Dementia Pathway Study - Patient & Carer Experience at University Hospital North Staffordshire

University Hospital of North Staffordshire NHS Trust

Craig Staples
Engaging Communities | Suite 2 Opus House, Priestly Court, Staffordshire Technology Park, Stafford. ST18 0LQ

evidence.insight@ecstaffs.co.uk 01785 224819
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Executive Summary

In our work delivering Healthwatch Staffordshire, we know from our communities that the issue of dementia is of crucial concern. Our belief is that as consumers of services, it is vital that the public have a say in how their services are run in order to ensure these services are fit for purpose, efficient and effective. To this end, we were delighted to be asked by University Hospital North Staffordshire to research patient and carer experience in relation to dementia care at the Hospital and in North Staffordshire.

Dementia is a challenging and debilitating illness that often causes great emotional and physical strain, not only for people with dementia but also for those who care for them. It is often the people who use services who best know where there are gaps or duplication in provision, where best practice can be identified and where there are areas for improvement. Therefore, it is crucial that both people with dementia and their carers are effectively supported and given a voice in the way that dementia services are developed.

In our ageing communities dementia is a sensitive, challenging and complex subject, but one that is of great importance to Healthwatch Staffordshire and to society as a whole. This report highlights the need for the system to work well together, the need to improve communication, and also the need to treat people with dementia as individuals, and not just as people carrying a label.

This report has sought patient and carer case studies concerning their journey into accessing services at UHNS, ECS has analysed the wealth of qualitative data this produced and cross referenced against the UHNS Dementia Care Pathway and Framework Guidelines for Practice.

The results were mixed with a variety of positive and negative experiences. It is clear that the experience of care is inconsistent. Perceptions of interactions between different agencies and organisations providing this care; uncoordinated. There was overwhelming support for the stages and elements outlined within the Framework Guidelines for Practice aimed at improving standards of care provided by the trust, but that it should be ensured that these are followed and fully realised with every individual accessing services at UHNS with Dementia.
Introduction & Background Research

Nature of dementia

Dementia is an illness which causes a variety of symptoms including: disturbance in memory, orientation, understanding, learning, calculation, language and judgement. It also reduces a person’s abilities and skills in carrying out daily activities such as washing and dressing and commonly comes with deterioration in motivation, emotional control and social behaviour. (Definition of dementia based on ICD 10)

However, people with dementia should each be treated as individuals and the symptoms of dementia and how fast they progress will vary by person. The vast majority of people diagnosed with dementia (94%) are aged over 65. However, some people under 65 are diagnosed with dementia and this is termed ‘early onset dementia’. Certain groups are at high risk of dementia, including people suffering from Parkinson’s disease, those who have had a stroke, the learning disabled and those with Down’s syndrome (Royal College of Psychiatrists, 2011).

Relevant ECS research

In November 2013 the Care Quality Commission (CQC) began a themed review of dementia care. As part of our responsibility to deliver Healthwatch Staffordshire, ECS was called upon to give a voice to the experiences of people with dementia in our local area.

Both to inform the CQC review and to further develop our own work around dementia, ECS released a short survey to ask local residents about their own experience of dementia care. In order to be as inclusive and far reaching as possible the survey was aimed at both people with dementia and their carers, relatives, colleagues and friends. The survey was released online through the ECS website and email database. Paper based versions of the survey were also available and were distributed in partnership through events held by the Alzheimer Society. Twenty eight respondents completed the online survey and twelve respondents completed the paper based survey. This survey was not specific to UHNS, or any other service, but simply collected experiences of dementia care amongst the general population of Staffordshire.

A major theme raised by respondents was the necessity of early diagnosis and proactive care of dementia. Some participants stressed that it was crucial that information and support was available
at the early stages of the illness so that the quality of life of the person with dementia can be extended as much as possible before their situation deteriorates.

Most respondents also felt that, in their experience, the physical health needs of people with dementia were not effectively managed. Some participants stressed that they had negative experiences because the various physical and psychological needs of people with dementia were not seen as a whole:

‘GPs see just the dementia and not the person or health needs, hospitals see just the medical problem that has brought them and ignore the person.’

Another experience was described that was positive specifically because medical professionals were sensitive to the added challenges of dementia in their testing of other health needs. Most respondents also felt that the different organisations involved in dementia care were too disjointed and not working together effectively. There was a perception that this was because different organisations were not communicating and sharing information with each other, and that this placed additional pressure upon carers.

Population in Staffordshire and Stoke on Trent with dementia

In 2011/12, 4,350 people in Staffordshire were recorded as having dementia, with the highest levels in Newcastle under Lyme and Staffordshire Moorlands. However, dementia is estimated to be under recorded in Staffordshire by up to 58.8%, meaning that there is likely to be around a further 6,200 people in Staffordshire whose dementia is undiagnosed or unrecorded (Staffordshire JSNA, 2012). In addition, there are around 3,000 people in Stoke-on-Trent that have been identified as having some level of dementia (Stoke-on-Trent JSNA, 2012). Furthermore, due to the ageing population of North Staffordshire and Stoke-on-Trent the numbers of people with dementia are likely to increase considerably as the population becomes older. The number of people with dementia within Staffordshire is projected to more than double between 2010 and 2030 (Staffordshire JSNA, 2012).

Dementia poses a particular challenge for UHNS as around 70% of patients admitted are aged over 65 and up to half of these patients are estimated to have dementia or delirium. Many of these patients will be undiagnosed, having gone into hospital for another reason (such as falls or chest infections), making it difficult for them to get appropriate support and care whilst in hospital. Early diagnosis and improved care for people with dementia whilst in hospital can not only improve their experience and ongoing care, but also reduce the length of stay of the patient and reduce costs for the NHS.
Delayed discharge

A 2009 study by the Alzheimer Society found that 86% of nurse managers felt that patients with dementia sometimes or always had a longer stay in hospital than people without the condition who go into hospital for the same reasons (Alzheimer Society, 2009). If nationally the length of stay of a patient with dementia could be reduced by a week this would save the NHS over £80 million a year. Problems within the dementia pathway can increase the length of stay in hospital of a person with dementia due to delayed discharge. A 2007 study by the National Audit Office noted that around half of patients affected by delayed discharge are patients with dementia. In the 6 months between August 2013 and January 2014 there were 3,118 days where the discharge of a patient was delayed. Of these days of delayed discharge, 36% were caused because a patient was awaiting completion of an assessment and 35% were caused because the patient was awaiting further NHS non-Acute care. Not all of these patients will be patients with dementia. However, this does demonstrate that clear, early and well-coordinated dementia pathways and integration with other services has the potential to significantly reduce costs for UHNS and create more efficient delivery of services.

UHNS Dementia Care Pathway and Framework: Summary

Early detection, Assessment and Diagnosis

Early diagnosis of dementia is essential in order to give patients and carers an opportunity to plan and influence their care and to improve quality of life. UHNS follows the FAIR process (Find Assess Investigate Refer) of early detection, assessment and diagnosis of dementia.

Find

Within 72 hours of admission, all patients aged 75 years or over without a formal diagnosis of dementia are to be asked the dementia screening question, as outlined in the nursing assessment documentation:

“Have you been more forgetful in the past twelve months, to the extent that it has significantly affected your daily life?”
Assess and Investigate

For those patients who answered positively to the screening question, assess signs of dementia and record the score.

