Draft February 16th 2015

Experiences, Perceptions and Expectations of Dementia Care in Suffolk (and Norfolk)

Working Document

Status:
This document is intended to be used as the foundation for the meeting on March 9th 2015.

Introduction: At the April 2014 meeting of the MH Focus Group of Healthwatch it was suggested that we needed a much clearer understanding of the actual situation for family carers and those they care for in terms of the demand for support services and the quality and supply of those services across the county - nature, numbers, locations, frequency, expectations, quality, etc. In effect, the requirement is to measure the scale of the situation in order to be able to balance the provision of services within the available budget. The Joint Dementia Needs Assessment[1] provides a wealth of data at a strategic level but there is a need for this to be supplemented by knowledge of the "on the ground" situation for those having to cope with the illness on a day-to-day basis. It is felt that by surveying / exploring things from their viewpoint we could gain a much better idea of where the holes and shortfalls lie and build up a "measured" picture which would enable (and justify) a coordinated and planned investment by the local authorities and the NHS. Hopefully, it might also lead to a much more stable funding regime - as indicated in the Dementia Needs Assessment. Furthermore, it should provide a realistic standard for the availability and quality of care provision for care providers to meet.

First Steps: An initial group[2] representing key stakeholders met together on the 9th of September 2014 to explore what were the possibilities to survey, quantify, and measure:

1. The provision (range, availability, and quality) of dementia care and support services as seen by the carers and those they care for with dementia
2. The potential for integrated community-based dementia care and support

The conclusions of the group were as follows:

1. There is a priority need to gather together the experiences, perceptions, and expectations of family carers and those with dementia as a basis towards understanding (quantifying, measuring, and recording) the state of dementia care in Suffolk from the viewpoint of those who are having to cope with the impact of the illness on their lives.
2. The purpose should be to establish a basis of the needs[3] (at the personal level) against which the volume and quality of service provision can be assessed, a statement of the strengths and

[1] http://www.suffolkobservatory.info/JSNASection.aspx?Section=127&AreaBased=False
[2] John Lambert, Ian Young, Jo Murray, Debbie White, Willie Cruikshank, Alan Reynolds, Jeff Stern, and Lynden Jackson. This group has since expanded to include further stakeholders and potential contributors.

shortcomings of dementia care provision in the county, what current and future service users need to enable them to "live well with dementia", and suggestions about how the expressed needs of those who are coping with dementia might be met.

3. The importance of the work requires:
   a) Active contributions from all group members in assisting the gathering of data
   b) Funding of administrative support for the management of the activity
   c) Funding of research staff to collect, collate and analyse the data,
   d) Support for existing and planned dementia support activities which will offer opportunities to gather data.
4. The need for an initial plan[4] for the activity to "get on and do something" as soon as possible.
5. The group should seek contributors who can represent all the key stakeholders[5] (Appendix 3 is a list of those who have, to date, expressed a desire to be involved with, and support the aims of, the project). These people should all be sufficiently senior in their organisations to facilitate the gathering of data for the activity, and/or have the recognised experience to represent the needs of patients and family carers, and/or bring specialist data gathering, collating and analysing skills, and/or have research experience in the field.

Deliverables:

1. A "quality assessment" database
   The collected experiences, perceptions and expectations of family carers and those they care for with symptoms of dementia which together represent a broadly representative picture of dementia care in Suffolk.
2. A "dementia care atlas" for Suffolk (and Norfolk):
   A picture of the practically available dementia care support, including a directory of the services/support/activities practically available to carers and cared-for, on a geographic basis.

Organisation:

The original thoughts centred upon just a small number of people getting together as a working group. However, as the proposal has developed it has become clear there are a significant number of potential stakeholders whose support and involvement are important. Perhaps, a small subset of the membership tasked with getting on with the activity should be defined, and given the ability to "draw on" the other members for help when necessary.

