Devon Dementia Strategy Refresh

December 2013

Healthwatch Devon
c/o Community Council of Devon
3 & 4 Cranmere Court, Lustleigh Close
Matford Business Park, Exeter EX2 8PW
Contact: Dawn Eckhart – dawn@devonrcc.org.uk – 01392 248919 x 170

Background:

The Devon Dementia strategy and refresh document has been jointly commissioned by Devon County Council and the two Clinical Commissioning Groups in Devon. It is the first strategy covering all of Devon, including Plymouth and Torbay, since the launch of the national strategy in 2009.The strategy covers all types of dementia – the term which describes a set of symptoms that include loss of memory, mood changes, and problems with communication and reasoning. The most common types are Alzheimer's disease and vascular dementia.

Currently, a review and refresh of the Strategy is being informed by an overview document entitled "Living well with Dementia in Devon - making progress 2013 – 2015".

Healthwatch Devon was approached via its Engagement Gateway with a view to enabling the engagement of service users, the public and carers in a "light touch sense check" of the strategy to inform a final draft update for consideration by the Devon Health and Wellbeing Board early in the new year.

The lead project manager of the strategy refresh was Jenny Richards on behalf of the Partnerships Directorate of NEW CCG and the Social Care Commissioning team of DCC.

In discussion with the commissioner it was decided that Healthwatch should run and facilitate a bespoke Focus Group on the afternoon of the 27th November, as a co-production with the commissioning team (Ian Hobbs and Jenny Richards).
In designing the Focus Group process we were mindful to take on board that this is a high level strategy which will be underpinned by more local and detailed action plans, as such commissioners did not require a full consultation at this stage as it is was simply a refresh of an existing document that was needed.

Methodology:

Healthwatch cascaded an invitation to the Focus Group: The lead HWD partner for recruiting the focus group participants was agreed to be members of Devon Senior Voice's Health and Social Care Forum as this group had been involved in earlier stages of the strategy development and many of them have experience of being carers of people with dementia as well as helping to run dementia friendly community initiatives. Healthwatch also invited expressions of interest from our broader audience via social media and our other delivery partner networks including Carers Voice and Hikmat (a support network for BME communities). A lot of expressions of interest were received and the 20 places available were quickly filled. Those who were unable to attend that date were invited to submit comments on the refresh strategy document and assured that they would be kept informed of the outcomes of the focus group along with further opportunities to be involved in the development and roll-out of the dementia strategy. This additional feedback received by HWD is replicated in the appendices of this report.

On the day, 15 service users and carers and one support worker from the Alzheimer's society participated in the Focus Group.

The Focus Group agenda included:

- An initial presentation from commissioners on the main themes, progress to date, and future plans for delivery of the strategy.
- Two group sessions where participants discussed key questions about the Strategy and their experience, they then fed back their views to the whole forum for discussion and consensus building.
- Followed by a third session with the task of providing a critique of a questionnaire aimed at carers and people living with dementia. The questionnaire was developed by Surrey County Council and considered to be good practice. Devon commissioners are considering using the questionnaire as part of a broader engagement process to ask carers about their experience in caring for someone with dementia, and people with dementia about what it's like to live with dementia in Devon.

All the feedback from the 3 group sessions was recorded and is transcribed below.

Focus Group responses:

Group session topics	Responses
Session 1: We would like to hear your comments about the strategy; **Are there any other important messages or elements missing?** **Is it clear enough?** **Do you think that the broad headings cover the things that are important to you?**	• Coordination remit needed for DCC – voluntary and community sector, statutory and provider sector overview of services and information • Access to information about support • North Devon Hospital produced a document outlining the patient experience through Care Pathways from observation. • GP's should be commissioned to screen everyone coming through the door, and refer those diagnosed in to local support options. • NHS and DCC should jointly fund copies of "Carers Pathway' to make it widely available. • Support for families and carers should be addressed as soon as condition is diagnosed (confidentiality allowing). • Respite care needs to be more easily available and free. • Tick box assessment forms more readily available (would need to be used with consent and training to use appropriately.) • More emphasis on training of carers both family and professionals. • More emphasis on the use of Dementia Pathway (David Light) which is really supportive and useful. • All written in 1st person. Is this really relevant for all those with dementia as some would not be able to decide? • Not sure that all carers and users need to be aware of the % of professionals maybe. Perhaps need for two different booklets – How am I going to get care? Is what service users and carers need. • Raising awareness through schools and "younger" networks e.g.- memory cafes in schools. • Where is the information? How is it available? How do you step on to the pathway? Is there a

