

NHS RightCare scenario: Getting the dementia pathway right



Tom and Barbara's story: Dementia

The story of Barbara and Tom's experience of a dementia pathway and how it could have been so much better

In this scenario – using a fictional patient, Tom – we examine a dementia care pathway, comparing a sub-optimal but not atypical scenario against an ideal pathway. At each stage we have modelled the costs of care, both financial to the commissioner but also the impact on the person and their family's outcomes and experience.

This document is intended to help commissioners and providers understand the implications – both in terms of quality of life and costs – of shifting the care pathway of older people living with dementia from a reactive approach (primarily based on an acute response) to a proactive approach, e.g. providing an integrated primary care and community-based response, with support from the voluntary sector.

It shows how the NHS RightCare methodology can help clinicians and commissioners improve the value and outcomes of the care pathway.

Two summary slide packs are also included as appendices.

Background

Dementia affects about 850,000 people in the UK¹. It describes a clinical syndrome with features of loss of memory, problems with activities of daily living and emotional changes. Dementia has a number of causes - Alzheimer's disease is the most common followed by vascular dementia. There are other types of dementia such as Lewy Body disease (associated with Parkinson's disease) and frontal lobe dementia (which causes changes in personality and behaviour). Dementia has overtaken heart disease and is now the biggest cause of death in England and Wales². Women are significantly more affected by dementia with double the number of women dying of dementia compared to men. Although, this could also be a result of women generally living longer.

¹ Dementia UK Update Report 2014.

http://www.alzheimers.org.uk/info/20025/policy_and_influencing/251/dementia_uk

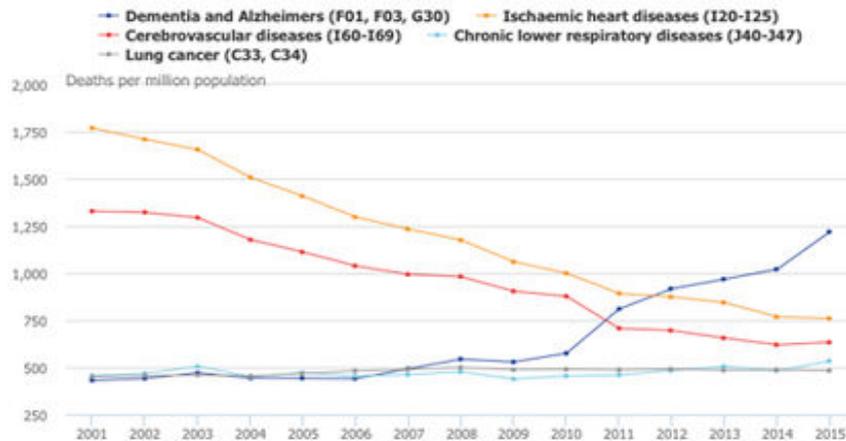
² Office of National Statistics report on Cause of Death 2016.

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath>

Figure 1: Office of National Statistics report on Cause of Death 2016

Figure 3: Female age-standardised mortality rates, for top 5 leading causes, 2001 to 2015

England and Wales



Source: Office for National Statistics

Aside from the numbers of people affected and the cost (for all dementia) which is estimated to be £26 billion a year³, there are three key features of dementia:

1. For people over the age of 55 it is the most feared illness⁴.
2. It often affects carers more than the person themselves (caring for someone with dementia is widely acknowledged to be a most stressful experience).
3. Linking up health and social care is vital in improving support available for people with dementia.

In the last few years, awareness of dementia has increased significantly. Today, two thirds (of the estimated number of people with dementia) have a diagnosis. In February 2017 the dementia diagnosis rate was 67.3%⁵; in 2010/11 the rate was around 43%⁶. This improvement in awareness is a result of increased activity in the area with the Prime Minister's Challenge on Dementia and dementia diagnosis being a recurring priority in the NHS Mandate. The dementia diagnosis rate is monitored nationally and at CCG level every month and published in a workbook format on the NHS England website.⁵