The way the project is anticipated as working is as follows:

a) A small coordinating group will work with stakeholders to define "what it is we need to know" and "the questions we need to ask"
b) This group will seek to find a way (using experience, and academic advice) of gathering the data which, ideally, can be achieved within the existing organisations by simply asking for limited additions to their current activities / procedures
c) The group will ask those who are involved in the quality assessment of services and service providers to routinely pass relevant data to the group for collation and "overall" analysis
d) The group will ask specialist (academic and other) collaborators to examine the data, analyse (in concert with the group), and report on the results
e) In the first instance the group will need some administrative support, and later an active research capability
f) In the longer term the activity should become an integral element of the Quality Improvement Team reporting to the Health and Well-being Board

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[3] Appendix 1 – Aims and a basis of needs
[4] Appendix 2 – Draft action plan
[5] Appendix 3 – Breadth of involvement in the activity – Group Membership

Potential avenues for research/survey work:
The activities that the group might wish to consider should attempt to provide quantitative, qualitative, and anecdotal data directly relating the provision of services for, and the individual needs of, those with dementia and their carers[6]. Ideally, the granularity of the data will ultimately enable meaningful comparisons between individual districts and communities. There are a number of opportunities:

1. Healthwatch with their authority to "enter and view" would be ideally placed to survey the experiences in the residential / nursing / hospital environment (combined with CQC reports).
2. The proposed network of "Dementia Learning Hubs" should, in time, be able to help with cataloguing and quantifying the level and availability of support facilities and services in the community.
3. The Dementia Needs Assessment[1] provides a comprehensive strategic-level source of data which may provide the foundation for an overall, county-wide estimate of the potential need together with the imbalance between the supply and the demand for dementia support services.
4. The "In at the Deep End" survey[7] capturing the Debenham community's perceptions, experiences, etc could be extended to other communities and also reviewed for its representativeness across the county.
5. A review of UEA survey work together with published national research might be able to provide a baseline to guide the group.
6. The membership of the group should be able to provide/acquire anecdotal evidence with which to compare the quantitative data with the survey results.
7. Drawing on existing published research, surveys, and other studies[8]

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Project plan:
The aim should be to "commission" the work to actively begin early in 2015 with a draft plan for the project's development over the following 2 to 3 years.

Resources, costs, and funding:
It is envisaged that the initial core coordinating / research team will consist of:
Management / Advisory group – 5 – nominated by EPEDCS – cost carried by home organisations
Team leader – 1 part-time - nominated by EPEDCS - voluntary
Admin/secretary/advisor – 1 part-time - appointed by team leader – funded - £10K pa
Researchers – 2 or 3 part-time – appointed by Management / Advisory group – funded - £30K pa
Data gatherers – 1 part-time per relevant organisation – cost carried by home organisations

In addition the team will require non-staff funding of about £10K pa and a similar level of contingency funding.

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[6] Appendix 4 – Draft question-base
[7] http://www.the-debenham-project.org.uk/downloads/articles/2014/0726JDC.pdf
[8] Appendix 5 – Links to useful documents/contributions/etc.

Appendix 1

Initial aims:
1. To capture the perceptions and experiences of carers and cared-for of dementia care in residential, nursing and hospital environments. We know that there are some excellent examples and some very poor examples but otherwise there seems to very little evidence of what the general level of care is (other than through the CQC inspections which don't address many of the questions that are important for people with dementia and their families).

2. To explore just what might be possible and practical to achieve in the home and community environments in order to avoid and delay admitting those with dementia into hospital and specialist homes.

If the joint aim of The Dementia Strategy is to enable as many people to remain in their homes and community, the adequate local provision of quality services and care is a must.

Linking together Adult Care, the clinical side, key dementia support charities, and the community, with a strong emphasis of being evidence-based and particularly close to family carers (and those they care for), will be a powerful demonstration of the various stakeholders developing a practical and realistic approach.