	usable description from beginning to end? • Care agencies shouldn’t be able to cherry pick.. and deprioritise e.g. rural care. • Post death follow up needed for carers: A good example cited the Care Centre in Bideford funded by Comic Relief. • GP’s still not aware enough. How can we encourage them to support patients towards the early diagnosis? • An easy-read version is needed as well as other accessibility formats. • How to reach people who live alone / do not visit GP / do not have internet access. • The young generation need to be involved – good example is Okehampton School’s connection to memory café. • What is the definition of “early diagnosis”?
Session 2; Your experience; what is in place and worked for you? what else needs to be in place to enable you to say: **I feel supported & understood by professionals I come into contact with (e.g. GP / community mental health team / care manager / consultant)** **I found information easy to get when I started to worry about memory problems** **There is enough help and support to enable me to get on with life**	• After care/ support – vital for Carer after patient has departed, either by death or going into a care home. • patient Information is hard to get – care pathway must be shared with carers and family. • Is dementia now a ‘cause of death’? • Diagnosis must include clear information about care plan and pathway options for patient and carers. • Stimulation helps memory – support for more volunteers to assist with dementia friendly meaning-full occupation and social functions. • Identification wrist bands – in community and in hospital; tracking by GPs? • Show-casing event for dementia awareness. • Education of professional staff needs to be in place: Not just GP’s but health Visitors, nurses / people dealing with Dementia in the community. • Respite care – support for carers: Bookable respite. • Celebrate memory cafes and memory café exchange of good practise e.g. craft sessions, singing . memory café organisers need to meet together. • Need to tighten up the commitment from professional health teams to visit the cafes so that dialogue is open between professionals, carers and dementia clients.

	• Not enough information re sources of support available – particularly localised information. • Although some towns and areas across the country are dementia friendly all should be. • Identification of Specialist GP in each surgery • Information is thin on the ground need to have knowledge to know where to go to get Dementia Pathway (David Light) . This should be readily available in every surgery and hospital. • Support available is a post code lottery. Also the changing criteria for care are not helpful to say the least! • Care received from practitioners is very much dependant upon their training levels: inconsistent quality. • Access to large print and other languages needed. • Option /offer of Advocate may be needed. • We suggest a show case and networking Devon wide event: Could this fit in with Dementia Awareness Day event run by DSV? • What about Southern area? – Services and opportunities should be consistent across the county, not patchy as it can be at present.
Session 3a: critique of questionnaire 1; For carers about being a carer and accessing service for someone with dementia. **Is it a good practice example for you?**	• Use a tick box response for questions with a box for anything further comment they need to contribute. • Q.22 – at top of hospital section – could start at Q. 26 and work back to Q.20 (2) • Do the medical team deal with the patient or the carer? (should be both if carer is acting as advocate / proxy) • Informed choice / understanding is most important – then other things fall into place. • Q.10 – we felt some carers refuse an assessment - should the question say ‘I have been offered a carers assessment”. • Q.17 – who is ‘people’ does this mean professional or other people? • Q. 24 – should ‘any additional comments…’ be added to this question. & Is this anonymous or optional; collection of some demographic / personal details would be valuable for interpretation of results.

Session 3b: Critique of questionnaire 2: For people living with dementia **Is it a good practice example for you?** **Could it be improved?**	• Tick box again please – could use range from strongly agree to strongly disagree. • No abbreviations should be used. e.g. CMHT. • Another question – do you have someone you can trust to speak for you or deal with your finances. • Not sure of which stage of dementia this is intended for some questions would be difficult for some, and they may not want to admit this. • Should be followed up by … who can make decisions for me if I cannot? • Free consultants / solicitors to make 'wills' for dementia sufferers. • No question asked about emotional wellbeing: whether the dementia sufferer is lonely or isolated - offer question "I feel isolated and alone" scale of responses – occasionally to frequently/all the time.

Participants evaluation of Focus group:

At the end of the focus group meeting participants were given stickers to place (anonymously) on "scoreboard" evaluation charts on their way out: Two evaluation targets were provided each for a different key question; in both cases stickers could be placed anywhere on 5 concentric tiers of the "score board" from the core" bulls-eye" signifying the highest possible score to the outer circle representing a poor score.