³ https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2323

⁴ Dementia Awareness Week Poll 2012

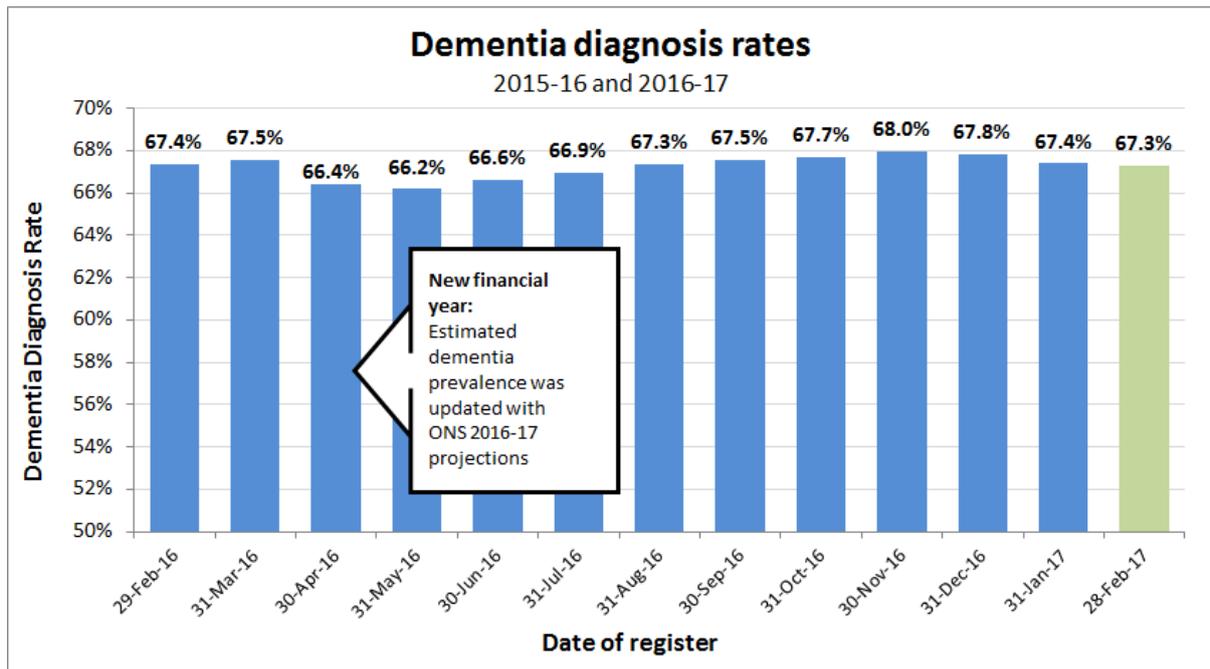
<https://yougov.co.uk/news/2012/05/22/are-you-worried-about-dementia/>

⁵ NHS England Analyst Monthly Dementia Diagnosis Rates Workbook

<https://www.england.nhs.uk/mental-health/dementia/monthly-workbook/>

⁶ The diagnosis indicator is calculated as the latest available number of people on the dementia registers who are aged 65 and over, divided by the estimated prevalence of dementia for those aged 65 and over in the area.

Figure 2: Dementia diagnosis rates over the past 12 months



It is important that we continue to maintain and improve dementia diagnosis rates as a diagnosis enables a person with living with dementia and their carer to access the appropriate post diagnostic support. The Next Steps on the NHS Five Year Forward View⁷ highlights the need for optimal support for people with dementia, their carers and their families.

All people living with dementia and their carers are entitled to the same level of access to dementia services. Care provision for those living with dementia and their carers will be personalised to include appropriate provision for and consideration of, all of the person’s characteristics including (but not limited to) age, disability, gender reassignment, marriage and civil partnership status, pregnancy and maternity status, race, religion and belief, sex and sexual orientation.

The following story of Tom and Barbara highlights areas of good practice and where practice could be improved across the patient journey.

⁷ <https://www.england.nhs.uk/publication/next-steps-on-the-nhs-five-year-forward-view/>

Introducing Tom and Barbara



Barbara and Tom recently celebrated their diamond wedding anniversary (60 years of marriage). Both of them have been retired for a while now. Barbara was a solicitor and Tom an engineer. About three years ago, not long after Tom's 77th birthday, Barbara noticed that Tom's memory was not quite what it used to be.