Refer

Refer those patients who have a positive or inconclusive assessment of dementia onto the relevant service.

National guidance indicates that:

‘at least 90% of patients aged over 75 who have been admitted as an emergency for over 72 hours, and have been identified as potentially having dementia, should be assessed and where appropriate referred to another specialist service’.

Between July and November 2013 the University Hospital of North Staffordshire has exceeded this target, with 100% of identified patients receiving an assessment and, if necessary, a referral.

Over five months (July to November 2013) a total of 3,549 patients over 75 who have been admitted as an emergency for over 72 hours were identified. Of these patients 1,548 (44%) answered positively to the ‘case finding question’) and so received an assessment. Of the patients who received an assessment 229 (15%) had a positive or inconclusive diagnosis of dementia and so were referred to another service. This means that over this period at least 6% of the emergency patients aged over 75 who were admitted to UHNS for over 72 hours required a diagnosis and referral to a dementia service.

Dementia care

UHNS follows 5 principles of practice for dementia care as outlined by the Department of Health with the Royal College of Nursing in “Commitment to the care of people with dementia in general hospitals” (2011).

- Staff must be informed, skilled and have enough time to care.
- Family carers and friends are seen as partners in care, unless indicated otherwise by the person living with dementia.
- Dementia assessment will be offered to all those at risk, to support early identification and appropriate care.
- Care plans will be person-centred, responsive to individual needs and support nutrition, dignity, comfort, continence, rehabilitation, activity and palliative care.
- Environments will be dementia friendly and support independence and well-being.

The Trust also follows 3 key procedures in the way that they care for people with dementia:

1. The use of the ‘this is me’ document
2. Use of the butterfly symbol
3. The care bundle approach

**Use of the ‘this is me document’**

This document is a routine collection of personal information and preferences, completed at admission with the assistance of someone who knows the patient well such as family or carers. The document should include information such as the patient’s name; routines and preferences; whether the person needs reminders or support with personal care; recurring factors that may cause or exacerbate distress; support or actions that can calm the person if they are agitated. Once completed this document is held within the patient’s notes, so that it is readily available and accessible to all those involved in the patient’s care to improve the planning, quality and communication of dementia care.

**Use of the butterfly symbol**

This is a symbol used to discretely identify patients with dementia so all staff caring for them are aware of the dementia and can offer appropriate care and support.

**The care bundle approach**

A care bundle is a small set of evidence-based interventions that, when implemented together, will result in significantly better outcomes than when implemented individually. They are descriptive rather than prescriptive to allow for local customisation and appropriate clinical judgement. Care bundle elements for dementia care include: effective communication, adequate hydration and nutrition and a safe and orientating environment.
Other key aspects of UHNS dementia guidelines

Use of antipsychotic medication

Many people with dementia experience behavioural and psychological symptoms (BPSD) which may include agitation and distress and can become aggressive when in hospital. However, use of antipsychotic medication in order to manage these symptoms can have serious side effects. Following NICE guidelines the Trust specifies that:

‘Use of antipsychotic medication should only be considered if symptoms are severe, distressing and create a risk for the patient or other individuals and reasons for antipsychotic medication should be clearly documented and regularly reviewed.’

Role of carers

UHNS recognises the vital role of carers to people with dementia, and also the invariable strain that the condition can place upon the emotional and physical wellbeing of carers. The Trust specifies that staff must work in partnership with carers through:

- Recognition and assessment of carers needs.
- Involvement of families / friends in assessment, care planning and decision making.
- Flexible visiting and flexible approaches to routines so that family/ carers can be involved directly in care where desired.

Role of Volunteers

In a busy environment, trained volunteers can be a valuable support to hospital staff in providing activity and pastoral care. This might include sitting with patients, engaging in conversation, offering individualised or group activities as appropriate and support at mealtimes. UHNS specifies that training and supervision must be in place for volunteers providing such support.

On discharge from hospital

Ongoing needs should be reviewed and summarised so that appropriate care and treatment can continue to be provided i.e. summary of persistent behavioural and psychological symptoms of dementia at discharge.
Safeguarding vulnerable adults

People with dementia are often vulnerable and an improved awareness, knowledge and understanding of the abuse of vulnerable adults is essential to all staff involved in care for people with dementia. The Trust provides all staff with safeguarding policy and protocols, providing clear information on how to report concerns about possible abuse to safeguard people with dementia. Staff also receive training in safeguarding vulnerable adults.

Complaints

The Trust provides all staff with clear information on how to complain about poor standards of care.

Staff training

Staff are given training to understand how to support people with dementia and their carers. This is upheld through a range of resources including appropriate policies and procedures, defined systems of data collection, and a three year training strategy.

In summary dementia is an illness that can have a devastating effect upon patients and carers. A significant proportion of the local population and the patients treated at UHNS suffer from dementia, and this issue is predicted to increase considerably as the population ages. An added difficulty is that many patients with dementia are unrecorded, making early diagnosis and referral to an appropriate service crucial.

The UHNS dementia guidelines and framework have been developed in order to tackle the growing challenge of dementia in a number of ways including: use of the FAIR early diagnosis systems, butterfly symbol and ‘This is me’ document. They also provide clear guidelines on the use of volunteers, involvement with carers, safeguarding, hospital discharge and staff training. ECS has developed the following methodology in order to better understand the ways in which the framework and guidelines are currently being used, and to develop the best method of their implementation as informed by carers and users of services.
Plan & Methodology

The methodology for the study was designed to address the overall objectives of the study to find

1. Recommendations to Improve Experience for Users
   a. Focus on Carers
      *(their own perspectives and on behalf of their [relative, friend, patient]*)
   b. Focus on Hospital Wards
      *(Trauma & Orthopaedics, Elderly Care, A&E, Outpatients)*

2. Recommendations to improve Signposting & Information Provision

UHNS currently carry out a programme of questionnaires for Dementia Patient’s Carers. This is successful and informative but the response rate is low. This study is designed to delve deeper into individual experiences and so on this basis a survey methodology had been ruled out. Therefore we planned to collect case studies via semi structured interviews in a variety of different settings.

Engagement Plan

A schedule of engagement was planned for March / April 2014 including Community Engagement Leads (CELS) from ECS, Healthwatch Champions, local community and voluntary sector groups and the hospital itself.

We planned to target existing groups and events in the North Staffordshire area and have a visible presence on the focussed wards for a number of days. With the help of UHNS we also organised an event at the hospital for carers to attend in a relaxed and informal atmosphere (coffee and cake afternoon), and finally a social media and online campaign / appeal for stories.