Evaluation question 1; Was this consultation event well run?

Bulls-eye: Yes, very – 3

Tier 4: Yes, fine – 7 (1 person said that it was not long enough)

Tier 3; Ok – 2

Tier 2; Not really – 0

Tier 1: Not at all – 0

Evaluation question 2: Did you feel listened to?

Bulls-eye; yes definitely – 9

Tier 4; Yes, fine – 5

Tier 3; OK, a bit – 0

Tier 2: Not really – 0

Tier 1: Not at all – 0

Other feedback that participants wanted to share with other carers and people living with dementia:

Bibliography recommended by participants to be promoted / provided to carers and diagnosed people :

- What your diagnosis means for you – Alzheimer's society publication.
- The dementia guide – Living well after diagnosis. - Alzheimer's society publication.
- Publications catalogue - Alzheimer's society publication Tel: 0207 423 3500.

Useful contact details recommended by participants to be promoted / provided to carers and diagnosed people:

- **Alzheimer's society**

Devon House. 58 St Katharine's Way London E1W 1LB

Tel: 0207 4230 3500

Fax : 0207 423 3501

info@alzheimers.org.uk

alzheimers.org.uk

Dementia Helpline; 0845 3000 336

- **Devon Dementia Support Service.**

Forde House, Harrier way Exeter. EX2 7HU

Enq’s : 0300 123 2029

devon@alzheimers.org.uk

- **Dementia Strategy Joint Commissioning Manager**

Jenny Richards, Partnerships Directorate - Northern, Eastern and Western Devon Clinical Commissioning Group

Social Care Commissioning - Devon County Council

Email: jenny.richards@devon.gov.uk

P.A: Kathy Mitchell | 01392 267864 | Email: kathymitchell@nhs.net

Healthwatch Devon’s suggested key messages that have emerged from the Focus Group:

1) The further development and implementation of Devon Dementia Strategy should be undertaken as a co-production between DCC-CCGs and key stakeholders in the voluntary community sector (including service users and carers).

2) DCC (& CCGs)’ remit should include a co-ordinating role to ensure better joining up and adding of value between the statutory bodies, providers, and the voluntary – community sector.

3) DCC (&CCGs) remit should include an awareness raising and educational campaign - both for the public to increase their understanding of dementia, its incidence and recognition, diagnosis and treatment options, being more dementia friendly and specialist support available and secondly, targeting the clinical practitioners who come into contact with it e.g. GPs, health workers, social care assessors, personal budget co-ordinators etc.

Appendix 1

Written submission from:

Anthony F Parker BA (Hons) M Phil FCIM
Co-Chair Devon Dementia Care and Support Partnership
Chair Tavistock Dementia Action Alliance
National REPoD Ambassador for Dementia Friendly Communities

“ I have been forwarded the email about your focus group, and specifically the questionnaire, by a number of people asking how this 'fits' with the questionnaires and focus groups for dementia-friendly communities.

As you will be aware surveys were conducted nationally in 2010 and 2012 to obtain the views of those with a dementia and their carers regarding their experiences of living with a dementia. Perhaps more importantly, as part of the national dementia-friendly community 'Recognition Process', local communities in Devon - from Ilfracombe to Torbay - have used questionnaires to identify local needs of those with a dementia and their carers to meet the elements of Foundation Criterion 6 of the Recognition Process. This is in addition to forming reference groups and lead groups of those with a dementia and their carers.

My immediate concern is that if we are not careful the sheer number of questionnaires, with replicated or similar questions, will be completed in many instances by the same people with a dementia and their carers. There are a limited number of potential respondents and I know some individuals have already completed surveys at local, county and national levels. This raises a number of issues to me - from questionnaire fatigue to duplication of effort - but I also believe it highlights how collaboration and integration of all our efforts in this field should be the number one priority for Commissioners.

Furthermore, on a technical point, I note the proposed questionnaire does not include the biographical data of respondents which ***is*** included in the dementia-friendly community questionnaires. The inclusion of the same can enable a more valid evaluation of impact and outcomes of any interventions, initiatives or projects. Such evaluation being required every six months, as part of the national Recognition Process. It affords the opportunity, for example, to answer questions such as: what, if any, correlation is there between age and access to services? Or what, if any, correlation is there between diagnosis rates and gender? What are the variables affecting these? And so on. A questionnaire which asks basic biographical questions could also include quite important details about other 'conditions' which can often affect, for example, accurate diagnosis of dementia”.

