

Report to the Scrutiny Panel 3 – Dementia Friendly Town Committee Meeting 27th November 2017

In January 2017, I was really pleased to be invited by the membership of the Northamptonshire Dementia Action Alliance (NDAA) to be its Chair. As a member, I have been the University of Northampton's representative on the NDAA since 2012. In my role at the University, I am the Professor of Applied Mental Health, Director of the Northamptonshire Dementia Research and Innovation Centre, Chair of the Dementia-friendly Community of Practice, and lead for Public and Patient Involvement. I am also the Deputy Chair of Research at National Young Dementia Network and a member of the pan European Group InterDEM. I am an experienced mental health nurse and have established three community-based social groups for people with dementia: the Forget-Me-Nots Social YOD Group; Qualified by Experience (QBE) for former carers in Northamptonshire; and the Lutterworth Share & Care Group for people with dementia and their carers in South Leicestershire. I have worked extensively with local organisations to evaluate their provision of health and social care services, including community-based interventions for people living with dementia.

As the Chair of the NDAA, over the next 12 months, I will be leading a number of exciting initiatives which have emerged from within its membership. These include:

1. Leading on the development of this Dementia Friendly Northamptonshire guide.
2. reviewing the current Northamptonshire Dementia strategy and contributing to the development of a County-wide dementia care pathway;
3. supporting Northampton to become a dementia friendly town & Northamptonshire to become a dementia friendly county;
4. establishing a Northamptonshire Public Patient Forum for people who are living with dementia and their carers.

1. Leading on the development of this Dementia Friendly Northamptonshire guide.

This is published and was launched at the UoN Future Directions in Dementia care Conference on the 14th November 2017. Our hope in developing this guide is that those who read it will find practical information about dementia and the sources of support that are available in the county.

The flowchart on page has been developed to highlight possible sources of support with the various stages of dementia, and this is supported with more detailed descriptions of existing and developing services, beginning on page xx. The guide also contains more general information about dementia, signs and symptoms, legal issues, how to live well with dementia, and sources of information and support post-diagnosis. You will find details of specific services and organisations that are available for information, support and care in Northamptonshire and nationally starting on page 69.

2. Reviewing the current Northamptonshire Dementia strategy and contributing to the development of a County-wide dementia care pathway.

Myself, Gerry McMurdie, and Dr Tom Howsman met on the 12th October to discuss the process for refreshing the strategy. We plan to complete the first draft of the refreshed dementia care strategy by the 5th Decemebtr 2017. This will then be circulated to the membership of the Northamptonshire Dementia Action Alliance, who will discuss it in their meeting on the 16th January 2018. We then

plan to discuss it at a final workshop on the 30th January from 3-5pm at the University, following which we plan to present it at the Health & Wellbeing Board Meeting on the 15th March 2018.

In the meantime, the CCG representatives are liaising with key organisations in relation to the objectives in the strategy that need to be reviewed, and will contact NCC and Councillors. We will also be inviting staff to the workshop on the 30th January 2018.

This work builds on work undertaken earlier this year in April/May by the CCG and members of the NDAA to review the current Dementia Care Pathway, which is now complete and which has been published in the Dementia Friendly Northamptonshire Brochure, which will be launched on the 14th November at the UoN Future Directions in Dementia Care Conference.

3. supporting Northampton to become a dementia friendly town & Northamptonshire to become a dementia friendly county.

The Northamptonshire DAA was the first local alliance to be set up in the East Midlands. The local alliance held their first meeting in February 2013 which was followed by an official launch in the May during dementia awareness week. Our aims for 2017-18 are to increase local involvement, develop a Northamptonshire-wide Forum for People living with dementia and carers; and make Northamptonshire a more Dementia Friendly place to live and work in. This is being actioned by:

- establishing a Northampton DAA.

Northampton has a strong commitment from public, private and voluntary sectors to support, promote and work towards a greater awareness of dementia.

We have a strong Northamptonshire Dementia Action Alliance and have recently created a local Northampton Dementia Action Alliance (DAA) which will feed into the Northamptonshire group. The aim for the Northampton DAA is to raise awareness about dementia and improve the lives of people living with dementia and their carers around Northampton. Our ultimate aim is for Northampton to become a Dementia Friendly Community, demonstrating our commitment to people living with dementia. We are in the very early stages of our Northampton DAA and are looking for any public, private or voluntary services who have an interest in Northampton to join us and form part of our Alliance. We are also aiming to engage with people living with dementia and their carers in the near future.