Tom prided himself on having an excellent memory and would often remember dates and anniversaries that other people could not.

Barbara noticed that when he went to the shops he would sometimes forget to buy things even if he had a list. He forgot one of the children's birthdays and would say he had forgotten the names of some of their friends. He kept repeating himself. He often had to ask her the storyline on some of their favourite TV programmes. Barbara was having her own physical check up with her GP and mentioned this. Her doctor was very friendly and said that she should either bring Tom in or he would go to see him. He said he couldn't do anything without Tom's permission. Tom was very reluctant to go to the doctor, saying that he felt fine and had no worries. She spoke to the practice receptionist who confirmed there wasn't anything the doctor could do without Tom's permission. Barbara said they had been married 60 years and when the receptionist said she could only talk directly to Tom about his treatment, Barbara got upset and put the phone down.

Over the next year the situation gradually became worse. Tom was starting to soil his clothes. Because things crept up on her, Barbara didn't really react and simply adjusted to things. It was easier to do the shopping herself than to send Tom and she got someone to do the garden because he was mixing up the plants. What was most upsetting was that they began to have arguments because she would get frustrated and admonish him for not remembering something. Their children and grandchildren began to notice all was not well. Tom liked walking and once did not come back for several hours. Barbara called the police distraught. Tom had never got lost before; his sense of direction had always been pretty good so she thought something awful might have happened to him. The police searched for him for five hours in the local woods near his house, on the high street even along the motorway. After searching extensively on foot they called on the helicopter team to continue the search as the light was fading with evening encroaching. Thankfully they eventually found him in a local park at 11pm unharmed but he was cold, hungry and thirsty.

Things came to a head one Saturday (Barbara will always remember the date – the 26th November 2010). Tom had been a bit more fractious than usual during the week. That afternoon he started shouting at her saying she had hidden his favourite book on fishing because he couldn't find it. He said that she had always resented him going fishing which is why she had taken it away. He had wet his undergarments and trousers but would not let her help him change his clothes. She became tearful and would have phoned her daughter but she was away on holiday. Later in the evening, he suddenly began shouting and threw a cup at her. She panicked and phoned her GP.

Unfortunately, when the GP arrived it wasn't her usual GP, Dr Turner and he didn't seem to know anything about Tom. He asked a couple of questions to Tom asking if he knew who the Queen was and the name of the Prime Minister. Tom got angry at this and threw a chair at him.

An ambulance was called and Tom went into hospital. Things got worse as no one seemed to know what was happening and Tom became more confused although he did have some lucid moments. He kept on trying to get out of bed, kept shouting for his wife and as a result, the cot sides were put up. By now, Tom was soiling himself every day. He didn't know where he was. A nurse wrote on a piece of paper that he should keep quiet and lie still but he could not read it because he did not have his glasses. For a few days, two security guards sat next to his bed and he told Barbara in one of his lucid times that he was scared he was going to be taken away - during the war he had been evacuated and had found this very upsetting.

10 days in a hospital bed (acute or community) leads to the equivalent of 10 years ageing in the muscles of people over 80

Gill et al (2004) studied the association between bed rest and functional decline over 18 months. They found a relationship between the amount of time spent in bed rest and the magnitude of functional decline in instrumental activities of daily living, mobility, physical activity and social activity.

Gill TM, Allore H, Guo Z. The deleterious effects of bed rest among community-living older persons. *J Gerontol A Biol Sci Med Sci.* 2004;59:755-761.



Over the next two weeks, Tom was transferred to three different wards because they always seemed to need the bed for someone else. He was now wearing wrap around nappies that he kept on trying to remove. Barbara asked the nurses about the urinary and bowel incontinence and was told that it was only to be expected to be at his age and with his problems.

Patients with dementia can develop incontinence but in the majority of people it can be treated and improved with simple measures such as regular reminders to visit the toilet, laxatives for constipation and medicines for the prostate and bladder.

During the transfer between one ward to another Tom's dentures went missing and could not be found. Tom struggled to eat and was placed on a pureed diet and started to often refuse food. There was no facility in the hospital to have dentures remade and Barbara was told that she would need to organise a dental appointment for Tom when he was discharged. This would mean that Tom would be without teeth for months.