Community Interest Groups

There are many different groups that provide activities, meetings and events for patients and their carers. We engaged with existing contacts to provide a strong foundation for collecting patient and carer stories. The following table shows the engagement activity with community interest groups in the local area.
<table>
<thead>
<tr>
<th>Event details</th>
<th>Date &amp; Time</th>
<th>Activity type</th>
<th>Staff / Volunteers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia Friends Session, with Approach. Churnet Room, SMDC.</td>
<td>15.03.2014 10am – 12pm</td>
<td>Drop-in, 1-2-1s.</td>
<td>Joan Buck Karen Bradley</td>
</tr>
<tr>
<td>Approach Cafes: Bucknall</td>
<td>04.04.2014 10.30am - 12.30pm</td>
<td>Drop-in, 1-2-1s.</td>
<td>Hester Parsons Sue Baknak</td>
</tr>
<tr>
<td>Approach Cafes: Leek.</td>
<td>15.04.2014 10.30am - 12.30pm</td>
<td>Drop-in, 1-2-1s.</td>
<td>Elizabeth Jarrett Joan Buck</td>
</tr>
<tr>
<td>Approach Cafes: Cheadle.</td>
<td>25.04.2014 10.30am - 12.30pm</td>
<td>Drop-in, 1-2-1s.</td>
<td>Elizabeth Jarrett Sarah Bromley</td>
</tr>
<tr>
<td>Approach Cafes: Silverdale Athletic Club, Newcastle.</td>
<td>08.04.2014 10.30am - 12.30pm</td>
<td>Drop-in, 1-2-1s.</td>
<td>Sue Baknak Will Taylor</td>
</tr>
<tr>
<td>North Staffs Carers Association, Carer Groups. Lymebrook Resource Centre, Bradwell Hospital site.</td>
<td>04.04.2014 10.30am - 12.00pm</td>
<td>Drop-in, 1-2-1s, focus group.</td>
<td>Joan Buck Chris Bain</td>
</tr>
<tr>
<td>Dementi Support Group at Blythe Bridge.</td>
<td>30th April - 10am – 12pm.</td>
<td>Drop-ins, 1-2-1s.</td>
<td>Hester Parsons John Cotterill</td>
</tr>
</tbody>
</table>
Hospital Visits – Ward & Event

Ward Visits

ECS has very relevant experience in conducting research on site in hospitals, having already completed several projects involving A&E, Outpatients and various wards and departments at Trusts in the local area. We continued to use that experience but with a greater focus on one to one interactions, encouraging patients and carers to talk openly and honestly about their experience at UHNS and cross referencing to the Dementia pathway. We were located directly on the identified wards, with the exception of the A&E. We decided to gather information about A&E indirectly through patients and carers that have been transferred to other wards from A&E. This promoted greater efficiency in targeting relevant patients.

Interactive Event - Coffee & Cake Afternoon

We organised an event that was on site at the hospital but would not include hospital staff. The event was informal and enabled carers to come and talk in a relaxed atmosphere with refreshments.

<table>
<thead>
<tr>
<th>Hospital Visit</th>
<th>Date &amp; Time</th>
<th>Activity type</th>
<th>Staff / Volunteers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ward 76a &amp; 76b</td>
<td>23.04.2014 10.30am – 12pm</td>
<td>Case Study Collection</td>
<td>Hester Parsons</td>
</tr>
<tr>
<td>Ward 78 &amp; 79</td>
<td>23.04.2014 1.30pm - 4.30pm</td>
<td>Case Study Collection</td>
<td>Joan Buck</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Sue Baknak</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Matthew Thompson</td>
</tr>
<tr>
<td>Ward 80</td>
<td>24.04.2014 1.30pm - 2.30pm</td>
<td>Case Study Collection</td>
<td>Elizabeth Jarrett</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Matthew Thompson</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Garry Hill</td>
</tr>
<tr>
<td>Wards 225 &amp; 226</td>
<td>25.04.2014 2.30pm - 4.30pm</td>
<td>Case Study Collection</td>
<td>Elizabeth Jarrett</td>
</tr>
<tr>
<td>Coffee &amp; Cake</td>
<td></td>
<td>Drop-in, 1-2-1s.</td>
<td>Hester Parsons</td>
</tr>
<tr>
<td>Seminar Room West Building</td>
<td>28.04.2014 1.30pm - 4.30pm</td>
<td></td>
<td>Craig Staples</td>
</tr>
</tbody>
</table>
Public Campaign

ECS undertook a public awareness campaign to collect stories associated with Dementia services from patients and their carers. To promote this campaign we used a social media: Twitter, and our own websites.

Patient Stories

The planned engagement provided the means of collecting and collating patient stories as case studies (Berg 2004, p251). These were collected sensitively, confidentially and objectively (Pope & Mays 2000, p13) in informal settings in groups, via telephone interviews (from carers willing to take part but at times more convenient to their schedules) and on site through ward visits. We did not use a survey or questionnaire methodology as these methods have already been used by UHNS with limited response.

We did not ask a rigid set of questions within the 1-2-1’s / interviews, instead we aimed to listen to people’s stories the way they wanted to tell them and by stimulating conversation and debate (Berg 2004, p80). We then framed the stories into the broad areas of the pathway through analysis of the primary research. Where appropriate we prompted using a fluid template of questions relating to their experiences, pathway and thoughts on available services.

Video

Finally, accompanying this report will be a short film designed by ECS and created by Shepherd PR. It was originally intended to be a number of talking heads comprising of carers revealing their experience to camera (Marshall & Grossman 2006, p120). This was still planned after collection of patient stories as three carers expressed an interest in being involved with the filming. But once we began to arrange times and venues for the films, two of the carers were unable to complete due to changing circumstances for the individuals they cared for. The decision was made to then use quotes from patient stories, where carers had gave permission for their quotes to be used. This meant an increase in the number of stories we could draw on and permitted the film to be created without filming carers on site. The film naturally evolved as and when we delved into people’s stories, and picked quotes that gave a rounded view using positive, negative and mixed experiences.
Quality Plan

ECS has a responsibility to ensure that the evidence and insight it creates is of high quality and aligned to best practice across the industry. Research ultimately provides the evidence on which sound decisions should be made, which is why it is important to state up front how quality will be ensured during this project.

The Evidence & Insight Team underpins its research activities by applying the Market Research Society Codes of Conduct, which allows us to demonstrate that we are credible, fair and transparent. ECS is now a company partner and accredited by the Market Research Society.

ECS also adheres to a strict data protection policy to ensure that:

- Everyone handling and managing personal information internally understands they are responsible for good data protection practices
- There is someone with specific responsibility for data protection in the organisation
- Staff who handle personal information are appropriately supervised and trained
- Queries about handling personal information are promptly and courteously dealt with
• The methods of handling personal information are regularly assessed and evaluated
• Necessary steps are taken to ensure that personal data is kept secure at all times against unlawful loss or disclosure

ECS also have firm guidelines for data storage, data retrieval, data security and data destruction. There is also a strict process in place should a data breach occur (which includes containment and recovery, assessment of ongoing risk, notification of breach, evaluation and response).

