

# 24<sup>th</sup> Alzheimer Europe Conference

## “Autonomy and Dignity in Dementia”

Glasgow, 20<sup>th</sup>-22<sup>nd</sup> October 2014

*The Forget-me-nots: Developing a social group for people with young onset dementia and their carers.*

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## ***The Forget-me-nots: Developing a social group for people with young onset dementia and their carers.***

- Based on the findings of some work undertaken by the Dementia Research Network at the University of Northampton (UK), it has been identified that individuals with young onset dementia and their carers wish to be actively supported in re-building normal social networks following initial diagnosis, while receiving timely and appropriate access to formal integrated care pathways.
- This presentation will present the development of a specific tailor-made community-based social group, which is designed to promote normalisation and social connectedness.

# Young Onset Dementia [YOD]

- Young onset dementia accounts for 2.2% of all people with dementia in the UK (Alzheimer's Society, 2012)
- Estimates state that there are now over 40,000 people with young onset dementia (Alzheimer's Society, 2014).
- As numbers of young onset cases are based on referrals to services, this number is likely to be an underestimate. The true figure may be up to three times higher.
- The World Health Organization (WHO) estimates that the real incidence of younger people with dementia can be 2 ½ to 4 times higher than registry studies reflect.

# Younger People with dementia

- People with Young onset dementia are of working age [<65 years of age]
- More difficult to recognise than late onset dementia (LOD) in the early stages of the disease (van Vliet et al., 2012).
- Atypical presentations and younger age contribute to delays in diagnosis.
- Lack of awareness and lack of education among GPs and other professionals, multiple and mis-directed referral into care pathways contribute to delayed or mis-diagnosis (Fardil *et al.*, 2009, Harris & Keady, 2004, McMurtray *et al.*, 2006, van Vliet et al., 2010)
- The psychosocial and personal impact of the illness on a younger person is known to have ‘devastating consequences for productivity, family and society’ (Fardil et al., 2009, Bakker et al., 2008, van Vliet et al., 2011)
- An individual experiences significant alterations to their sense of self, feelings of social isolation and dependency, and a ‘lack of meaningful occupation’ (Harris & Keady, 2004).

# Making a Difference in Dementia:

## Nursing Vision and Strategy-2012

- Launched in the UK by the Department of Health in 2012
- Builds on *Compassion in Practice*, the national general vision, highlighting how nurses can demonstrate the 6Cs in dementia care
- Maximising the unique nursing contribution to high quality compassionate care and support for people with dementia and their cares.



# Commitment to compassionate care

**Care:** Know the person as well as their condition, focus on strengths and unmet need.

**Compassion:** Support people with dementia to live well and be independent for as long as possible

**Competence:** Recognise the value of your role in dementia care no matter what speciality or field of nursing

**Communication:** Work in partnership with the carer/family

**Courage:** Make dementia everyone's business, and champion excellent dementia care

**Commitment:** Commit to action such as the delivery of a dementia friendly environment and communities

## Making a Difference in Dementia: Nursing Vision and Strategy

NHS Health Education England | NHS Commissioning Board | Royal College of Nursing | Public Health | Department of Health

**All nurses will:**

- Care**
  - Know the person as well as their condition, focus on strengths and unmet need
  - Respect an individual's autonomy
  - Work in partnership with the person with dementia and their family, and take time to listen and recognise the individual's views and preferences, and to identify ways to support the individual to live as well as possible
  - Support the rights to live in one's own home and to be independent
  - Connect families to resources and support groups to support health and wellbeing
  - Commit to an environment that is safe for dementia care and that maximises safety and maximises wellbeing
- Compassion**
  - Support people with dementia to live well and be independent for as long as possible
  - Recognise the value of your role in dementia care no matter what speciality or field of nursing
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- Competence**
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- Communication**
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  - Recognise the value of your role in dementia care no matter what speciality or field of nursing
- Courage**
  - Recognise the value of your role in dementia care no matter what speciality or field of nursing
  - Recognise the value of your role in dementia care no matter what speciality or field of nursing
  - Recognise the value of your role in dementia care no matter what speciality or field of nursing
- Commitment**
  - Recognise the value of your role in dementia care no matter what speciality or field of nursing
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  - Recognise the value of your role in dementia care no matter what speciality or field of nursing

**Maximising the unique nursing contribution to high quality, compassionate care and support for people with dementia and their carers/families.**

**Key Facts**

- There are currently 800,000 people with dementia in the UK
- By 2025, this is expected to rise to 1.2 million
- Over 90% of people with dementia live in the community
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**Purpose**

The vision and strategy in recognition of the needs for a much greater number of people with dementia to live in the community and to be supported to live as well as possible.