Barbara asked if she could stay with him but the staff said she couldn't because it would be disruptive for the other patients and there would be nowhere for her to sit. Evidence has shown that people with dementia are at greater risk of having adverse outcomes following treatment in a hospital. Even a brief stay may intensify an older person's dementia, and make them more prone to problems such as falling and malnourishment⁸. It has been found that people with dementia who are inpatients on average spend three times as long as others when admitted to hospital⁹.

Two weeks later, Barbara got a phone call to say that Tom had slipped over the cot sides. He had an x-ray the same day to confirm whether he had broken his leg. Luckily his leg was not broken but badly bruised and he was able to be discharged and returned home then next week with his wife Barbara. Barbara was provided with incontinence pads for Tom to use.

Alzheimer's Society 2009 report *Counting the Cost: caring for people with dementia on hospital wards*¹⁰:

- Over a quarter of hospital beds in the UK are currently occupied by people with dementia
- One third of people with dementia who go into hospital for an unrelated condition NEVER return to their own homes
- 47% of people with dementia who go into hospital are physically less well when they leave than when they went in
- 54% of people with dementia who go into hospital are mentally less well when they leave than when they went in

Tom's dementia was advanced by this point, (four years after the onset of his symptoms) as he had worsened in hospital, his wife found he had been hiding his prostate and bladder medication at home. His capacity to make decisions about his future was questionable according to the ward consultant upon discharge and would

⁸ (<https://www.agingcare.com/articles/hospital-stay-for-dementia-149913.htm>)

⁹ (<http://www.telegraph.co.uk/news/health/elder/11502563/Dementia-patients-stay-in-hospital-because-of-home-help-care-shortage.html>)

¹⁰ https://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=356

need assessing in the near future to develop a care plan according to the Mental Capacity Act. It was too late for him to give Power of Attorney. The assessment would need to be completed in accordance with the Mental Capacity Act. Knowing Tom needed assessing and knowing that she did not know how to organise this put a lot of stress on Barbara and she also worried about what Tom would want if she would have to make decisions on his behalf.

Many of those who lack or have fluctuating capacity miss out on their fundamental rights to make, or influence, important decisions about their own care¹¹. Good, person-centred, care and support planning is a vital part of protecting our freedom, choices and rights when we are at our most vulnerable⁵. It is important that all staff working with people living with dementia have undertaken training in the Mental Capacity Act (MCA) and the Deprivation of Liberty Safeguards¹².

In Tom's case the team looking after him in hospital were under pressure to release his bed and assumed that his care plan would be developed when he got home. This resulted in Tom having no say in his future care as his capacity soon deteriorated even further which goes against all fundamental principles of the MCA. His bladder and bowel control wasn't assessed and options considered for him, other than providing pads. Tom's memory problems meant that he couldn't recognise the toilet and needed guidance along with a toileting plan to enhance his dignity.

14 months after leaving hospital Tom became highly confused. He was soiling several times a day and Barbara was beside herself trying to manage it. Barbara noticed he was not himself as he often failed to recognise her and his surroundings. He was becoming highly agitated and restless so she took him to A&E to see if it was the result of an infection as she knew this was fairly common in people with dementia. Tom was admitted and had an examination and blood test which suggested he had an infection. It was following the blood test result that the A&E consultant suggested that Tom be referred to a memory clinic for diagnostic assessment for suspected dementia. Tom spent that day in hospital but was discharged with a prescription of antibiotics. Tom recovered well. In December 2012 following a referral from his GP, he went to the memory clinic and was given a formal diagnosis of Alzheimer's disease at 82 years old. He was then prescribed an acetylcholinesterase inhibitor to treat his Alzheimer's disease. Given his history of a gradual onset and symptoms it was decided a brain scan was not required.