To further ensure the quality of the final report, an internal peer review process will be initiated to ensure that the report is fit for purpose before submission to UHNS. Where data is not robust it will be statistically suppressed to prevent disclosure.
Findings

In the course of this project we interacted with over 100 people through engagement at community groups and on site at UHNS, and carried out in-depth interviews with twenty three people who care for someone with dementia, the findings of this were diverse and complex. From the twenty three people that we spoke to, we identified a number of case studies which were representative of the key issues raised through the engagement process. In addition to the selected case studies, the key themes of the interviews as a whole are analysed and discussed at length. Following this an analysis of information specific to individual wards will be considered. The information gained from this project is qualitative, this is positive in that it provides rich information and can give us a deeper understanding of the experience of individuals. However, a potential issue of qualitative research in this area is that negative aspect of experience may garner more attention than positive aspects of experience, even in experiences that are generally positive. This is because whilst positive experiences of care tend to be very similar, for example good relationships with staff and good communication, negative experiences of care tend to be much more diverse in nature and so require more discussion. Throughout the research particularly on site UHNS staff have been very helpful and understanding which created a conducive atmosphere for obtaining the case studies.

Case Studies

Mary and John

Mary’s husband, John (pseudonyms used) was diagnosed with dementia in the community and she is his main carer. On two occasions John needed to go to UHNS to have day surgery under general anaesthetic. He was referred by his GP, who made the hospital aware of his dementia condition. The appointment letters offered for transport by ambulance to be booked but Mary was happy to pay for a taxi instead.

Overall Mary described the support that she received from UHNS as ‘very good’. All the staff were knowledgeable and treated both Mary and John with dignity. Because of John’s dementia Mary was able to stay with him as long as possible, she was able to go with him to the theatre door and stay with him in the recovery room afterwards. As she was with John the whole time Mary was able to help staff to interpret his needs. The communication with staff was good, and they explained the effects of anaesthetic on dementia sufferers very well so Mary could be well prepared. Advice on post-operative care was also clear, and a nurse checked that Mary and John had enough support in the community.
Overall Mary and John’s experience at UHNS was positive and can be used as an example of good practice.

Sarah and William

Sarah’s husband William (pseudonyms used) has dementia, he has had to go into hospital on a number of occasions due to falls. Sarah feels that hospitals are not the best places to treat people with dementia as they need specialist care and can disrupt the other patients:

‘Hospital is not the best place to cope with his needs.’

After a fall William was sent to UHNS for rehabilitation, although he has previously gone to Leek Moorlands Hospital. Sarah would rather that William went to Leek Moorlands Hospital because UHNS is ‘too big’. It is expensive and time consuming for Sarah to get to UHNS and she has gotten lost in the hospital. Although Sarah found the Porters to be ‘marvellous’, William was moved a lot whilst in hospital and she often found it difficult to find him. Sarah did not understand why her husband was moved so much and described it as ‘bizarre’. She felt that William was just put anywhere where there was a spare bed. Because William was moved frequently it meant that he and Sarah could not get familiar with staff, and often made communication difficult. Sarah felt alone and believed that nobody wanted to talk to her, or seemed to know anything about her husband’s progress.

‘Sometimes you never found anyone to talk to, let alone the same person.’

Although, Sarah commented that her husband was generally treated well, there were some obvious problems. William had problems with incontinence and she sometimes found that he was wet. While in hospital William also fell out of bed a lot and Sarah believed that bed rails were not used.

Sarah felt that she did not get support or information from UHNS, and found out the most by speaking to groups of other carers, memory clinics and day centres. In order to improve things Sarah thinks that groups in the community should be better publicised. Sarah also felt that dementia wards with specialised staff in a central location would be a very good idea.

Tom and Jane

Tom cares for his wife Jane (pseudonyms used) who has vascular dementia. Jane was first diagnosed by her GP and was then sent to UHNS. The communication that John has had with the hospital has been mixed. John says that the hospital has given him specific information on vascular dementia and its symptoms and that they have always listened to his questions. However, he felt that the hospital were
not proactive in giving information and that he got information only because he asked detailed questions. When Jane was on the ward the butterfly symbol was used, but Tom has never completed a ‘this is me’ document. Tom felt that he was supported as a carer but that staff did not always listen to his advice about his wife’s care.

Tom feels that the care that Jane gets from the Outpatients department at UHNS is ‘very good’ but is concerned that when Jane is on a ward the staff do not always have the right understanding and knowledge to deal with her in the best way. Tom believes that he has got the most information and advice from Approach and thinks that staff could benefit from all having training with Approach. Although the hospital was helpful in telling Tom about Approach and other groups, he felt that the hospital could offer more direct support. Tom felt that the hospital did not give Jane enough aftercare when she was discharged.

**Key Themes**

**Diagnosis & Assessment**

When carrying out interviews with carers for people with dementia, we first asked them about the initial stages of dementia diagnosis. There was a great deal of variation in the experience of dementia diagnosis. Some participants described a gradual decline and interaction with a number of different services, eventually leading to a diagnosis of dementia. Other participants describe the shock and distress of a more rapid deterioration in quality of life. One carer described the ‘whirlwind’ of a hospital visit turning into a dementia diagnosis, another commented:

‘Up to two months ago Mum was fine, playing bingo three times a week.’

One of the carers that we spoke to said that the person they care for was diagnosed with dementia after initially coming into hospital with a Urinary Tract Infection, another commented that the person they care for was diagnosed during a stay on the short stay ward. As set out in the background to the study, the UHNS Dementia Care Pathway adopts the FAIR approach of early detection, assessment and diagnosis of people with dementia. However, most of the people we talked to were already diagnosed in the community or by GPs before they were admitted to UHNS. In many cases people with dementia were passed between a number of different services before eventually being diagnosed with dementia, in some cases with lengthy delays before dementia could be formally diagnosed. The Dementia Care Pathway notes the importance of early diagnosis because for some:
'The diagnosis can come at a time of crisis which may have been avoided if the diagnosis had been made earlier.'

Delays in diagnosis can be particularly difficult because some carers found that they could not get information, advice or support until the formal diagnosis was made, creating confusion and anxiety.

'Due to lack of a formal diagnosis we have not received any information.'

In most cases the diagnosis of dementia, and the start of the pathway, began with the GP. A minority of carers described difficult relationships with GPs and commented that this created delays in diagnosis. In one case a carer described their GP as having a very dismissive attitude and commented that the person that they care for had been repeatedly going to a GP for five years before a diagnosis could be made.

'Doctor kept saying it was depression... told him to pull himself together'.

Although this feedback is not specifically in relation to UHNS it is useful to understand the full journey of the dementia patient, including their pathway from initial GP consultation and any contradictory information they may have received.

'Alright when you’re in the system, but it’s tough getting into it.'

Treated with Dignity

The UHNS Dementia Care Pathway and Framework sets out commitment to the principle that:

‘Care plans will be person centred, responsive to individual needs and support... dignity’.

Many of the people we spoke to felt that the person they care for was treated with dignity and respect.

“Staff always use her first name and explain what they are going to do first...puts her at ease.”

‘Always treated with dignity and respect... the nurses are doing a great job!’

However, other carers discussed their perception that although staff were not deliberately treating patients disrespectfully, they were not willing or able to be attentive enough to their needs. For example, many patients with dementia also have problems with incontinence and two carers felt that their relative did not get enough help to go to the toilet. One carer described upsetting experiences of
finding the person they care for lying in bed ‘wet through’. Another carer commented that people with dementia who are very dependent get anxious and distressed if they cannot be taken to the toilet ‘in good time’. A number of people we spoke to shared the perception that staff members did not give as much attention to patients with dementia as was needed because there was not enough nursing staff on wards.

