

# Dementia webinar for World Alzheimer's Month

Wednesday 27 September



# Memory Assessment Services



NORTHAMPTONSHIRE  
HEALTHCARE NHS  
FOUNDATION TRUST

Dr Louise Birkett-Swan  
Consultant in Neuropsychology



MAKING A  
DIFFERENCE  
FOR YOU,  
WITH YOU

## 4 services

- Service based across Northamptonshire
  - Northampton
  - Wellingborough/Rushden
  - Corby/Kettering
  - Daventry/Towcester

## Staffing

Service Lead

Medical staff (Consultant Psychiatrist/Speciality Dr)

CPNs

OT

Support Worker

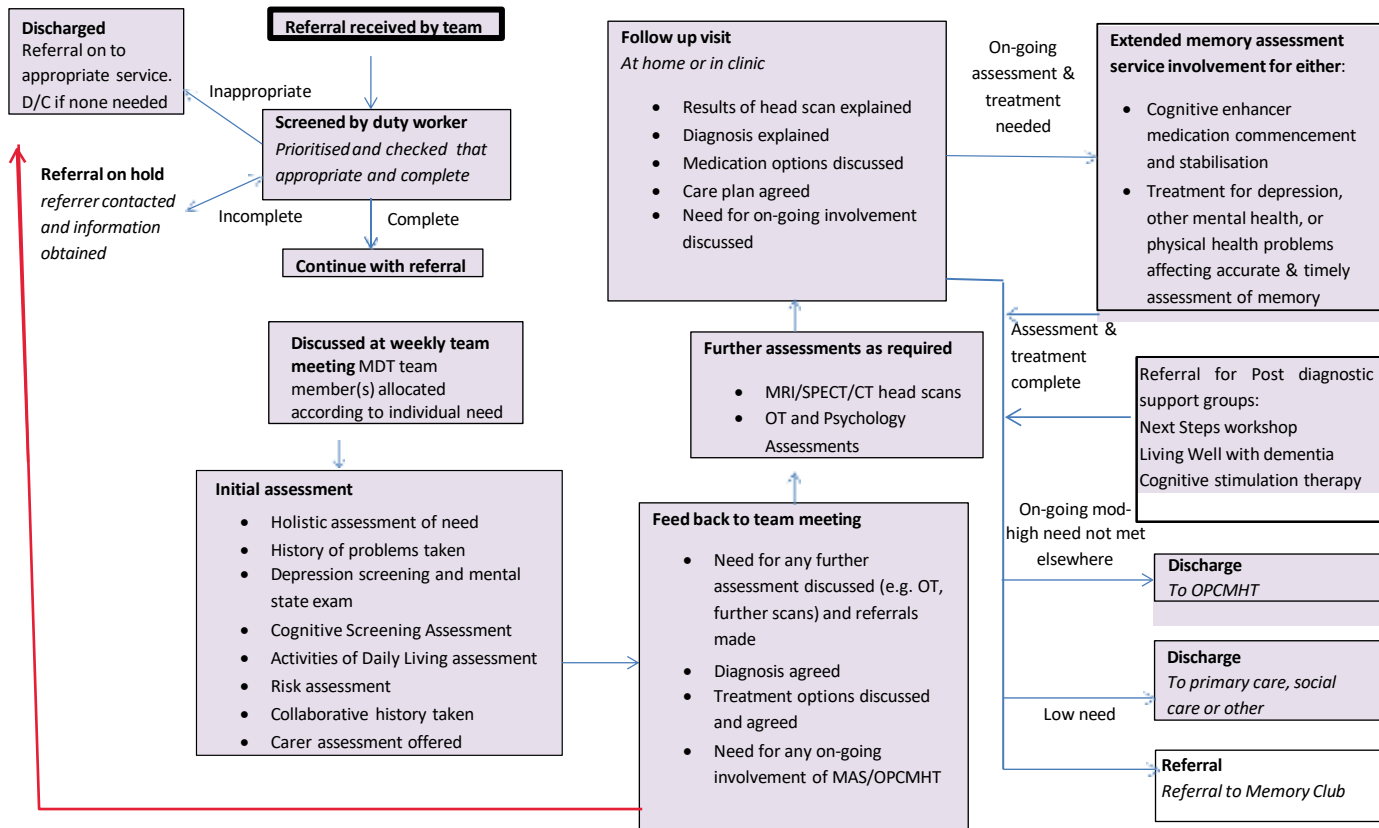
Psychology – team based Assistant Psychologist – support from  
Consultant Neuropsychologist