**End of life and bereavement support**

Examples of nursing professionals who have a contribution across the pathway include public health nurses, infectious, mental health nurses, hearing, disability nurses, dental nurses, community nurses, practice nurses, Admiral nurses, specialist nurses (including specialist dementia nurses), acute nurses, Maudsley nurses and palliative care nurses. This list is not exhaustive - the vision is intended for all nurses, irrespective of provider eg NHS, Social, Private, Voluntary or Prison Sector.

**To make this happen within dementia care (all settings including care homes and nursing homes) nurses need to take the lead in the 6 areas below:**

- Maximising health and wellbeing**
  - Helping people to stay independent
  - Contributing to dementia friendly communities
  - Link, deliver and evaluate care responses
- Working with people to provide a positive experience**
  - Recognising the rights of dementia living in care
  - Recognising the rights of dementia living in care
  - Recognising the rights of dementia living in care
- Delivering care and ensuring people**
  - Recognising the rights of dementia living in care
  - Recognising the rights of dementia living in care
  - Recognising the rights of dementia living in care
- Building and strengthening leadership**
  - Act as a professional role model for all
  - Recognising the rights of dementia living in care
  - Recognising the rights of dementia living in care
- Ensuring we have the right staff, with the right skills and attributes in the right place**
  - Recognising the rights of dementia living in care
  - Recognising the rights of dementia living in care
  - Recognising the rights of dementia living in care
- Supporting positive staff experience**
  - Recognising the rights of dementia living in care
  - Recognising the rights of dementia living in care
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## Model for Dementia Nursing

**Delivering through partnership and in all environments of care to ensure nurses work collaboratively with GP and primary care (including practice nurses) to manage the interface with wider community services:**

- Person's home;
- Hospitals;
- Care homes;
- Care homes with nursing;
- Hospice services;
- Community (social care and voluntary sector organisations) services;
- Out of hours service.

**Connecting all services to form services around the person and the family**

**Connecting to and with all relevant services**

**Dementia Specialists – Experts in the field of Dementia care**

- Nurses with an expert level of skill and knowledge / specialist role / dementia champions in the care, treatment and support of people with dementia, their carers and families.
- Their educative and consultative role aims to improve the delivery of dementia services, making changes in practice.

**Dementia Skilled – All providing nursing to people with dementia directly**

- All nurses that have more regular and intense contact with people with dementia, providing specific interventions, care and services.
- They have an enhanced knowledge and are skilled in dementia care.

**Dementia Awareness – All Nurses**

- All nurses to have an awareness of dementia
- Basic training
- Making every contact count
- Ability to support and support public health messages.

**Intensive or Case Management**

- e.g. Admiral nurse, dementia specialist nurse

**Assisted Care of Care Management**

- e.g. mental health nurse, liaison nurse, community nurse, home nurse, hospital nurse

**Usual Care with Support**

- e.g. district nurse, practice nurse, PHN

**Developing and delivering seamless services within the person's home, community, care settings and between the two**

# Forget-me-not Project: Exploring the experiences of carers of people suffering from young and late onset dementia: A comparison of the nature of caring

## Project aims:-

- Explore the specific care and support needs of the carers of people living with both young and late onset dementia.
- Consider the difference and diversity of experience caring for a relative with dementia.
- Explore how carers adapt and respond to their caring responsibilities.
- Identify the adequacy and appropriateness of the current formal and informal support networks utilised by carers to support their role.

 THE UNIVERSITY OF  
**NORTHAMPTON** 

## Forget-me-not Project

Are you currently the main carer for someone who is suffering with dementia?  
Or  
Are you someone who has been the main carer for someone who has suffered with dementia?

We are a research team from the Dementia Research Network at the University of Northampton who specifically carry out research projects which seek to understand the 'lived' experiences of people with dementia and their informal carers. The aim of the Forget-me-not project is to explore the specific care and support needs of the carers of people living with both young and late onset dementia. Therefore, we are inviting both current carers and those who have previously cared for someone with dementia to take part in an individual interview which will explore your experiences of caring. The interview will take no longer than 1 hour and will be digitally recorded. If you are currently caring for someone with dementia, you will also be invited to record your day to day thoughts, feelings, and experiences in an Aide Memoir (diary format).  
The information you provide will be used to inform the development of further projects and applications for future funding in dementia research.