- The UoN Dementia Friendly Community of Practice

The CoP facilitates a number of projects, but its main successes for Northampton Town are its Memory days, the Forget-me-Nots Social Group, the UnityDEM Centre, and the UoN Dementia Research & Innovation Centre (NDRIC)

- a. Memory days in the town in 2016 and 2017

In 2014, the University of Northampton set up a 'Dementia Friendly Community of Practice' (CoP) for Northamptonshire, with the aim of bringing together like-minded individuals from across research, education, and practice to enhance the quality of care for people living with dementia and their family and carers. The CoP were looking for ways to raise the profile and awareness of dementia and memory loss in Northamptonshire. During one of their regular meetings, a colleague from Denmark

was visiting and spoke to the group about remembrance days, which are run in Aalborg municipality, in Northern Denmark. These events are run in community venues with the aim of showcasing the work of local organisations who provide services for people with dementia and their families.

The CoP decided to run a similar day where we could take awareness and information to the community about dementia and memory loss. This led to running a Northampton Memory Day in 2016 and 2017. The event aimed to engage with the general public and businesses to highlight the work of local organisations who provide services for people with dementia, their families and carers. The Memory Day sought to:

- Provide an opportunity to meet local services and find out about memory problems and dementia;
 - Access peer support for families living with dementia;
 - Share knowledge about local care and services;
 - Learn how to become a dementia friendly organisation and share information on supporting dementia friendly initiatives;
 - Attend a dementia friends training and other related sessions.
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- b. The Forget-Me-Nots social group

The Forget-me-not group is a social group is run by and for people with dementia, their partners, carers and family. We meet on the last Tuesday of every month, usually from 5.00pm to 7.00pm. Join us for a meal, a chat and a chance to have a fun evening out. All new members are welcome, whether you are a person with dementia or a carer/family member. You view our programme of activities for 2018, www.copnorthants.co.uk/forget-me-nots-social-group. The group is sponsored by Women in Business Northampton and Stress at Work Northampton. For further information, please contact Alison Ward.

Email: alison.ward@northampton.ac.uk

Facebook: www.facebook.com/groups/ForgetMeNotsNorthampton

- c. Launching the UnityDEM Centre providing post-diagnostic support for people with dementia and their carers.

Opening in the Central Library on Abington Street in Northampton in February 2018, the UnityDEM Centre will provide social support and informative activities for people who have been recently diagnosed with dementia and their carers. A team of professionals and volunteers will provide an enjoyable, flexible and adaptive programme from 10.00am until 4.00pm on Mondays, Wednesdays, and Fridays. What will make our programme of activities unique is the emphasis on helping the person with dementia and their carer to feel:

- less isolated and more supported
- able to adapt and cope with the diagnosis
- valued for their existing knowledge, skills and abilities
- they have improved self-confidence and mental wellbeing

The UnityDEM Centre Project will initially run as a 12-month pilot, during which it will be evaluated. For further information about this project, please contact Jacqueline.parkes@northampton.ac.uk

d. Launching the the Northamptonshire Dementia Research & Innovation Centre (NDRIC)

At NDRIC, we work in partnership with people living with dementia, carers, health and social care providers, voluntary organisations and students. We aim to design, develop, implement, and evaluate new approaches to person-centred, community-based care and support. These approaches include the development of the UnityDEM Centre, a Northampton centre for post-diagnostic dementia support, as well as working with Northamptonshire County Council to inform the design of the first dementia friendly village in the UK.

In conjunction with our UoN Dementia Friendly Community of Practice (CoP) membership, our team looks at the social and care related experiences, and hopes and expectations of people living with dementia and their carers. This knowledge can then be used to improve the quality of life and social and health care outcomes for people living with dementia and those caring for them. With this in mind, five key priority research areas have been identified. They include:

1. Designing, developing, implementing, and evaluating community-based services which are specifically designed to promote social interaction.
2. Investigating the challenges faced by health and social care professionals in detecting the early signs and symptoms associated with dementia.
3. Exploring the impact of initial diagnosis on quality of life and life choices from the perspective of people living with dementia and their carers.
4. Identifying the sources of community healthcare and social support networks for people living with dementia and their carers.
5. Promoting the integration of policy into practice, for example in relation to dementia friendly initiatives.

NDRIC is committed to ensuring that people living with dementia and their carers are actively engaged in all aspects of training, education, and research undertaken by the centre. Their views are at the heart of all we offer, in the hope that together we can shape service delivery across Northamptonshire and beyond.

4. establishing a Northamptonshire Public Patient Forum for people who are living with dementia and their carers.

This Forum is currently in the process of being established by the Northamptonshire Dementia Action Alliance.

Professor Jacqueline Parkes

17th November 2017