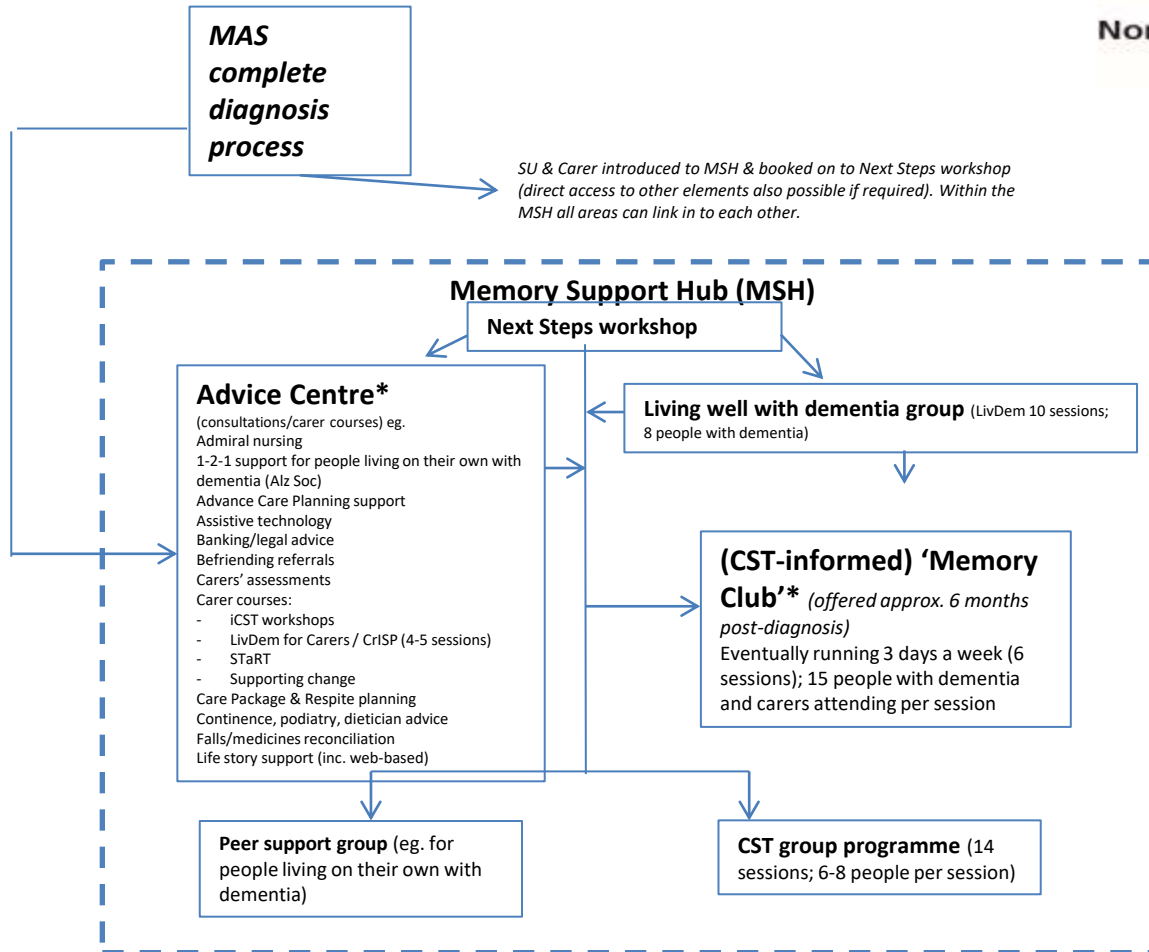
Admin

## Referring into MAS

- Usually, referral in through GP
- Is there a history of cognitive change or is it a sudden change?
- Need to complete screening bloods prior to referral to rule out common physical causes of symptoms similar to dementia:
  - Full blood count, Electrolytes, Urea and Creatinine, Glucose, Liver Function Test (LFT), Thyroid Function Test (TFT), B12 and Folate levels, Urine MSU – negative if previous was positive
- Complete cognitive screen
  - 6 item cognitive impairment test (6CIT) – very brief (3-4 minutes)
  - Mini mental state examination (MMSE) – copyright withdrawn
  - Addenbrookes cognitive examination (ACE-III) – more thorough screen, longer

# NHFT Memory Assessment Service (MAS)







# Co-producing Care Planning with people living with Dementia

Dr Inga Stewart

Consultant Clinical Psychologist

Clinical Research Fellow

Head of Patient Co-production & Inclusion

27 09 2023





## St Andrew's Toolkit for Care Plan Co-production in Dementia



We want people with dementia, and their partners-in-care, to be actively involved in writing their own care plans.