These difficulties surrounding the amount of personal attention that nursing staff are able to give to patients is not unique to patients with dementia, but is a particularly pertinent issue for these patients due to their increased vulnerability. The increased vulnerability of patients with dementia can also make them particularly susceptible to falls. Many of the people we talked to told us that the person that they care for ended up in hospital because of a fall. However, two carers we spoke to also discussed experiences of their relative falling whilst in hospital. One carer told us that their relative with dementia fell out of bed a lot whilst in hospital, commenting that a bed rail was never used when he was sleeping.

Some carers also felt the communication with people with dementia was sometimes inappropriate. For example, one carer felt that the language and wording that staff used was not suitable for the person that they cared for who was in the late stages of dementia.

The UHNS Dementia Care Pathway and Framework notes that dementia is associated with complex needs, including behavioural and psychological symptoms, and in the later stages a high level of dependency. Many of the carers we spoke to stressed that people with dementia need very specialised care, and some believed that members of staff needed more specialised training in dementia.

‘On the wards is where I feel worried, they don’t have the right understanding and knowledge to know how to deal with her... They should all go to do the training with Approach.’

There was also support for a specialised dementia ward which is purely for dementia patients and run by staff that are specialised in dementia care. As discussed within the background research, levels of dementia within North Staffordshire and Stoke-on-Trent are high and, due to an ageing population, are projected to more than double between 2010 and 2030.

‘There should be a ward purely for dementia patients... you have to live with it to understand it.’
Fluid and nutrition

Some carers were concerned about the food and drink that people with dementia receive whilst in hospital. For example, in three separate instances carers were worried that the person they care for was dehydrated because their fluid intake was not monitored enough or patients were not given enough help to be able to drink. The UHNS Dementia Care Framework and Pathway adheres to the principle of care that:

‘Don’t assume that if you put a drink/meal in front of me. I’ll drink or eat it.’

However, based on evidence from the carers that we spoke to, this principle is not uniformly adhered to. One example was given of drinks being placed out of reach, and another of fluids repeatedly not being available for a patient when needed. Another carer raised a serious concern about the way that meals are ordered for people with dementia. Their relative with dementia could not complete a meal order due to memory loss, and nobody checked whether the meal order was completed. Due to this he had nothing to eat but chips and gravy for two days, compromising his physical and mental wellbeing.

Movement between wards

Another principle of care referred to in the UHNS Dementia Care Pathway and Framework is:

‘Don’t keep moving me from ward to ward. I don’t understand and am afraid in unfamiliar surroundings.’

However, based on the experiences of the carers that we spoke to, this principle is not always followed. A number of carers commented that the people they care for with dementia were moved frequently whilst staying in hospital, and that they were not always sure why. There was a perception that people were moved to ‘wherever there was a spare bed’ due to a shortage of beds in the hospital. This was a particular concern for carers because they felt that the people they care for were sometimes put on wards which were not appropriate to deal with the needs of someone with dementia.

‘They put him in the cancer ward. Why didn’t they know where to put him?’
‘The next day he was sent to short stay unit at UHNS because there were no beds in elderly care. There’s no specialist care in short stay for dementia care. Our impression was get them in and get them out, but he was in there for 2 weeks as there were no beds in 76 a or b.’

Frequent movement between wards whilst in hospital can be particularly disorientating for people with dementia, and can also act as a barrier to communication due to the lack of continuity of staff. One carer commented that it was difficult for her to find her husband in hospital because he was moved so often, and that it was hard to know who to talk to for the right information. Other problems that carers experienced due to frequent movement between wards was the loss of personal possessions and patients being moved at inappropriate times, such as 1 am in the morning.

‘Done the rounds of A&E, MIU, fragile conditions three times.’

‘Went onto surgical ward and then moved at 1am to ward 79.’

‘We lost a significant number of personal possessions in the hospital from transferring things from one place to another.’

Use of ‘this is me’ document and butterfly symbol

The UHNS Dementia Care Pathway and Framework adopts the butterfly symbol as a system of good practice. The symbol is used to discretely identify people with a cognitive impairment or established dementia. The Pathway also endorses the use of the ‘this is me’ document which is a routine collection of the personal information and preferences of a person with dementia. Of the people we spoke to that referred to the butterfly symbol, nine said that the symbol was used, three commented that the butterfly symbol was not used and two were unsure because they did not know what the butterfly symbol was. One carer also commented that they had to ask for the butterfly symbol to be used. Although most carers said that the butterfly symbol was used, use of the ‘this is me’ document appears to be less frequent. Of the people we spoke to only three could confirm that the ‘this is me’ document was used. From the available evidence this suggests that the document is not extensively implemented, although a number of carers felt that it was a good idea.

“It’s a great idea and I wish we had had the chance to do one.”

It is possible the ‘this is me’ document is only being implemented for patients with dementia that are new to the hospital, and not those who have been in contact with the hospital previously. However,
there was generally strong support for the use of ‘this is me’, and patients who have been in previous contact with the hospital could also benefit.

Information and support

Within the UHNS Dementia Care Pathway and Framework, UHNS stress that they are committed to:

‘Help the person with dementia and their carer(s) to understand and manage their illness through timely referral for treatment and support, the provision of information and appropriate communication.’

A few carers that we spoke to felt that they were given appropriate information and support. For example one carer commented that they had ‘excellent’ information and support from the A&E department.

“We had really good information on infections .... Some great support and advice.”

However, the general feeling from the carers that we spoke to was that there was a lack of timely information and support for people with dementia and those caring for them. A recurring theme was that people felt the hospital was not proactive in providing information, and that the responsibility fell upon the carer or patient to push for information and support.

“How do people cope that don’t have the wherewithal to know what to ask? I don’t think I’ve asked the right questions yet.”

This creates difficulties because it places an additional strain upon a carer at an already distressing time. In addition, a lack of proactive communication could also lead to inequality in care because particularly vulnerable patients and carers may not know the right places to go for information, or the right questions to ask. One carer commented ‘you don’t know what you don’t know’. An additional problem is that because some carers experience significant delays, misdiagnosis or confusion in the diagnosis of dementia, this acts as a further barrier to them being able to access appropriate advice, information and support.

Many carers commented that rather than getting information and support from the hospital they went to other services such as GPs, nursing homes or voluntary community groups.
'If the hospital could do more directly that would help, because I feel like once they’ve put you in touch with groups it’s up to them.’

In particular, many carers stressed that Approach was a valuable source of information and advice.

“it’s been ok but nothing special, we have learnt much more outside the hospital from our own experience and groups like Approach than at the hospital…”

North Staffordshire Carers service was also praised, with one carer describing them as:

‘Like the base of a spider, and the legs go out to all the local groups that help.’

Discharge

The UHNS Dementia Care Pathway and Framework dictates that:

‘In all cases post-discharge information must include assessment result and actions. Ongoing needs must be reviewed and summarised so that appropriate treatment and care can continue to be provided.’

However, amongst the carers that we spoke to, difficulties around discharge was a strong theme of the responses. One of our carers described a positive experience of discharge. She was given enough advice on how she should care for her husband with dementia post-operatively and the nurses also checked that she had enough support in the community. However, other experiences of discharge were less positive. Some carers did not feel that there was enough aftercare or ongoing treatment for people with dementia leaving hospital. One carer described feeling ‘abandoned’ by the hospital because of lack of follow up after discharge.