If you are interested in participating in this project, please contact:-

Alison Ward (Researcher) at: [alison.ward@northampton.ac.uk](mailto:alison.ward@northampton.ac.uk)  
Tele No: (01604) 893559

CENTRE FOR HEALTH & WELLBEING RESEARCH 

# Increasing isolation

**Can you give us a feel of how your social life together changed?**

- R Completely.

**Give us some examples?**

- R Well, we didn't have any social life, you see.

**And did you find that hard?**

- R I did, we had this friend ...he was the boy next door, Eric that's who we was at Tenerife with, so, we've known each other all our lives and on a Friday we always went up to Eric's to play cribbage you see. Well, Eric had noticed, and Ethel, and of course I had, that he was getting slower, Reggie was getting slower and he wasn't playing the cards that he should have played, but we didn't take any notice, we just sort of let it go. Now, they was what I should say was our closest friends, and when Reggie got diagnosed like with the dementia it just all stopped, and I mean you can count on that hand how many times I've seen them since Reggie died.

## Diminishing social connections

*“It’s as though we’ve been ostracised and we don’t exist. Whether they actually know that [Alison’s] got Alzheimer’s, I don’t know, but I think out of everybody that we knew, the people that have been constant are my cousin, my daughter, I can’t say my son because that’s not true, ...”*



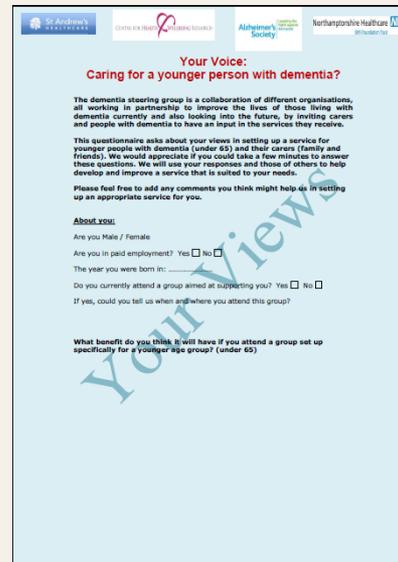
# Ever decreasing circles!

- *“No, we haven’t changed our social life. We still go to the cinema, we still go out for a meal and a drink. We will still go and visit friends, you know, we’ll go up and see my cousin, we’ll go to [local town] to see my daughter”.  
(A & D 1)*
- *But other than that we still laugh, we still joke, we still argue, we still cry together, we go to the cinema and I think that was a little bit of a turning point on Saturday. We went to the cinema to see a film, she was OK, we came out into the foyer and it was packed with people, loud noise, a lot of people in your face and she just gripped hold of my arm like there was no tomorrow and she went deathly white, “We’ve got to go home, I need to go home, I’ve got to go home now.” (A & D 2)*

# Your Voice: Caring for a Younger person with dementia

## Collaborative Project

- A collaborative project between the dementia research network; Alzheimer's Northamptonshire; St Andrews Healthcare; and Northamptonshire Healthcare Foundation Trust.
- Explored the views of the PwYOD and their informal carers
- Survey questionnaire –exploring the formal and informal care networks people access
- Proposed the development of a new community-based social group








**Your Voice:  
Caring for a younger person with dementia?**

The dementia steering group is a collaboration of different organizations, all working in partnership to improve the lives of those living with dementia currently and also looking into the future, by inviting carers and people with dementia to have an input in the services they receive.

This questionnaire asks about your views in setting up a service for younger people with dementia (under 65) and their carers (family and friends). We would appreciate if you could take a few minutes to answer these questions. We will use your responses and those of others to help develop and improve a service that is suited to your needs.

Please feel free to add any comments you think might help us in setting up an appropriate service for you.

**About you:**

Are you Male / Female

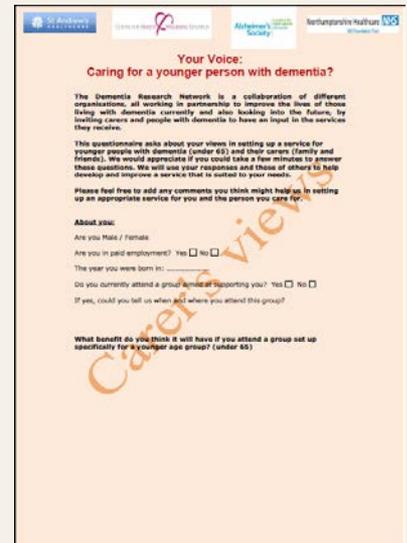
Are you in paid employment? Yes  No

The year you were born in: \_\_\_\_\_

Do you currently attend a group aimed at supporting you? Yes  No

If yes, could you tell us when and where you attend this group?