# Introduction

People living with dementia can often find themselves sidelined. Being in hospital can also mean that a person could become isolated from their support networks. Needing a period of care in hospital when also living with dementia can make a person even more vulnerable to not being heard.

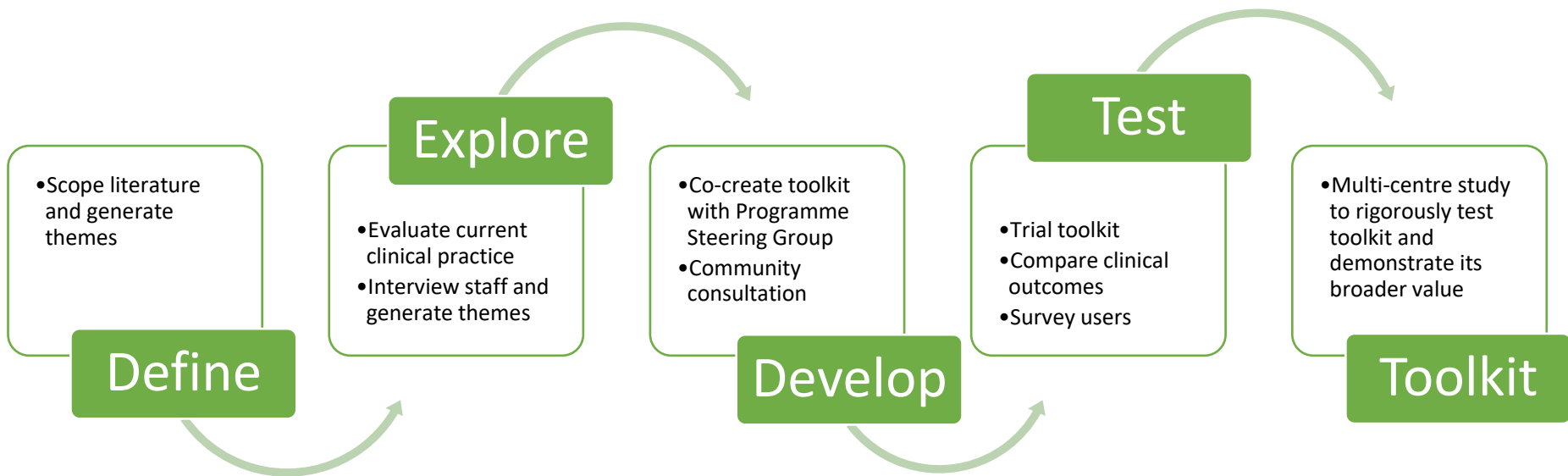
Co-production means working together to do something. It is about treating each other with respect and equal value. It is also about people with different experiences and ideas coming together to make things better for everyone.

When someone moves to a care home or is admitted into hospital, their care plan states their care and support needs and outlines how these needs can be met. Care plans are vital for the wellbeing of the person, and are important to everybody.