Day to day tasks at home were becoming increasingly difficult for Tom. He could no longer remember how to dress himself or prepare even a simple meal. He would often forget to eat and drink as he had no concept of time. Tom didn't visit the toilet anymore, only using his pads. Barbara tried her best to provide Tom with as much

¹¹ Care Planning

<http://www.scie.org.uk/publications/mca/care-planning/foreword.asp>

¹² Mental Capacity Act 2005

<http://www.legislation.gov.uk/ukpga/2005/9/contents>

Mental Capacity Act: deprivation of liberty safeguards 2010

<https://www.gov.uk/government/publications/mental-capacity-act-deprivation-of-liberty-safeguards>

structure as possible getting him up and dressed at the same time each day with meals at set times¹³. Barbara had to coax Tom to drink as he would not be interested.

Barbara also had to help Tom wash which was very tiring for her as he often did not want to and she would try to persuade him for hours on end.

Tom and Barbara joined a post diagnostic support group but often had to cancel plans to attend as Tom did not want to go out, he often had very low mood. Barbara tried to invite friends over but Tom could be inappropriate and rude without meaning to be nowadays and many friends had backed away. The only respite Barbara had was from the children coming by to look after Tom but it upset Barbara that they had to see all the changes in him and she wanted to shelter them from how badly he had deteriorated.



Barbara continued to try and find things for Tom to enjoy like walking, music and gardening but he never seemed to react as she expected any more. He had a very short attention span now and got tired and disinterested on their walks. Often now when listening to music it would make him emotional and Barbara would have to console him. He could never explain why he was upset to her and so she did not know how to avoid these triggers.

In the summer of 2014, Tom was in the garden planting with Barbara when he buried the key to the house in a flower bed. Barbara lost her temper with Tom as they were locked out of the house. Tom could not even remember Barbara giving him the key to put in his pocket and shouted back at her. Barbara broke down in tears eventually calming Tom and getting him to take a nap in the deck chair while she looked for the key. It took an hour for Barbara to find the key on the grass next to the flower bed.

By Christmas Barbara was really exhausted; Tom was becoming increasingly frail. He was very lethargic, sleeping much of the time and had no interest in food. Barbara started to really worry when Tom's clothes were falling off him. She was concerned he was becoming dangerously underweight. Barbara took him to A&E when she was unable to get him to eat for 2 days as she thought he would need to be tube fed.

Tom was admitted to hospital after being checked over in A&E. The situation was heart-breaking for Barbara as she thought maybe Tom wanted to die and that was why he was refusing to eat but she could not let that happen. Barbara had worked

¹³ <http://www.scie.org.uk/publications/mca/care-planning/>

tirelessly to adapt his diet to suit him but nothing had worked. In hospital Tom was drip fed for week to build him back up again. He was discharged with a prescription for some weight gain supplement drinks to stop him losing any more weight. Barbara spoke to people at the hospital that had been looking after Tom including a social worker who agreed Tom was too frail and advanced in his dementia to possibly go home and that he would need to be admitted to a care home.

Tom moved into a care home in summer 2016. Following a bout of pneumonia, he died on 26 October, two days after his 85th birthday.

Tom had only been living at the care home for three months when he passed away. Barbara felt guilty she could not care for Tom at home - where she believes he would have rather been at the end of his life. She also believes he would have lived longer if he had been cared for at home as she knew how to care for him best.

Questions for GPs and commissioners to consider

At the CCG population level, there are likely to be thousands of people living with dementia related issues; many will not have been identified formally to the care system.

In the local population, who has overall responsibility for:

- Promoting dementia as a condition for which targeted interventions (including preventative) must be planned and delivered?
- Identifying individuals living with dementia?
- Planning care models to address key stages of dementia (pre/early, moderate or severe)?
- Identifying and reporting on measurable positive and negative dementia associated outcomes?
- Quality assurance and value for money of care for people living with dementia?
- Quality assurance and value for money of continence care?
- How do we do the right thing for the patient and at the same time recognise that costs may shift from health to social care?
- Has any engagement activity taken place with patients with regards to dementia care?¹⁴
- Do you already have valuable local data around patient experience and outcomes for dementia care in your area?
- How could this local data be used to identify and drive improvements?

¹⁴ If you require advice and resources around engagement please contact The Involvement Hub through this link: <https://www.england.nhs.uk/participation/>

Fundamental question for this specific scenario are:

- What could have been done earlier to ensure crisis point was not reached?
- Why was a dementia advisor not offered to Tom and Barbara?
- Why was there no continuity of care in this pathway?