‘The hospital were very good and they did treat us with dignity, but when you leave the hospital you just feel you’ve been abandoned. We are just passed from one place to the next.’

“We haven’t had the right support, the information is given to you whether you get it or not, they just seem to want to get rid of you after the appointment…”

On a national scale, delays to discharge are particularly common for patients with dementia. A 2007 study by the National Audit Service noted that around half of patients affected by delayed discharge have dementia. Fitting with these national findings, two carers described experiences of discharge at
UHNS being delayed because of waits for a social worker assessment or for care to be put in place at home.

‘Something at home needs to be put in place before he can go home.’

‘Needs to be discharged but waiting until a social worker is assigned and approval for discharge to go to a care home.’

These individual experiences may be indicative of a wider trend within the hospital. Of all the days of delayed discharge at UHNS in the six months between Aug 2013 and Jan 2014, 36% were due to the patient awaiting completion of assessment. In the same time period 35% of days of delayed discharge were due to patients awaiting further NHS non-Acute care and 10% due to patients awaiting care packages in their own home.

Delays to discharge can be particularly distressing for patients with dementia, who can find the hospital environment particularly disorientating. Many of the carers we spoke to stressed that their relatives want to go home as soon as is possible.

‘Desperate to go home, feels like she is cooped up and wants to go out.’

However, three other carers described contrary experiences where they believed that the person they cared for was discharged too soon, or without appropriate discharge arrangements being put in place.

‘Care was great but [I] got upset with discharge arrangements.’

For instance, one carer commented that the person they care for was discharged from hospital but then readmitted within 24 hours due to dehydration. They believed that this re-admittance could have been avoided if the person they cared for was discharged later and more appropriately.

‘If they could have kept her in another 24 hours the re-admittance wouldn’t have happened’.

Coordination between services

Most of the participants we spoke to had experience of the person that they care for being passed between a number of different health and social care organisations in their treatment and diagnosis. Some carers have found this challenging because services were not always coordinated and there was a lack of consistency in care and the staff you deal with. Some carers also described experiences of being told different things by different organisations.
'There’s a disconnect between Doctors and hospital. We kept going to doctors but never got the right diagnosis...all along the line it feels like a mess. We are just passed from one place to the next.’

‘No one seems to tie it all together, especially the GP they are useless.’

One carer suggested that ideally there would be one person to help to guide a person with dementia through the system of different services.

‘I’ve not really been given the opportunity to discuss treatment, moving from hospital to hospital so don’t really have consistency. It’s nobody’s fault...If at all possible it would be ideal to have the same person to follow through the system.’

Another pertinent point to make is that following conversations about the “this is me” documentation, many carers felt that it was underutilised at UHNS but that very similar programmes were also being used by care homes and care in your own home providers. An opportunity identified by ECS would be to attempt to bring joined up thinking between services on this, creating just one set of notes relating to the patient and revealing personal information that could follow that patient through the different services they access, becoming a “Dementia Passport”.

Involvement of carers

The UHNS Dementia Care Pathway and Framework commits to the principle that:

‘Family carers and friends are seen as partners in care, unless otherwise indicated by the person living with dementia.’

It was generally very important to the carers that we spoke to that they were fully informed and involved in the care of their loved one. Numerous examples were given of the involvement of carers benefiting patients and improving their experience. For example, some carers explained that their loved ones felt more comfortable eating, drinking or taking medication with someone familiar there to help them.

‘I visit daily to feed lunch and tea, and the staff welcome it.’

‘She’s better at taking medication when I’m there... she needs the extra confidence of the support of close relative.’
Other carers described examples of the hospital supporting their valuable role as a carer, for example by arranging transport which can be a great difficulty for some carers.

‘When he was moving to the different hospitals UHNS asked if it was convenient for me.’

However, some examples were also given where carers were not as involved as they would like, and they did not feel that staff always listened to their advice on how to care for their loved one.

‘When you’re at the hospital the nurses have been good, but I don’t feel like they listen to me with my thoughts about my husband. I know him better than anyone but they don’t always listen to me.’

When visiting their relatives some carers were also not always able to get the information and updates that they needed, and this lack of communication acted as a barrier to their involvement. A number of carers commented that when their relative was staying in hospital it seemed like staff were too busy to talk to them, and it was difficult to find someone to talk to during a limited visiting time.

‘Sometimes it was difficult to find anybody to talk to, let alone the same person.’

One carer added that a particular problem was that sometimes information was given to her relative, but due to problems with his memory he could not repeat this to her.

Focus on Wards

When considering the original objectives of the research UHNS asked for us to take into account four wards within the hospital and understand patient and carer experiences specific to those wards.

A&E

There were experiences gathered in the case studies which related to A&E. They were mainly positive with two of the carers stating that

“A&E was very good” and “excellent”

Other carers spoke of their experiences being admitted via Ambulances to A&E initially before transfer to other areas of the hospital. They were neither positive nor negative. A&E had been the first port of call following falls and serious infections.
However one carer although not directly negative about A&E their concern surrounded the suitability of A&E for patients with Dementia

“need to try and avoid dementia patients ending up in A&E system”

This is understandable as the nature of A&E could provide many opportunities for confusion and destabilisation due to the continual flow of emergencies into the department and the often busy waiting rooms.

**Outpatients**

Outpatients was only mentioned in two of the case studies with one positive comment and one negative. The positive comment referred to the ability of the carer to be involved in the appointment scheduling, be with the patient at all times for reassurance and that it was much better for them to be done in a day than face prolonged stays for the patient on the wards. It was acknowledged that scheduled appointments are much easier to plan for.

“In outpatients they are very good, but you go for a scheduled appointment and it’s all done in a day..”

However one experience described that the carer was upset with the lack of good administration and procedural compliance. Pinpointing the lack of care when reading the case notes and their safe keeping.

“At outpatient visits they do not read files, lost file at one stage and it was never found”

**Trauma & Orthopaedics**

The trauma and orthopaedics ward has very limited visiting times and this was highlighted within carer experiences. Carers felt it was very difficult to get updates from staff with such limited visiting times.

“difficult to get the right information when as a carer you’ve got limited time when you’re visiting, they’re not proactive in supplying detailed info and that is specific to her diagnosis…”

There were observations from carers where the patient had been transferred from Elderly Care to Trauma & Orthopaedics and felt that Staff were appropriately trained on the ward. Although this does not make the direct comparison to Elderly Care in the context of the case study it is implied within the wider story.
Elderly Care

The majority of the experiences from carers relate to the elderly care wards within the West Building at the UHNS site. There are mixed responses throughout these stories and even within an individual case study. The overriding impression is that the level of care is not consistent and this creates anxiety for carers who cannot be with their relative overnight.

“some of the staff don’t seem to have a clue, I worry when I leave her on the wards because I don’t think they can always deal with her when she starts her wandering…”

“they should be more confident in how to deal with dementia patients….”

There was also a general feeling that staff were too busy in Elderly Care to spend times with carers providing reassurance, information and support. This was underlined by another negative perception that staff turnover on the ward was too high resulting in an inconsistent approach.