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Appendix 2

Draft Action Plan

1. The basic tasks of the group should be:
   a) to collect/gather data from those with dementia, family carer, and relatives in order to develop as comprehensive a picture as possible from the viewpoint of the service user.
   b) to try to find out what those with the illness and their carers want in terms of services, and what services, if they were available, would make the greatest difference in their being able to "live well with dementia"
   c) to provide quality data on which to base commissioning decisions and dementia care provision
   d) to attempt to define a set of aspirations for the provision of dementia care in Suffolk

2. The initial thoughts on how this might be done were:
   a) to explore and catalogue what relevant data already exists in recent, reports, inspections, surveys, and evaluations
   b) to talk to residents and relatives of a representative selection of care and nursing homes
   c) to do similarly for family carers and those they care for living in the community

3. The way the work is carried out should be characterised by:
   a) being user-focused - as opposed to service provider orientated
   b) being based upon a "structured interview" model
   c) looking at the whole journey experiences - as opposed to only the current situation
   d) viewing anecdotal evidence as being equally as important as quantitative evidence
   e) using the suggestions in Appendix 4 as a starting point for development of the question-base

   4. The initial thoughts about how the work might be started are:
   a) As an element of Healthwatch's remit for "enter and view" inspection programme

b) Collaborating with the CQC to gather data during routine inspections
c) By involving the existing synergy cafés and community projects in the "Dementia Learning Hub"
d) By seeking help from UCS and UEA to review existing results and provide an academic foundation

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Appendix 3

Group Membership

The aim of the membership is to combine those who can facilitate the work of the group and those who have a deep knowledge and experience of the needs of those who are coping with the impact of dementia on their lives.

Initial membership:
Debbie White - Director of Operations, Norfolk, NSFT
Willie Cruikshank - Director of Norfolk and Suffolk Dementia Alliance
John Lambert - Adult & Community Services, Suffolk County Council
Alan Reynolds –Consultant, Make it Happen Associates
Jo Marshall - Neurological Centre Director, Sue Ryder
Debbie Foster - Services Manager, Suffolk, Alzheimer's Society
Jeff Stern - Chairman, MH focus Group, Healthwatch
Lynden Jackson - Chairman, The Debenham Project
Alison Armstrong – Director of Operations, Suffolk, NSFT
Roz Brooks – Deputy Director of Operations, Suffolk, NSFT
Di Wright - Healthwatch
Ian Young – Deputy Director Operations, Suffolk, NSFT – Standing in for Roz Brooks
Jep Ronoh – Public Health
Jo Murray - Suffolk Dementia Team Leader
Anne Chapman - SCC Quality Improvement Team
Alison Leather – Ipswich and East Suffolk CCG
Paddy Fielder – GP rtd, Trustee Debenham Project, Trust Member NSFT
Val Mann – Senior lecturer for Bioscience, University Campus Suffolk
Sharon Lane – Director of Operations, Age UK Suffolk
Sarah Potter – Suffolk Family Carers
Mohamed Abdel-Maguid – Head of department for science and technology, University Campus Suffolk

Other potential contributors with particular interest and/or special experience:
Karen Blades – Dementia Lead, Ipswich and East Suffolk CCG
Hilary Green and ?? - Age UK
Louise Burroughs – Consultant
Laura Meadowcroft - Operations Manager, Norfolk and Suffolk, Alzheimer's Society
Tessa Harding – Halesworth Project
Sue Vincent – Alzheimer's Society

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Appendix 4

Draft Question-Base

Some thoughts about what questions might address, for which the group is not aware of much in the way of evidence-based answers. The aim is to use these to develop user friendly questionnaires that can be used in surveys, CQC and Healthwatch inspections, and structured interviews.

A1) Concerned with the situation in residential / Nursing home care.

1. What is the minimum level, range, and quality of dementia care and support services that a resident / patient should reasonably be able to expect from their care home? - routine GP / specialist nurse contact; daily and weekly group activities and social events; one-to-one interaction; personalisation of care procedures; specialist reminiscence and therapy support; etc. - is this sufficient?
2. What are the experiences and perceptions of the carer and the person they care for in a) the transfer from the family home to the care facility, b) the current level and quality of care (physical, social, and emotional) provided to the resident, c) the response to crises, and d) the quality of care in the final stages? - what is the severity of their symptoms; what triggered the move into the home; are they happy; have there been incidents that raised concerns; are they actively involved; are they left alone for long periods; is their physical health properly attended to; does the home achieve an ethos of empathy and unconditional care; etc?
3. What are the problems, benefits, and costs (practical, social, and emotional) of residential / nursing care compared with caring for the person with dementia in their own home? - financial; separation; respite; disorientation; distance; loneliness; family carer's physical and mental health; etc.