The above questions are vital in understanding who manages which components of a whole system. Most importantly, it is impossible to effect optimal improvement if the system is not aware of the answers.

What could have happened differently?

Not long after Tom's 77th birthday on October 24th 2007 he started having symptoms of memory loss, forgetting names and significant dates. He and Barbara discussed this. Tom was aware of dementia from a conversation with his younger brother who had recently had his health check where he learnt about how to prevent a number of long term conditions. Tom and Barbara agreed it would be a good thing for him to go to see Dr Turner. Tom and his wife went together. Dr Turner checked his bloods, reviewed his medical records and did a brief memory test which even Barbara could see he did not do very well on.

The doctor asked if Tom would be prepared to go to a memory clinic to have some more investigations. Tom said he was not keen on this and didn't want to make a fuss. Dr Turner said that someone from the memory clinic came and did a surgery in the practice which would just be like seeing his GP. Tom said he would be happy to see him.

The appointment took place three weeks later. The doctor, Dr Fisher, asked Barbara questions and did some more memory tests with Tom. At the end, Dr Fisher explained that Tom could possibly have early symptoms of dementia due to Alzheimer's disease. He said he wanted to check a brain scan just to make sure that there was no other cause for his symptoms and would introduce them to the practice dementia advisor. Tom agreed.

As Dr Fisher predicted the brain scan confirmed Tom's diagnosis of early Alzheimer's disease, it showed that the hippocampus and surrounding brain tissue had shrunk. Dr Fisher met with Tom and Barbara at the memory clinic a week after their meeting at the GP surgery to confirm the diagnosis and to introduce them to their dementia advisor, Kevin. After checking with Tom that he understood his diagnosis, Dr Fisher prescribed Tom donepezil (an Acetylcholinesterase inhibitor) and emphasised that Tom had done the right thing in seeking a diagnosis as despite there being no cure for Alzheimer's disease; treatments can improve symptoms in some people and may have an effect on slowing down its progression¹⁵. Dr Fisher

¹⁵ https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1045

also highlighted that by having a diagnosis Tom will now be able to access a great deal of support locally.

Kevin and Dr Fisher also asked Tom if he would like to learn more about dementia research and potentially get involved. Tom was excited by the opportunity to get involved as it would keep him active and could make a real difference to people getting dementia in the future. Tom and Barbara both signed up to the Join Dementia Research¹⁶ register (the register is not limited to those living with dementia). Dr Fisher highlighted what a great resource Kevin will be going forward and noted that Dementia Advisers are not at present universally available but the local CCG had agreed to fund the Dementia Advisors for the next five years to improve post diagnostic support locally. Together an initial personalised care plan was drafted. Kevin would be responsible for reviewing the care plan every 12 months with Tom and Barbara to ensure they were both receiving adequate care and support. The care plan would in time cover: post diagnostic support; advanced care planning; medication review and any other conditions Tom developed. This ensured the care plan stayed up-to-date and took into account Tom's needs

Tom took to Kevin straight away as they were both Manchester City supporters. Kevin gave them advice on as how to stay fit and how to manage some of the potential disagreements they may have had. For example, Barbara appreciated that Tom's snappiness was because of the illness and not that he was being deliberately awkward and Tom appreciated that he did not realise how difficult it can be looking after someone with a poor memory. Kevin offered to enrol Barbara in the local Strategies for Relatives (START) programme¹⁷. He explained that START was a manual-based, eight session intervention, which promotes the development of coping strategies amongst family carers of people with dementia. This includes working with carers to identify individual difficulties and implement strategies to overcome these. Barbara agreed that she would like to take part in the programme.



Tom didn't realise it but there was a local Dementia café near where he lived. Kevin pointed it out to him and he and Barbara went into one of the drop-ins. He recognised an old work colleague who was there with his wife. Tom used to sing in a Welsh male voice choir and was very interested to learn that there was a 'Singing for the Brain' group.