“find it very difficult to talk to someone about him, their either too busy or they don’t want to talk to you, you can feel so alone no real connection with anyone…”

“sometimes never saw anyone let alone the same person to talk about treatment and support?”

When collecting case studies there were several patients from Staffordshire Moorlands and in every case the carer desired the patient to be located much closer to home and often requested that the patient be transferred to either Cheadle or Leek hospitals. This meant a lot to those individuals as the travel was prohibitive but also the size of UHNS was disorientating to their relative.

“she is desperate to go home, and the possibility of transfer to Cheadle is our only hope at the moment”

“Leek Hospital was much more desirable…. its more local and you have that connection with the area and you can build relationships with the staff”

Carers were very wary of their relatives staying for long periods of time as they felt that it was part of a road to deteriorating health. This often supported one of the common suggestions received through the research process (and particularly visits to the elderly care ward), concerning the creation of a dementia specific ward with specialist care from dedicated dementia staff.

“….each time mum has been in hospital we seem to lose a bit more of her.”
"hospitals are not good places for patients with dementia they need more specialist care there should be a separate centre dealing with individuals"

The following word cloud uses analysis to visually represent some of the main themes and comments that we obtained as part of the research. The cloud shows the prominence of the “Involvement of Carers”, “Communication” and “Dignity and Respect”.
Conclusions

A number of positive aspects of the dementia care pathway can be identified through our engagement with carers. A number of the carers we spoke to praised the attitude of individual members of staff who went the extra mile to ensure that they and their loved ones were as comfortable, well informed and involved as possible whilst in hospital. However, many carers shared more negative experiences of care which should also be discussed. Some described experiences where members of staff were not attentive enough to meet the needs of people with dementia at a high level of dependency. For example, some carers believed that their relatives were not given enough support to eat, drink or go to the bathroom quickly. Some also described instances where the needs of patients with dementia were not monitored closely enough. For example, it was not checked whether they had made a meal order or whether the rail on their bed was upright to prevent falls whilst sleeping. By some this was perceived to be due to inadequate staffing levels or insufficiently trained staff.

There was strong support amongst the people we spoke to for the use of the butterfly symbol and the ‘this is me’ document, however, these tools were not always put in place. Similarly, although the Framework stresses that the movement of people with dementia between wards should be avoided, some carers nonetheless stated that their relatives were transferred between wards frequently without explanation. An interlinked issue is that of communication. Many carers felt that the hospital did not communicate proactively, and that the strain was placed upon them as carers to push for information and support. An added complication was that sometimes in a very limited visiting time it was difficult for carers to get the information and updates they needed to be as involved as they would like. There were also instances where the communication with patients with dementia was inappropriate or insensitive. This problem is not unique to UHNS, and some of the carers we spoke to also talked of the barrier of difficult relationships with GPs in delaying the diagnosis and appropriate care of dementia. In instances where carers felt there was a lack of information or support many found voluntary services, particularly Approach, to be an invaluable help.

The pathway of a person with dementia and their carers is complex and involves many different organisations. For example, a particular difficulty was that sometimes the discharge of patients with dementia was delayed because they were awaiting an assessment or awaiting care to be put in place in the community. Therefore, multi-agency working is crucial and UHNS is simply one part of a larger pathway.
The findings of this research strongly support the policies and principles set out in the UHNS Dementia Care Pathway and Framework, however they suggest that further work may be needed to ensure that they are fully and consistently implemented within the hospital.

To improve the experience for patients and carers there should be an examination of how care is delivered to patients with dementia and how staff interact with carers. The Trust should continue to inspire the staff to truly understand, embody and apply the guidelines for practice.
Recommendations

♦ Diagnosis & Assessment

- There were examples of misdiagnosis and/or delays of formal diagnosis caused by miscommunication and a lack of collaboration between services. Patients & Carers did not receive advice, information or support in the interim period. We therefore recommend that even without a formal diagnosis of dementia, patients and their carers should be given interim advice, information and support as early as possible to cope with symptoms they are experiencing.

♦ Information & Support

- There were many instances where carers found it difficult to obtain information without having to push for it or without prior experience and consequently the knowledge of the right questions to ask. Systems should be put in place to ensure that information and support is offered proactively to all people with dementia and their carers.

♦ Treatment

- Ensure Attentive Care
  - There were number of incidences where carers described inattentive nursing care when their relatives with dementia were staying on hospital wards, for example, the help they need to go to the toilet. The possibility of inconsistent levels of nursing care should be further explored by the hospital and staffing levels should be assessed.

  - Concerns were raised about the fluid and nutrition that some patients receive whilst in hospital. Patients should be given support to eat or drink where necessary and their fluid levels monitored carefully. One example was given of a patient with dementia being given inappropriate nutrition for an extended period of time because they were unable to place meal orders and their needs were not checked. Systems should be put in place so that patients with dementia are given support to place meal orders if needed. It should not be assumed that patients with dementia are able to place meal orders without assistance.

  - To avoid falls, it should be checked that people with dementia have bed rails in use if this is necessary.
One example was given where the communication for a patient with dementia, or indeed any patient, was highly inappropriate and whether deliberate or not could be perceived as threatening. It should be stressed to staff that care should be taken when communicating with patients and that offhand comments can have a greater impact than intended, particularly with regards to highly vulnerable patients.

- **Increased involvement of Carers**
  - In some instances the involvement of carers was enabled and encouraged by the hospital and in some cases it was not. All carers should be enabled to be partners in care through initiatives such as flexible visiting time, support with transport and regular communication and updates from appropriate members of staff.

- **Implement the Dementia Care Pathway and Framework Guidelines Systematically and Universally**
  - Based on the available evidence the butterfly symbol is not used uniformly. Care should be taken to ensure that the butterfly symbol is always used where it is appropriate and that its use is explained to carers.
  
  - Some carers described experiences of patients with dementia being moved frequently between wards. As is stated in the Dementia Care Pathway and Framework frequent movement of patients with dementia between wards can be disorientating and should be avoided as much as possible.
  
  - Where movement between wards is necessary the reasons why should be fully explained to both the patients and their carers as a matter of course. Carers should be proactively informed about any ward movements and all efforts should be made that it is at an appropriate time of day, not very late at night or early in the morning.
  
  - The vast majority of the carers that we spoke to said that they had not been given a ‘this is me’ document but supported the idea. A process should be put in place to ensure that ‘this is me’ documents are used for all relevant patients, including those patients that have already been in contact with the hospital previously.
Public Awareness and Coordination of Services

- Many carers stressed that the support that they got from Approach or the North Staffordshire Carers Services was invaluable. UHNS should work closely and continue to publicise these groups.

- Patients with dementia tend to be particularly affected by delays to discharge and strategies should be developed to minimise this problem. In particular, multiagency working should be enhanced to avoid delays to discharge because of patients awaiting assessment, further non-acute NHS care or care packages in their own home.

- In some instances coordination between the different organisations involved in dementia care was lacking. One of the carers we spoke to suggested that there should be more of a common thread to follow and support a person with dementia throughout the whole system. This clearly is an issue that involves many different organisations and is not entirely under the control of UHNS, but UHNS should be a driving force in influencing and encouraging multi-agency coordination.