Lowther Dementia Village  
Seeing the Person First



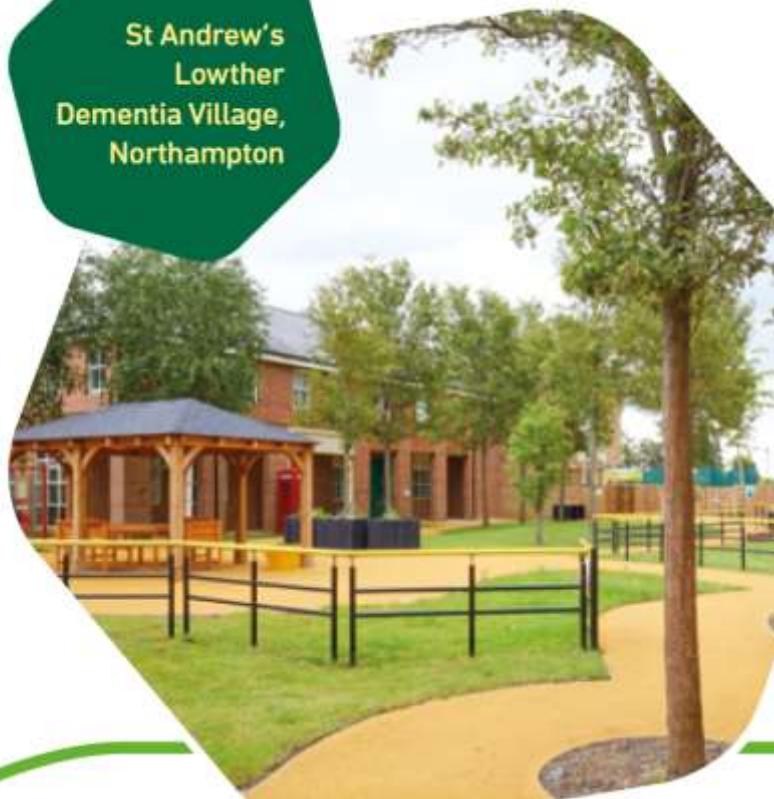
# Co-producing Care Planning with people living with Dementia



# Test

- Trial toolkit
- Compare clinical outcomes
- Survey users

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Dementia Village,  
Northampton



Lowther Dementia Village  
Seeing the Person First





# What is in this toolkit?

The toolkit includes practice standard statements, checklists and tips for staff

## The Practice Standard Statements

These standards represent how care plans should be written in full partnership between me, as the person who the care plan is about, and all those involved in my care.

## The Checklists

These list markers of co-production. They can be used to demonstrate that the standards are being met by my care team. They can also be used as a self-assessment or audit tool.

## The Tips

These can be used to help overcome barriers you might experience when co-producing my care plan with me and my partners-in-care.



# 1

## I am an equal partner in planning my care.

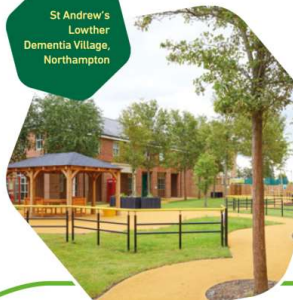
- The person has been involved in conversations that focus on what matters to them, their care values and the things that make for a good life for them.
- Decision specific capacity has been assessed according to the principles of the Mental Capacity Act (2005), and how to involve the person has been clearly written in their care plan.
- The person has been able to jointly develop their care plan, and their views are evidenced.



## Tip

- Not everyone is able or wishes to be involved in care planning. This might change in future, so others can start to build the care plan and come back to it with the person when they are ready.
- Care planning is never a completed activity in one shot! Rather, it should be seen as an ongoing process.
- The person could be involved in all or part of the care planning, with different levels of involvement at different times.
- Ensure everyone knows where the care plan is being stored and how it can be accessed.
- Before starting a care plan, check for existing care plans and other documents such as a 'This Is Me' document, Advance Decisions or Advance Statements, and medical record forms specifying treatment in a future emergency (such as resuscitation), as well as legal documents such as Lasting Power of Attorney.

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Northampton



# 2

## I am at the heart of decision making.

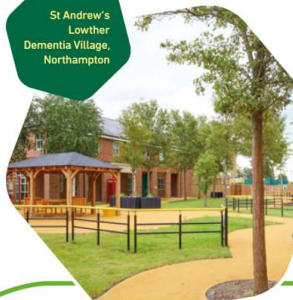
- The person and/or their partners-in-care has been involved in the decision-making process.
- Ways to support the person in decision making have been implemented and clearly written in their care plan.
- The person's priorities and preferences have been included.

## Tip

- Just like any other adult, a person with dementia has the right to make their own decisions.
- You must assume the person is able to make decisions for themselves, unless it is assessed to be otherwise for that specific decision at that time.
- A person cannot be treated as being unable to make a decision just because other people think it is a bad idea.
- If the person is unable to communicate at that time, consider who else and/or what other documentation can help you to make a decision that aligns with the person's known preferences.



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# 3

I have had a conversation about care planning and I feel ready to start.

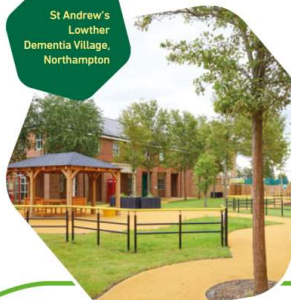
- The level of the person's understanding of their care has been checked.
- The person has been given care planning information at a time and in a way that meets their individual needs.