¹⁶ Join Dementia Research

<https://www.joindementiaresearch.nihr.ac.uk/>

¹⁷ The START (Strategies for Relatives) trial tested an intervention to support the mental health of carers of people with dementia. https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2753

Kevin told Tom about some dementia research that was taking place in Manchester including a trial on a new drug that could slow down the progression of Alzheimer's disease he asked if Tom would be interested in getting involved in the trial and he readily agreed.

Kevin visited them a couple times in the first month and gave them a number to ring if they needed help. He also discussed with them the benefits of advanced decision making and advised on how to begin the process of agreeing a lasting power of attorney when they felt ready. Barbara's friend unfortunately had cancer and she remembered her speaking about the support she had received from her McMillan nurse and she was reminded that the help she and Tom were receiving was similar. Kevin always reassured Barbara that Tom was a lucky man to have such a supportive wife.

Around a year after Tom's diagnosis he began to get up during the night to go to the toilet which is wife thought was unusual. He even got caught out a few times unintentionally passing urine throughout the day before reaching the toilet. Barbara spoke to Kevin who said that people with dementia were much more likely to become confused if they had an infection and suggested that he see his GP. Dr Turner agreed it was probably an infection and prescribed some antibiotics and Tom had no more trouble. The GP also checked that there wasn't any other co-existing conditions such as a prostate problem and provided the necessary treatment. Dr Turner also at this point referred Tom to a specialist continence service to ensure effective management of his bladder and bowel health going forward. The specialist continence service undertook an initial assessment and then a 6 week follow up. Barbara and Tom were also advised on how to keep his bladder and bowel healthy, which included good fluid intake, switching to decaffeinated tea and coffee, maintaining a well-balanced food intake and regular toileting.

Kevin was helpful in advising what to do when Tom became a bit upset when he perceived Barbara was admonishing him for difficulties with his memory. Kevin was also invaluable when the need came to convince Tom to give up driving. He was very reluctant to give up but eventually saw it was the right thing to do. They also talked about lasting power-of-attorney. Barbara felt supported as both she and Tom had people to talk to about any concerns they had. Kevin was a rock and Barbara knew that if Tom developed symptoms due to a physical or emotional illness they could be treated and she knew that Kevin would be there for support if she was worried about anything.

Tom continued to be very active which pleased Barbara, taking part in local groups, enjoying taking part in the medical research and continued to love his walking. Unfortunately he slipped on leaves when out walking in the autumn with a local dementia group and hurt his leg. He was taken to A&E and given pain relief, but as it was not clear on the x ray whether there had been a fracture, he was admitted to hospital. Tom's medicines were reconciled by the ward pharmacist, which meant that accurate information was available in a timely manner about his medication and

compliance/concordance prior to admission. The nurses recognised he had a diagnosis of dementia, completed a 'This is me' form which gave lots of information about him and his life story and was identified by the Butterfly scheme¹⁸. They were particularly careful about providing Tom with information and made sure that his drinks were within reach so that he would not become dehydrated. The ward had signed up to John's campaign¹⁹ and so Barbara was able to stay the night with him as he was a bit nervous about being in hospital. Tom was discharged the next day returned home with his wife as his x ray confirmed that his leg was not broken just badly bruised. Tom's medication regime was reviewed and continued as it was not felt to have contributed to his admission.

At the point of discharge Tom's GP and memory clinic were informed that there had been no changes to his medication regime whilst an inpatient and clinical pharmacists on the in-patient ward ensured that Tom had sufficient medication to last until his usual supply was available from his GP and local pharmacy. The ward staff also offered to make arrangements for Tom and Barbara to meet with the ward clinical pharmacist if they had any unanswered questions about Tom's medication regime.

Often just small adjustments need to be made in order to continue with day to day activities and remain independent.

When Tom was out of hospital he and Barbara continued to be social and stay active. They were still avid walkers and liked to get out in the great outdoors as much as possible making sure never to miss any local dementia support group walking activities. Tom also continued to attend 'singing for the brain' at the local church each Friday morning. This group was particularly good in that it enabled Barbara to get some respite from caring for Tom. Respite is important for a carer's physical and mental wellbeing and can enhance the relationship with the person they care for²⁰. The person with dementia may also benefit from the break with it providing an opportunity for new social interactions and a chance to pursue interests. Tom also attended an art class weekly which Barbara helped a local charity set up, she was passionate about fund raising. Barbara also would help run this class with a local artist for a number of people living with dementia in a community hall.