Submission from Carers Voice Support Worker

“ I have spoken today to a carer, who advised that he has been involved in a national working group developing a Triangle of Care for Dementia which has been launched in the last couple of days. You can view it on the Carers Trust website at: http://static.carers.org/files/the-triangle-of-care-carers-included-best-practice-in-dementia-care-final-6870.pdf Unfortunately this carer is unable to attend tomorrow’s meeting but he felt it is important that the local strategy should refer to this work particularly since the RD&E are involved in piloting a programme of work to better support carers of people with dementia and this all needs to be joined up. You may well be aware of this work already but…it would be worth flagging it with the focus group to ensure that one local piece of work informs another!”

Healthwatch Speak-Out Case Studies

Healthwatch Devon Speak-Out Case Study 1:

The HWD telephone advice line has been supporting a lady this week in relation to her reported lack of advice and signposting for her father who has dementia and Alzheimer's. You may be interested to read the case:

The lady rang to gain advice on who she can ask for support to help with hospital meetings to discuss and arrange the appropriate care home transfer for her father who has dementia/ Alzheimer's. With her consent we gained advice from PALS (the NHS Patient Advice and Liaison Service) which she said was very helpful, we spent time on the phone with her giving her advice on how to ensure that she gets the right notes / actions from the meeting and then we can refer her / signpost her to SEAP next week if there are more meetings required.(It was too late to get SEAP to attend the first meeting as they require 10 days notice) Although not finished and closed as yet this is a good news story as the advice HWD was able to give her has ensured that meeting attendees are now bringing the relevant papers/ care plans to the meeting for her and her mother as the main carers, to see , which may not have happened unless she had contacted them following our advice.

We will contact the daughter following their initial meeting to hear the outcome and if appropriate, either refer her case to SEAP directly, with her consent, or signpost her there if she prefers

Healthwatch Devon Speak-Out Case Study 2:

"I am speaking from recent experience with my mother being diagnosed with Dementia:

On diagnosis neither the GP/surgery or hospital consultant provides a practical service to link you to care services. All you receive are a few related flyers in our case the Alzheimer's Society & Devon Carers. The follow up support such as mental health care team take time to materialise.

We focused on the patient and didn't understand the role of Devon Carers. (my sister & I are in our fifties and healthy so felt we didn't need help). We have since learnt that carers (organisations & individuals) are the best source of help rather than the NHS & Social Services (not interested if you have money and not able to jump over the high bar set very high). The GP/ surgery do not offer support or guidance. We have had good help with transport from the surgery league of friends. I think the GP's believe that their Friends Group provide the social link.

I therefore propose that it would better if there was someone in the Surgery who sat down face to face with the patient, family, carers and gave some face to face guidance/signposting on how to get the help they need. In light of the rapid response and quality of advice by Devon Carers; at the very minimum you should be advised on diagnosis of a serious illness to register immediately with Devon Carers.

The GP has arranged regular appointments but only focuses on medical issues and never questions or emphasises the care issues.

In the case of my sister & , we are educated and have some experience having had a child with cancer, another with learning difficulties and involvement with Age UK. And yet it has taken us 5 months to get matters adequately arranged. We are aware of people still not getting services and support through a lack of knowledge or because they fail to pursue matters strongly. During this initial post diagnosis period the condition of the patient has continued to decline rather than be contained.

The suggestion that a joined up system and the greater use of social care (in its various) forms to prevent expensive hospital resources is all words and is not supported by practice on the ground. Particularly by the medical profession.”

Healthwatch Devon Speak-Our Case Study 3:

Client wants to highlight some of her experiences. Not wanting to raise a formal complaint but wants to help improve services for others in the community. Daughter concerned about the lack of signposting that she and her mother have received whilst dealing with her father who has been suffering from a very aggressive from of dementia for the last 2 years. He has been sectioned under mental health act and has been in Franklin hospital and they are trying to transfer him to a relevant care home that is easily accessible to the family.

There have been lots of issues and miscommunication and the daughter is keen that other people/ families do not suffer like they have to get the right and appropriate care for their parents.