## Tip

- Consider what times of day are better for the person.
- Think about the location; try to choose somewhere that the person may feel more relaxed.
- Limit distractions, such as background noise from the television or music.
- Consider who is going to do the care planning with the person; pick someone who is most likely to put them at ease and build confidence. Could anyone else help, such as a partner-in-care?
- Ensure the person has all the information they need at the right time for them.



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# 4

## The language and approach is understandable to me.

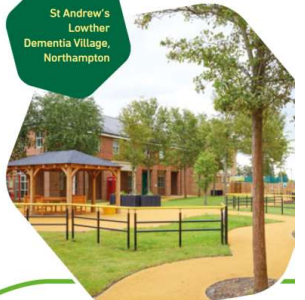
- How the person likes to plan and the language they prefer has been clearly written in their care plan.
- Additional support to help the person in their care planning discussions have been put in place.
- The time and number of sessions necessary to enable the person to discuss their care plan have been made available.
- Information is recorded in a format and language that is accessible to the person and partners-in-care.

## Tip

- The person should be given all reasonable support to make and communicate their own decisions.
- Make care planning enjoyable so that the activity reinforces participation.
- Speak slowly, clearly and in short simple sentences.
- Avoid offering too many choices or using open-ended questions.
- Use nonverbal communication to act out what you are saying, such as a gesture for drinking from a cup.
- Using objects to represent options may help the person to make a choice.
- Use visual aids to explain what you are saying, such as a photo of where you are going.
- Check the person has all their essential medical devices. For example, do they wear a hearing aid or need glasses? Do they have false teeth and are they wearing them?
- Give the person plenty of time to answer because their processing of information might be slow or they might have difficulty in finding words.



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St Andrew's  
Carers Centre,  
Northampton

## Tip

- Even when partners-in-care are involved, it is essential to create space for people with dementia to express themselves. Others might need to step back and pause, and support the person to contribute.
- Not every partner-in-care is able or wishes to be involved in care planning with the person and the care team. This might change in future, so check in with them on a regular basis, and come back to it with them if and when they are ready.
- If the person has been assessed as lacking capacity for a specific decision at a specific time, any decisions that other people make for them must be made in the person's best interests.
- If there is disagreement or a conflict of interest, consider an advocate, such as an Admiral Nurse or other healthcare professional, to support the discussion.

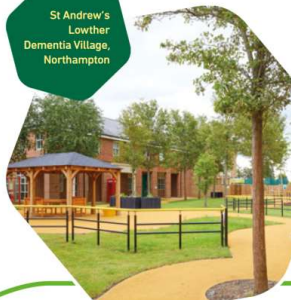
# 5

People significant to me could be invited to be involved in planning my care, where appropriate and acceptable to me.

- The partners-in-care are clearly identified.
- The level of involvement of the partners-in-care is clearly documented.
- There is good communication about the expectations of the person and their partners-in-care.
- The care plan clearly captures each person's view, documents the reasons for any disagreements and explains why a certain decision was taken.
- Where involvement of partners-in-care is not appropriate, it is recorded why they were not involved.



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# 6

I am the expert in my own experience. My knowledge, and that of my partners-in-care, is respected and included.

- The person's voice must be included throughout their care plan.
- Wherever a partner-in-care has been involved in the care planning, their voice is included.

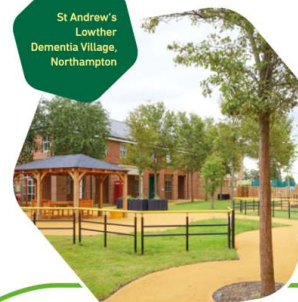


## Tip

Co-producing the care plan is beneficial for all those involved. Bringing different experiences and ideas together makes things better for everyone. With everyone's voice included, the care plan will naturally be more responsive to the needs of the person and be of a better quality.

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Main Building,  
Northampton

St Andrew's  
Lowther  
Dementia Village,  
Northampton





## Tip

- The inclusion of long, mid and short-term time frames can help to measure progress along the way.
- Make sure it is clear to the person, their partners-in-care and the care team, how everyone will know when the goals have been met.
- Goals can change over time, so it is important to review them.
- If a goal seems unachievable think about what the underlying need is behind it. Consider how it could be met in a different way.

