in good practice examples to the Dementia Team to publicise on the national website. These may be new services, pilot schemes, training material or use of assistive technology or local initiatives which have made a difference and could be used elsewhere.

The Policy Network’s workshop was seen as a contribution to this process. The session began by Jane Weller [Liverpool & NW Lead] giving a short presentation on the recent North West Regional Workshop. It had been an encouraging day. Carers provide the vast majority of care for people living with dementia. They had diverse needs and circumstances. There were particular issues for carers from black and minority ethnic groups. There had been lots of things to talk about in terms of improving care and outcomes for carers and people living with dementia. They included:

- Raising understanding and awareness
- Early diagnosis and access to Carers’ Assessments
- Dementia friendly communities
- Information, advice and advocacy
- Having personal choice and control
- Carers being seen and treated as partners in care
- Ensuring dignity and respect
- Opportunities for a break
- Carers’ voices being heard
- Stigma from others and social isolation resulting from caring roles
- Responding to carers under stress or at risk of harm

Jane Weller highlighted five areas where “added value” was seen as important. They were:

- Information as early as possible to enable people to come to right decisions
- Contact with other people with similar experiences
- Supporting and responding to people in ways that match their needs and experience [includes using opportunities of assistive/communications technology]
- Commissioning services that make sense to the people who receive them
- Having well trained and experienced staff to work with people – understand dementia

Network Members then broke up into small groups to consider what carers of people with dementia were saying locally about:

- What works well for them?
- What does not work well?

This was followed by a first feedback session and discussion. This was very productive and was firmly rooted in local experience, knowledge and practice. The focus on learning and moving forward was encouraging in terms of what could make a difference or could be used elsewhere.

## **What works well**

### **Supportive Communities**

- Dementia friendly places
- Awareness raising and training

### **Diagnosis & Assessment**

- Managing diagnosis – living well with dementia
- Dementia carers pathway [Torbay]

### **Information & advice**

- Dementia Navigators [Surrey]
- Dementia Guides [Richmond]
- Dementia Advisors [South West]
- Mediated information
- Information sessions [wider family]
- DVDs challenging behaviour – growing skills in caring – carer information programmes

### **Carers as Partners**

- Materials for carers by carers – real carers – real situations
- Finding coping mechanisms

### **Choice & Control**

- Partnership with providers
- Admiral Nurses
- Memory Box schemes
- Tom's Club [Haringey]
- Carers Café- opens up to support
- Innovation Panel – reciprocal care/respite [ Suffolk]

## **What does not work well**

### **Supportive Communities**

- Assumptions – family awareness
- Communication – impact on attitudes

### **Diagnosis & Assessment**

- Keeping in touch as the journey progresses and changes
- Physical and mental health dichotomy – co-morbidities – issues of well being
- Health – own health issues, checks and assessment
- Not talking about it [dementia] - normalising it or not knowing

### **Information & Advice**

- Information for carers
- Awareness and understanding
- Alertness to financial issues for those involved
- Finding out what people want [see me] – includes understanding expectations and concerns
- Link to Print – short, timely print runs that are up to date [non-dating]

### **Carers as Partners**

- Checking what works for both parties
- Training for clinicians [? and other professionals –carer aware]

### **Choice and Control**

- Use of word “carer” to access support rather than own terminology of how they see themselves/role [Diversity issue]
- Supporting families to be families
- Use of trusted relationships - key
- Early respite – right time, place and way
- Not always using opportunities available [or not aware of what could do – learning from others]

## **Making a difference -**

[Having an outcome focus in all that we do within what we have to do it]

### **Supportive Communities**

- Grow local alliances
- Demonstrate added value of carers
- Link issues to joint strategic needs assessments and Health & Well-being Boards
- Have local dementia champions

### **Diagnosis and Assessment**

- Pursue early diagnosis and awareness – links to future planning and removal of uncertainty where no diagnosis
- See the “person” not the “condition”
- Dementia is not an homogenous condition- recognise diverse of situations and issues of diversity [BAME]
- Track change as it happens
- Evidence – what works well

### **Information and Advice**

- Have systems that work with carers – tell their story only once- talk to a person
- Affirm – it is possible to live well with dementia – can do things

### **Carers as Partners**

- Affirm - No come backs in the system
- Ensure parity of esteem throughout

### **Choice and Control**

- Respond to older people with learning disabilities and dementia [see earlier *Caring Conversations: Caring, Coping and Mutual Caring<sup>iv</sup>*]
- Advance ethical technological solutions – awareness of opportunities to help
- Quality [skilled-competent] people to deliver quality support

### **Evidence Based**

- Build on what works – on what we know and use it

### **Close**

Joe Blott thanked everyone for their attendance and their contributions at what had been a very positive session and a productive day. He found the material encouraging and pointed to lots of things we can build on locally. The discussions today and regionally along with support materials showed there were challenges and some barriers to work on. Councils faced real issues on funding. At the political management level the implications of an aging population needed to be both understood and sustainable ways forward identified.

Overall, *well being* was a key concept at the individual and community level. The potential for assistive technology to help had to be explored and grasped. Examples from the materials showed what could be done and drawn upon in meeting the national challenge on dementia.

**ADASS November 2012**

**Notes:** Feedback points do not necessarily appear in the order made. Some have been grouped to bring together thinking and facilitate use as further conversation points for exploring local issues and action in response. There has been some editing to facilitate consistency in presentation of issues for future use.

**References:**

<sup>i</sup> Association of Directors of Adult Social Services in partnership with Alzheimer's Society and Carers Trust, **Caring Conversations**, Carers and Dementia –Meeting the Challenge, 16 November 2012.

**Practice Examples from *Caring Conversation – Carers and Dementia*:**

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>

<sup>ii</sup> Department of Health, The Prime Minister's Challenge on Dementia, Delivering major improvements in dementia care and research by 2015: A report on progress, 8 November 2012, Gateway Ref: 18175 <http://ahp.dh.gov.uk/2012/11/08/dementia-challenge/>

<sup>iii</sup> Department of Health, Gateway Ref 17392 [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_133170](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_133170)

<sup>iv</sup> **From *Caring Conversations, Caring Coping and Mutual Caring*, ADASS, 2011:**

*"Mutual caring* is where an adult with a learning disability and their relative are supporting each other to remain living together. In older families this usually happens when a family carer needs more support. The family develops routines and ways of coping that result in both the older person, often a parent and the person with learning disabilities are looking after each other. Every mutual caring situation is different. Issues we need to think about include:

- People with learning disabilities:
  - not realising they are carers
  - not being recognised or supported as "carers"
  - missing out on work and social opportunities
- Families becoming isolated or at risk
- Feelings of anxiety and worry about being separated and about the future
- How to facilitate planning for the future
- Greater awareness about mutual caring by professionals across all local agencies and within mainstream services such as general practice.
- The value of practical support and joined up working
- The value of carers' assessments being carried out with people with learning disabilities

If we are to move forward the starting point is to identify more completely the number of people with learning disabilities living with older family carers and finding the best ways to support them."

The ADASS [Association of Directors of Adult Social Services] web site contains a range of materials prepared in support of implementation of the national strategy for carers thanks to ongoing support from the Department of Health. See [http://www.adass.org.uk/index.php?option=com\\_content&view=article&id=504&Itemid=386](http://www.adass.org.uk/index.php?option=com_content&view=article&id=504&Itemid=386)

**A Key Quality Outcome for people with Dementia:  
"those around me and looking after me are well supported" [Department of Health 2010]**