**What benefit do you think it will have if you attend a group set up specifically for a younger age group? (under 65)**








**Your Voice:  
Caring for a younger person with dementia?**

The Dementia Research Network is a collaboration of different organizations, all working in partnership to improve the lives of those living with dementia currently and also looking into the future, by inviting carers and people with dementia to have an input in the services they receive.

This questionnaire asks about your views in setting up a service for younger people with dementia (under 65) and their carers (family and friends). We would appreciate if you could take a few minutes to answer these questions. We will use your responses and those of others to help develop and improve a service that is suited to your needs.

Please feel free to add any comments you think might help us in setting up an appropriate service for you and the person you care for.

**About you:**

Are you Male / Female

Are you in paid employment? Yes  No

The year you were born in: \_\_\_\_\_

Do you currently attend a group aimed at supporting you? Yes  No

If yes, could you tell us when and where you attend this group?

**What benefit do you think it will have if you attend a group set up specifically for a younger age group? (under 65)**

# Your Voice Project: Summary of Findings

## A basis for developing a new service.

- Sample of 17 respondents: 12 carers, 4 PwYOD, 1 not known
  - 16 people felt it would be beneficial to have a separate service for PwYOD
  - Age being a barrier to accessing current services
  - Locally-based service
  - The majority of respondents wanted the service to meet every four weeks for two hours.
  - The most popular time of day for the service to be in the afternoon on a weekday.
  - The service should provide a peer-support group for PwYOD and their carers
  - All respondents were prepared to travel to attend such a service
- 

# Your Voice: Survey findings

- *I think younger people have different social needs and preferences.*
  - *understanding what younger people can and can't do; friends disappearing and understanding – acceptance.*
  - *Issues of still functioning as a younger person in society who is not retirement age.*
  - *Because other services are suited to older people.*
  - *A service aimed at younger people would cater more for their interests and tastes. Support of the person and carer would be more relevant as need are different depending not just on the dementia but also age.*
  - *To be able to communicate with people of my own age going through similar things.*
  - *My husband is 60 years old with dementia and day centres are not ideal for him. I am younger and would appreciate some help and advice.*
- 

# Your Voice Survey findings

## Locally-based services?

- *Nothing currently in Northamptonshire; most things are in London and Oxford.*
- *It would enable more proactive input, more physicality.*
- *To ease the feeling of isolation, to gain help/advice from people in similar situations.*



# Your Voice Survey findings

## Social connection?

- *Peer support available for similar age and at different stages of dementia. Otherwise not sure what we will need in the future.*
- *Encourage hobbies, encourage interaction, meeting to resolve problems e.g. “why do I feel useless?, why can’t I work? Etc. Talk about these and other feelings. How to move forward.*
- *Anything that would help us as carers know/understand more about dementia and how we can care/support our family member with dementia and other family members i.e. our children, would be really good/helpful/useful.*

# A Social Group for PwYOD & their informal carers



## The Forget-me-nots

- The group meets monthly for two hours from 4-6pm
- The venues for the meetings are community-based.
- The aim of the group is relaxing and socialising in a safe, non-judgmental environment
- The group will be developed by its members for its members
- 11 members in attendance

Launch of a New Social Group for Younger People with Dementia & their Carers

**Thursday 25th July 2013, 4-6pm**  
**The Pavilion, University of Northampton,**  
**Boughton Green Road NN2 7AL**



The Dementia Research Network would like to invite all younger people with dementia (65 and under) and their carers to come and enjoy a few hours of relaxation and socialising.

Our aim is to provide a safe and non-judgmental environment where younger people with dementia and their carers can meet, talk, have fun, arrange events and if they wish to, share ideas and discuss issues which are currently affecting them. This is a new group which will be developed by its members for its members. We hope this will be the first of many social gatherings to take place for you in Northamptonshire and that you will help shape *your* 'social group' at this first meeting.