# 7

The steps that we are going to take together to attain my aims are clear and achievable.

- There are clear goals that reflect the person's wants and needs.
- There is a plan for how these will be achieved.
- The goals are measureable, and how someone would know when the goal has been achieved is written in the care plan.

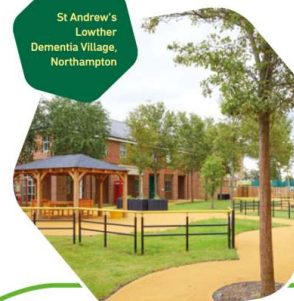


[www.stah.org.uk/medialia](http://www.stah.org.uk/medialia)



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Northampton



# 8

## We can review my care plan together at any time.

- There is a date set up for the next formal review.
- The process of requesting additional reviews of the care plan is clearly documented, allowing the person, their partners-in-care or the care team to ask for reviews at any point.

### Tip

- It can be helpful to agree a review schedule at the beginning of the care planning process.
- Wherever possible, the review dates and review process should be mutually agreed.



This toolkit is the outcome of a research programme funded by a St Andrew's Clinical Research Fellowship

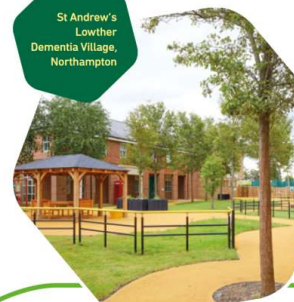


**Research & Innovation**  
Part of St Andrew's Healthcare

[www.stah.org/dementia](http://www.stah.org/dementia)

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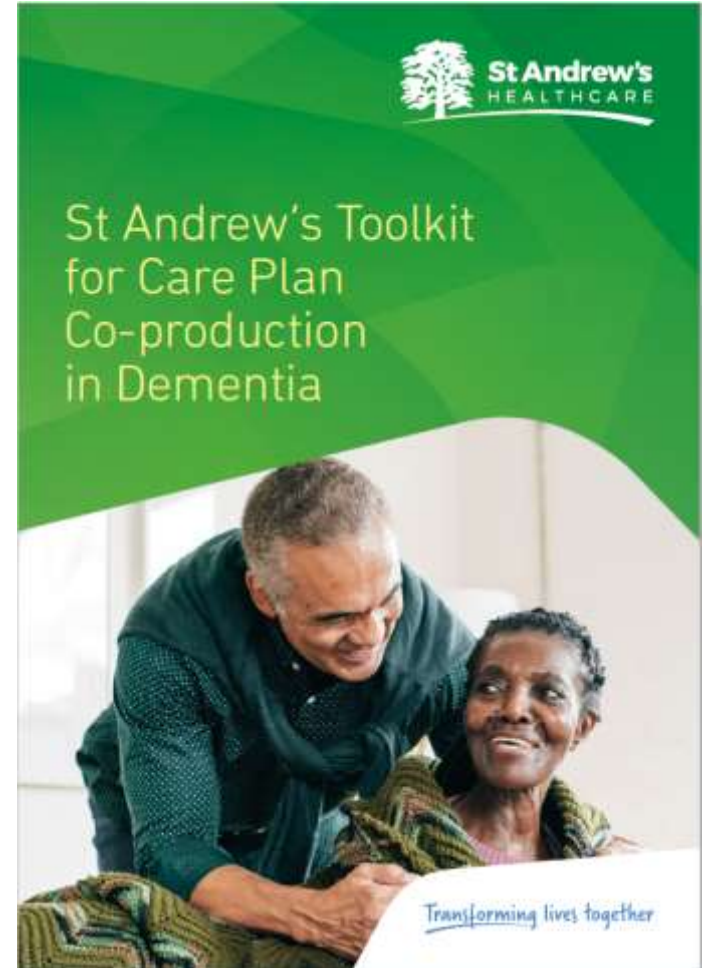
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# Any Questions?

Dr Inga Stewart  
[research@stah.org](mailto:research@stah.org)





Continuous  
Quality  
Improvement



STAY  
WITH ME



# John's Campaign

Dr Vincent Harding

Clinical and Forensic Psychologist

# Who was John?



Above: John with his daughter, Nicci.



# What is John's Campaign?



- A campaign to change legislation and provide people in care homes and hospitals with the legal right to a partner-in-care.