- Multi service approach to combine all similar “this is me” programmes into one set of personal notes that act as a Dementia Passport through wider pathway accessing health and social care services: GP - Hospital - Community Support - Care Home - Residential Home - Care in your own Home. Ensure that these are made available and completed for all Dementia Patients.
References


Berg, L. B. 2004 Qualitative Research Methods 5th Edition Pearson Education


University Hospital North Staffordshire NHS Trust 2013 Dementia Care Pathway and Framework Guidelines for Practice
Appendix

Case Study Template

Dementia Pathway Study – Patient Story – CASE STUDY TEMPLATE

This template is designed to:

- Examine the Patient & Carer Journey
- To understand the Patient & Carer Experience
- To cross reference to Dementia Pathway Guidelines and Service Provision at UHNS

Suggested Steps

1. Identify Patients & Carers willing to participate
2. Decide on collection method (face-to-face, telephone, self-completion)
3. Use prompts (Diagnosis, Information and Support, Staff Treatment, Public Awareness)
4. Analyse the information and produce as a story (ECS)
5. Look at themes, main issues and measure improvements (ECS)
6. Send the write up back to the Patient & Carer for final approval and gap filling.

Participant Information Sheet

‘Patient & Carer Stories’

You are invited to take part in a short interview to help us understand your experience of Dementia Care. We are interested in hearing about your personal experiences particularly with reference to services received at University Hospital North Staffordshire, so that we can identify ways to continue to improve the service offered to you as a Patient and Carer.

Your insights about your experience will be shared with representatives from University Hospital North Staffordshire. While we may talk about aspects of your experience, you will not be identified in any reports, presentation or papers arising from the project.

In sharing your insights about the Care pathway, any information that we collect about you in connection with this interview will remain confidential, and will be disclosed only with your permission.

We also invite you to nominate an ‘alias’ so that references to the information you provide us will not identify you. If you have any questions about the interview, you can contact the following Engaging Communities Staffordshire representative: craig.staples@ecstaffs.co.uk or on 01785 224819.
**Participant Consent Form**

I agree to participate in an interview regarding my recent experiences with health and/or social care services.

I consent to taking part in the discussion and have understood the information contained within the Participant Information Sheet, a copy of which I have been given to keep.

I understand I can withdraw my comments at any time and do not have to give any reason for withdrawing. I also understand that I may be contacted in the future as part of an evaluation of this Carer Interview method and my telephone number or email has been requested for this purpose.

I understand that my personal information will remain confidential as outlined in the Participant Information Sheet.

**PATIENT and / or CARER**

Print Name: ___________________________ Date: ______________________

Signature: ___________________________ Telephone: ______________________

Alias: ________________________________

Print Name: ___________________________ Date: ______________________

Signature: ___________________________ Telephone: ______________________

Alias: ________________________________

**Video Expression of Interest**

Would you be interested in filming some of your patient / carer experience in a short video that would be included in the research project? The filming will be anonymous and no details passed to the hospital.

Print Name: ___________________________ Date: ______________________

Email: ________________________________ Telephone: ______________________

Alias: ________________________________
Story Template

The following questions provide the framework for the types of questions you may ask a Patient or Carer when collecting their story. This is flexible and should not form a list of questions for the respondent to answer but to broadly frame the story within the realms of the Dementia Pathway to care and support.

**Diagnosis**

a. Were you assessed before accessing service at UHNS (i.e. GP, Previous Hospital visits)?
b. Were you assessed whilst at UHNS?
c. Were you given support and information about initial management of dementia?
d. Were you given support and information about treatment and support options in your local area?
e. Were you given the opportunity to discuss and make decisions about treatment and support options?
f. What is your experience of using this service?
g. How would you improve the service in the future?

**Information and Support**

h. Describe the way you currently get information, advice and guidance
i. What gaps in information are there?
j. How would you like to receive information?
k. Did anyone check that you understood the information?
l. Were the details you needed about the services correct?

**Treated with Dignity**

m. Do services pay sufficient attention to your physical and mental wellbeing?
n. Were you given the Butterfly Symbol?
o. Were staff appropriately trained in dementia care?
p. If you need an interpreter is one provided?
q. Have you ever been in need of emotional support and training?
r. Were you given the “This is Me” document to complete?
s. If so, what are your thoughts on the process and are there any potential improvements to this document?
t. Where would you go for help if you needed support/reassurance?
u. Were any problems or complaints dealt with promptly/adequately?

**Other**

v. Are there an adequate range of services on offer for you as a Carer and for the person you care for?
w. Describe the usefulness of the services you were offered?
x. Were you referred to the services closest to where you live? Is it more important for you to receive services close to home or is it the type of support service even at a distance which is more important to you?
y. Were the means of transport taken into account by staff when suggesting services?
z. Were you told/ given access to extra support you may have needed?
aa. Have you been offered support with housing or equipment and adaptations to make your caring role easier? What difference has this made?

**PLEASE USE BOXES PROVIDED FOR COLLECTING PATIENT STORIES**
### DIAGNOSIS – First Stage of Pathway.

- Assessment prior to or at UHNS?
- Initial Management & Support.
- Decision making on Support Options, Experience, Suggestions for Improvement
### Information and Support – Second Stage of Pathway.

How, When, Why - do you receive information? How would you like to receive info?
Understand fully? Experience of support at UHNS? Appropriate Signposting?
### Treated with Dignity – Following Stage of Pathway.

- Were you given Butterfly Symbol? Were you given the “This is Me” document to complete?
- Have you been offered support at home?
- Were you given access to further support if needed?
Public Awareness – Final Stage of Dementia Pathway

Adequate range of services and support at UHNS?
Initial Management & Support.
Decision making on Support Options, Experience, Suggestions for Improvement
Healthwatch Staffordshire Social Media Posts

Healthwatch Staffs @HWStaffordshire Apr 11
@age_uk Healthwatch Staffordshire collecting patient & carers experience of dementia care in UHNS healthwatchstaffordshire.co.uk/have-your-say/... #haveyoursay
Expand

Healthwatch Staffs @HWStaffordshire Apr 11
@Dementia_Action Healthwatch Staffordshire collecting patient & carers experience of dementia care in UHNS healthwatchstaffordshire.co.uk/have-your-say/... #haveyoursay
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Healthwatch Staffs @HWStaffordshire Apr 11
@AlzheimerUS Healthwatch Staffordshire collecting patient & carers experience of dementia care in UHNS healthwatchstaffordshire.co.uk/have-your-say/... #haveyoursay
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Healthwatch Staffs @HWStaffordshire Apr 11
@alzheimers @ HWStaffordshire looking for people with recent experience of dementia care at UHNS #Healthwatch RT pic.twitter.com/7c55fcsZf6

Healthwatch Staffordshire

Are you affected by Dementia or care for a friend or relative that suffers with Dementia?
Do you have a recent experience of accessing services at University Hospital North Staffordshire?
Please share your story with us to help make recommendations that will improve services.

If you want to be involved
Please contact us direct:
Call us on Freephone
0800 051 8371
Email us at contactus@ecstaffs.co.uk

Engaging Communications
Staffordshire