Healthwatch Devon Speak-Out Case Study 4:

“ Previously members of the Community Mental Health Team including OT's, CPN's etc. used o attend monthly meetings at the memory cafes for people with dementia and Alzheimer’s. This enabled patients and the carers to meet and get to know the people directly involved in their case. The Alzheimer’s society has now taken over the contract and despite it being in the contract nobody attends the meetings anymore. Patients and their careers are now confused as to who is dealing with their care as there seems to be no consistency”.

Healthwatch Devon Speak-Out Case Study 5:

An individual contacted Healthwatch Devon today. Her father has dementia and was admitted to hospital with a urinary tract infection in June 2012, following visits from the GP and Devon Doctors. Individual, who is fathers main carer expressed that while her father was in hospital there was not anyone who could offer guidance and support to carers of patients with dementia whilst they were in hospital. She suggested that , in her experience, it would have helped if there was someone available at all times who could offer support, advice or someone to talk to who can help to present choices that are available to the patient and their carers around aftercare and on-going support. Individual had raised concerns with PALS and DCC.

Healthwatch Devon Speak-Out Case Study 6:

This client sent a copy of a letter that they have sent to the Chief Exec of NDDH - this letter is asking for some reassurance in relation to inpatient dementia service. They have concerns over the why that the patients who have dementia are moved to different wards within a hospital and also to other hospitals. They have asked for the rationale behind this, since they are concerned that it is destabilising for the patient.

Appendix 4

Hikmat Healthwatch Hub Feedback

Topic: **Dementia Strategy Overview**

Date: **Wednesday 13th November 2013**

No of participants: 4

Ethnicities represented: 4

- People suffering with dementia are aware of what is happening and have their family and support workers available to let them know what is happening.
- Others found that they did have control and choice because of their religion.
- Some found that services were not designed around people and their needs, others found it very easy to access services.
- Three people found that they had their family for support in their lives, one person had a lot of support from additional services.
- There is often difficulty in getting the services you need from the GP when mental health is involved. Others relied on the library and the internet as a first port of call. Hikmat has helped people gain knowledge about services available for them.
- Those people suffering with Dementia who have a close family around them feel more valued and understood. Although it is often difficult for the family. One person living alone with Dementia feels very lonely and upset, although she has services and support around her daily she is upset when people leave. Family help people to feel valued and understood.
- Joining a group like Hikmat has helped sufferers with dementia to feel like a valued member of the community and reduces isolation.
- People and families are generally aware of research taking place but not breakthroughs in Dementia health and care. There is awareness that you need to go to the GP then be referred to hospital for assessment.

When discussing what is important for assisting people with Dementia;

- People facing culture issues with regards to respect and the difficulties overcoming barriers, for example language and being accepted as a person with Dementia illness in the community

- Family support, getting people out and about in the community, having a person to share a caring role and Respite.

More information would be helpful relating to;

- More awareness and understanding would be helpful, it also helps the early diagnoses if there is higher awareness of the illness. Appointment times at the GP are not long enough when living with a mental health illness. Early diagnoses and awareness is very important.

- Dementia is not well known in the Philippines. Some Filipino's working in care homes are working with people with Dementia and are more aware of the illness.

- Living in remote areas in Devon makes it more difficult to access support. When people go into hospital the food may be different to what they are used to. Some cultures hide that there is a problem and don't access the help they need and require. When accessing a service some people may not ask for an interpreter because they don't realise they can ask for one. When a family does not except Dementia as an illness in the family or community, confidentiality from external services and building trust can be helpful.

Devon Senior Voice Directors Feedback

Dementia Strategy Refresh document – feedback from Ken Crawford, Devon Senior Voice Director:

1. The document needs to concentrate on the strategy not the need for a strategy.
2. Document in wrong format for visual accessibility:
    2.1. Portrait not Landscape
    2.2. Minimum of 14 point
    2.3. No Columns
3. Co-production not informed by views
4. Strategy needs to be prominent at the front, past achievements etc as appendices, perhaps not at all.
5. No commitment by either DCC, CCG or NHS, need names and signatures
6. Two list of commitments ??
7. Statistics need to be current not 2012
8. Need to set targets for 2013 – 2015 with more detail and projections.
9. Space for endorsement by other organisations
10. No commitment to support grass roots voluntary sector
11. No “Rural Proofing”