# Why is John's Campaign important?



- It helps to support a person's psychological needs.
- It promotes collaborative working with PiC when planning, delivering and supporting care.



# Neuropsychiatry Division, St Andrew's Healthcare





# What have we achieved?

- Liaison with our patients, PiC's and clinical teams about their experience.

Name of individual: \_\_\_\_\_  
Date: \_\_\_\_\_

**St Andrew's HEALTHCARE**

### John's Campaign Patient Survey

John's Campaign recognises the importance of involvement from families and friends in your care and treatment.

We would like your feedback about your experience of family and friend involvement.

For the following statements, please mark the answer which best represents your experience.

1. I am happy with the amount of contact with my family and/or friends.

Strongly agree  Agree  Neutral  Disagree  Strongly disagree

2. I have enough time between contact and other activities.

Strongly agree  Agree  Neutral  Disagree  Strongly disagree

3. They follow my guidelines or concerns I have about my care and treatment.

Strongly agree  Agree  Neutral  Disagree  Strongly disagree

4. They respond and support me with my guidelines or concerns.

Strongly agree  Agree  Neutral  Disagree  Strongly disagree

Do you have any other wants, needs, or concerns about contact with your family and/or friends please add these below.

\_\_\_\_\_

Your name: \_\_\_\_\_ Your friend/relative: \_\_\_\_\_  
Date: \_\_\_\_\_

### John's Campaign patient/carer survey

John's Campaign is a movement which recognises the importance of welcoming families and friends as equal partners in the care and treatment of people with dementia and neurodegenerative disease, who are in hospital.

As part of implementing this campaign, we would like to know the level of involvement you would like in your friend or relative's care.

Please tick one box for each question, unless indicated otherwise.

5. How frequently would you like contact with your friend/relative?

\_\_\_\_\_

6. What activities (if any) would you most like to be involved in with your friend/relative? Select as many as you wish.

Meal times	Morning routines	Evening routines	Ward based activities	Non ward based activities	None
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. Would you like to receive written/oral updates on your friend/relative care and treatment? If yes, how often would you like these?

No	Daily	Once weekly	Fortnightly	Monthly	Other (please specify)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Would you like to contribute to the production of your friend/relative care plan?

Yes  No

9. Do you like to attend Ward Rounds and Care Plan Approach (CPA) review meetings for your friend/relative?

Yes  No

10. Do you have any other requests regarding your involvement in the care and treatment of your friend/relative? If yes, please record below.

\_\_\_\_\_

11. Do you consent to being contacted again about John's Campaign?

Yes  No

12. Do you consent to your contact details being added to the Carers Centre database? Please speak with the team on 01899 638123 or [carers@stah.nhs.uk](mailto:carers@stah.nhs.uk) if you have any questions.

Yes  No

13. Do you consent to your feedback being anonymised and shared?

Yes  No

14. What is your preferred means of contact by us?

email  telephone  other

Thank you for your time and feedback.

# What have we achieved?



Dear Mark,

John's Campaign Staff Survey

John's Campaign is a movement which recognises the importance of listening families and friends to input patients to the care and treatment of people with dementia and Parkinson's disease, who are in hospital.

As part of implementing this campaign, we would like your opinion on the best ways to make the network in a way that will be beneficial for patients, their families and friends, and all staff.

Please tick one box for each 5 questions unless indicated otherwise.

1. Increased opportunities for contact from families and friends will improve the patient experience.

Strongly agree	Agree	Disagree	Strongly disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. Increased opportunities for contact from families and friends will improve staff the delivery of patient care.

Strongly agree	Agree	Disagree	Strongly disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3. Increased opportunities for contact from families and friends will improve standards across all parts.

Strongly agree	Agree	Disagree	Strongly disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4. I am in favour of increased opportunities for family and friend contact?

Strongly agree	Agree	Disagree	Strongly disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5. Do you have any other questions regarding the implementation of John's Campaign? If yes, please record below.

If you have any concerns regarding the implementation of John's Campaign please record these below, and indicate what solution, if any you consider appropriate.

Thank you for your time and feedback.

- Feedback is helping us to identify areas of best practice and opportunities for development.
- We are changing the culture so that the John's Campaign philosophy becomes the norm.

# What have we achieved?





# A quote from a previous partner-in-care



"There was a stark difference in approach between the general hospital where my husband was first diagnosed with dementia, and [St Andrew's]. In the first, it felt like carers were regarded with suspicion. Their views and experiences were to be treated with the proverbial "pinch of salt", if listened to at all, and they were held at arms length and told about care decisions, not involved in them. It was really hurtful to be side-lined like this. And patronising.