Support staff from Alzheimers Society will be available. Refreshments will be provided.  
If you have any questions please call Ilze Sinfield on 01604 879000,  
Ilze.Sinfield@alzheimers.org.uk

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**Younger people with dementia & their carers social group**

I will be attending on 25th July/I will not be attending on 25th July but would like information on future meeting dates (please delete)

**Name:** \_\_\_\_\_ **Name (Carer):** \_\_\_\_\_

**Email address:** \_\_\_\_\_

**Telephone Number:** \_\_\_\_\_

Please email your reply slip back to: [Ilze.Sinfield@alzheimers.org.uk](mailto:Ilze.Sinfield@alzheimers.org.uk) or post to Ilze Sinfield, Dementia Support Manager, Alzheimer's Society, The Old Mill, Blisworth Hill Farm, Stoke Road, Blisworth, Northants NN7 3DB





# Evaluating the Group: One year on!

The Forget-me-nots group is supported by Alzheimer's Society Northamptonshire and the University of Northampton. The group is also sponsored by Women in Business Northampton and Stress at work Northampton.



## The Forget-me-nots

Welcome! We are a social group run by and for young people with dementia (under 65 years), their partners, carers and family.

## Afternoon Tea

29<sup>th</sup> July The Bridge Hotel, 4-6pm

Bridge Street, Thrapston, Nr Kettering  
Northamptonshire NN14 4JP



We would like to invite you to join us for afternoon tea. And to celebrate the 1 year anniversary of the Forget-me-nots



Enjoy a mouth watering array of freshly cut sandwiches, cakes and scones with cream and strawberry jam as well as chance to chat and laugh!

All new members are welcome, whether you come as a person with dementia or a carer/family member, and we look forward to seeing you at our next meeting.

### For further information and to let us know you are attending:

Please contact: Ilze Sinfield on 07545 701263 or  
email: [Ilze.Sinfield@alzheimers.org.uk](mailto:Ilze.Sinfield@alzheimers.org.uk)

If you have any queries, would like further information or have difficulty with transport, please let us know

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## The Forget-me-nots

Welcome! We are a social group run by and for young people with dementia (under 65 years), their partners, carers and family.

## Forget-me-nots Social Group

Date and Time	Venue	Event
28 <sup>th</sup> October 2014 4-6pm	Brewers Fayre, Rothwell Road, Kettering NN16 8FX	Join us for a pub meal, an opportunity to talk, laugh and share experiences.
25 <sup>th</sup> November 2014 4-6pm	The Windhover, Brampton Lane, Chapel Brampton NN6 8AA	Join us for a drink, an opportunity to talk, laugh and share experiences.
16 <sup>th</sup> December 2014 5-7pm	The Bridge Hotel, Bridge Street, Thrapston NN14 4JP	Join us to celebrate Christmas with a Christmas Buffet, all family members welcome. £10pp

All new members are welcome, whether you come as a person with dementia or a carer/family member, and we look forward to seeing you at our next meeting.

### For further information and to let us know you are attending:

Please contact:

Ilze Sinfield: 07545 701263/ [Ilze.Sinfield@alzheimers.org.uk](mailto:Ilze.Sinfield@alzheimers.org.uk)  
Or Alison Ward: 01604 893559/ [alison.ward@nothampton.ac.uk](mailto:alison.ward@nothampton.ac.uk)

If you have any queries, would like further information or have difficulty with transport, please let us know



## Strengths

- Range of 'normal' activities
- Group has grown
- Gained in confidence
- Has a stronger voice
- Very close knit group
- Face book page
- Funding



## Challenges

- Change of venue
- Group leadership
- Growing the group
- Getting our name more well known
- Integrating new people
- Arranging to activities

# Conclusions

- There is a need for specialist services for young people with dementia and their carers and family.
- Constantly evaluating and getting feedback is important to ensure the group is running the best way.
- The need for organisations to collaborate is vital for the success of such projects
  - Getting the word out there
  - Providing support
  - Signposting
- Variety of activity and providing 'normalisation' is important

## **Acknowledgments to :**

- NHS Northamptonshire & Milton Keynes
- Northampton Healthcare Foundation Trust (NHFT)
- School of Health, University of Northampton
- St Andrews Healthcare
- DeNDRoN
- De Montfort University
- Northamptonshire County Council
- Institute for Health & Wellbeing, University of Northampton
- Alzheimer's Northampton
- Dementia Action Alliance
- User/Carer representatives
- University of Leicester

**Thank you**  
**Any questions?**



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