A2) Concerned with admissions and stays in general, mental health, and intermediate hospital care.

1. What are the perceptions and experiences of family carers, and those they care for, of their treatment and care? - what were the circumstances of, and response to, the crisis; was there a prior diagnosis of dementia; how long did the admission take; were the family involved in and happy with the admission and assessment process; what were the family carer's expectations for the nature and quality of care provided in the immediate period following admission and were they met; what was the rest of the stay like; were there incidents that raised concerns; etc.
2. What are the experiences and perceptions of the discharge process? - was the discharge achieved appropriately, successfully and to the satisfaction of the family; did the family carer feel that the decision was in the best interests of themselves and the person they cared for; were all essential facilities put in place in time; were there any delays; what was the condition of the patient immediately following the incident and subsequently; was an appropriate and effective care package put into place on discharge; etc?

B1) Concerned with quantifying the supply and demand for dementia care and support in the community environment.

1. What local services and support should family carers and cared-for in the community be reasonably able to expect? - diagnosis; medication; advice and information; emergency support; personal care; specialist care; social integration; counselling; pre-diagnostic support; transport; therapies; etc?
2. What is the current availability across Suffolk of such services compared with the local actual / estimated incidence of dementia? - what is the likely demand for services; what is the likely limit to the percentage of diagnosed cases; what are the key services; how can they be provided; etc?

B2) Concerned with estimating the potential for dementia care in the community.

1. What proportion of those who are being cared for in a residential setting could be cared for in a local setting with the right services and facilities? - what degree of severity of symptoms; what additional services and facilities; how many in a community; what is the likely cost; etc?

2. What organisational and funding changes might be needed to significantly reduce the numbers of those with dementia who have to be cared for in a residential setting? –

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Appendix 5

Links to Useful Documents/Contributions/Etc

Suffolk Dementia Needs Assessment:
http://www.suffolkobservatory.info/DownloadFile.aspx?q=Rm1lejBxV1g4UFhqdjRlZk01b3U3dGZaWXlmb09vNkd5cVhaLzJzS1VWVlJpN0FFRktLaFNRMGRRU3NJTE5PaTZWaUtyRWx3TXFsajRqWWU1WXplRTlVcXkreG9WNWVvVUY3WlhlMEg4dVJ6WE1meWcxN0FOQ2xvWVpuaWZvYjhGT1Vyd1oyMHpuK0xZQ2RKMDhqcS9ZRHVaUmhSTUIzcWtmU283ZTNjWGFuOE9OSWpzWlVHTVE9PQ==-Uns2evjiYGY=

APPG (2014) report – "Building on the National Dementia Strategy":
http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2249

A typical CQC Inspection Report:
http://www.cqc.org.uk/location/1-115224122#accordion-1

The Commission on Residential Care - "A vision for care fit for the twenty-first century...":
http://www.demos.co.uk/files/Demos_CORC_report.pdf?1409673172
Progress for Providers - Checking your progress in delivering personalised support for people living with dementia

NICE Dementia Quality Standard
http://www.nice.org.uk/guidance/QS1

The Dementia Care Audit Pilot
http://www.hqip.org.uk/dementia-care-audit-pilot/ and http://www.scie.org.uk/news/dementia-care-audit/

The Care Audit Pilot Tool content can be obtained from:
Anne.Chapman@suffolk.gov.uk or lynden.jackson@the-debenham-project.org.uk

Quality standard for supporting people to live well with dementia
http://www.nice.org.uk/guidance/QS30

Progress for Providers (Care Homes only)
Progress for Providers - Checking your progress in delivering personalised support for people living with dementia

DEEP (The Dementia Engagement and Empowerment project)
http://www.mentalhealth.org.uk/our-work/research/dementia-engagement-and-empowerment-project/

Kings Fund Dementia Friendly Environments
http://www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-in-dementia-care
http://www.kingsfund.org.uk/time-to-think-differently/trends/disease-and-disability/care-demands-dementia

How Sweden cares for its elderly population
http://www.bbc.co.uk/news/health-28654739