I'm glad to say my experience at St Andrew's has been completely different. I have been listened to, involved in care decisions, and treated as a valid part of the care team. I really welcomed being invited to contribute. Although I am not a mental health professional I still know my husband better than anyone else.

This involvement has been as important for me and my wellbeing as it has been for him. Important for me because I trusted you with the person who I love most in the world because I could not care for him myself. Giving him up to full-time care was a big deal. I felt desperately guilty that I could not care for him at home. Your welcomes, openness and friendliness every time I came to visit made me realise that he was in the best place for him. Thank you for letting me do some things for him while I was there, like feed him lunch or give him drinks. It felt good to be involved even in a small way. I became part more of the St Andrews family, and that felt good.

Involving me was important for him because I was able to speak on his behalf when big and small decisions were required, knowing what he himself was likely to have asked for. I think it also helped slow the effect of dementia.

Thank you for looking after my husband and me with such care, compassion and professionalism. You always saw beyond the disease and treated him as a person, not a condition, and I am immensely grateful for that. You are all remarkable people with a remarkable vocation."



# What next?

- Continue to embed John's Campaign.
- Seek continued feedback.
- Measure success through compliments and complaints, PREMs and John's Campaign survey data.



For more information...

[johnscampaign.org.uk](http://johnscampaign.org.uk)



[johnscampaign@stah.org](mailto:johnscampaign@stah.org)

# Professor Jacqueline Parkes

CHAIR OF THE NORTHAMPTONSHIRE  
DEMENTIA ACTION FORUM [NAF]





At NDAF, our aim is for Northamptonshire to become a Dementia Friendly Community, demonstrating our commitment to people living with Dementia. We want to make the county a more dementia friendly place in which to live and work. We want to raise awareness about dementia, enhancing the lives of people living with dementia and their carers.

We would love to have more members from public and private sectors, third sector and voluntary organisations. If you would like to know more about joining, please contact the Chair at [Jacqueline.parkes@northampton.ac.uk](mailto:Jacqueline.parkes@northampton.ac.uk) or come along to a meeting.

NDAF was formerly the Northamptonshire Dementia Action Alliance and the University of Northampton Dementia Friendly Community of Practice



A PARTNERSHIP  
WORKING TO IDENTIFY & ADDRESS  
THE CHALLENGES  
**IN OUR**  
DEMENTIA COMMUNITY

NDAF

# NDAF PROJECTS

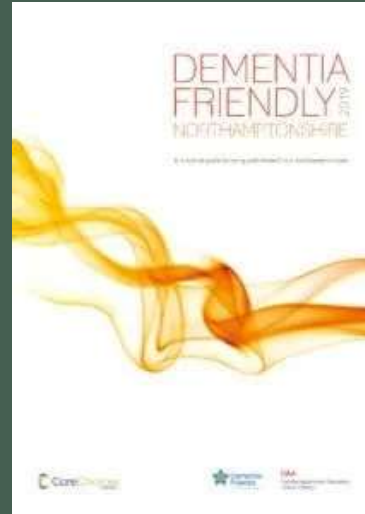


**Draft Northamptonshire Dementia Strategy (Plan) 2015 - 2018**

This strategy has been made with local people in Northamptonshire and these organisations:

- Cebly Clinical Commissioning Group
- New Clinical Commissioning Group
- Northamptonshire County Council

Easy Read



**DEMENTIA COMMUNITY EXP. PRACTICE PARTNERSHIP**

**Memory Day 2016**

What do you know about dementia?  
When? 13<sup>th</sup> September, 10am-6pm  
Where? Grocers Shopping Centre, Northampton NN1 2SD\*\*  
Why should I attend? You can meet individuals and organisations from across Northamptonshire who provide information and advice about dementia and memory.  
Who should attend? The memory day is for everyone; members of the general public, people with dementia and their carers, employees from local businesses, and health and social care providers.  
What should I expect? There will be a range of stands for you to browse, collect information from and ask questions.  
We will be having FREE Dementia Friends training sessions, wellbeing assessments and demonstrations of chair based exercises, storytelling and reminiscence sessions.  
[www.dementiafriends.co.uk](http://www.dementiafriends.co.uk)



# Q&A