It was not until 2014 (almost eight years post diagnosis) when it was clear that Tom was struggling to keep up with all their commitments. He was more forgetful these days and could get quite agitated in unfamiliar surroundings.

¹⁸ The Butterfly Scheme provides a system of hospital care for people living with dementia or who simply find that their memory isn't as reliable as it used to be <http://butterflyscheme.org.uk/>

¹⁹ John's Campaign is a campaign for extended visiting rights for family carers of patients with dementia in hospitals in the United Kingdom, founded on 30 November 2014 by the writer Nicci Gerrard and Julia Jones <http://johnscampaign.org.uk/#/>

²⁰ Dementia: supporting people with dementia and their carers in health and social care [CG42] <https://www.nice.org.uk/Guidance/CG42>

The forgetfulness seemed to correlate to Tom's bowel movements as Tom began to soil himself quite regularly and so Barbara self-referred Tom to the specialist continence service again for refresher advice and support.

Tom was still involved in a clinical trial but had to drop out as the trips to the local hospital each month for a blood test was causing him a lot of distress. Barbara noticed he was getting physically weaker as he was not preparing meals/ snacks as he used to. Going forward Barbara would be responsible for all the cooking which she did not mind, as she thought she was the better cook anyway. Increasingly, Barbara was doing more and more for Tom but she often called on Kevin for support who reassured her she was doing a great job. Tom had great quality of life for a long time living at home with Barbara as she ensured he had everything he needed.

Barbara really started to notice a difference in Tom in January 2016 (almost ten years since the original diagnosis) as he was forgetting the layout of their home and how to function using everyday items such as doors, drawers and stairs. Tom had lost his appetite also and was much frailer than he used to be which meant he did not much care for physical activity any more as he soon grew tired. Barbara recalled the bladder and bowel advice they had previously received from the specialist continence service and she self-referred to them again; this time (as Tom's condition was becoming more serious at this point) the specialist service had an Occupational Therapist visit to check that the environment was safe, for example, that the bathroom was easy to recognise and use (different coloured toilet seat used etc.).



Tom lived well with dementia at home with his wife for 10 years before his care needs became too much for Barbara to handle alone. Creating a bespoke care package for individual patients can make a significant difference and enable patients to remain in their own homes for much longer.

Tom was 86 years old when he moved into a local care home. Many people with dementia move into a care home once their dementia progresses to a certain stage. Some people with dementia have other illnesses or disabilities that make it difficult for them to remain at home. Upon moving into the care home Tom's medication was reviewed again by the care home management with Tom and his GP. There are often risks of miscommunication about medicines whenever a person moves across boundaries of care there is a need for 'medicines reconciliation'.

Barbara ensured that the management and care staff were all aware of Tom's advanced care plan that Tom had put together with Kevin. Knowing that Tom's

wishes would be upheld as his dementia advanced reassured Barbara. Barbara stayed very involved in Tom's care and visited him daily at the care home. The staff implemented an individualised toileting plan for Tom along with Barbara's help, which helped to maintain his continence and dignity²¹.

The life expectancy of a person with dementia is unpredictable, and the disease can progress for up to around 10 years. It is estimated that a third of people with dementia at any one time will be in the later stages of the disease. Although dementia is a life-shortening illness, another condition or illness (such as pneumonia - an infection in the lung) may actually cause a person's death²².

Commissioners need to ensure that these last years are well managed, for the wellbeing of the patient, the carer and for potential financial efficiencies for the NHS ensuring appropriate use of NHS resources.

The 'bills' and how they compare

What is the cost of Tom's journey to the NHS and the wider social and economic impacts?

This scenario is using a fictional patient, Tom. It is intended to help commissioners and providers understand the implications (both in terms of quality of life and financial costs) of shifting the care pathway of older people living with dementia from a reactive to a proactive approach. The financial costs are indicative and calculated on a cost per patient basis. Local decisions to transform care pathways would need to take a population view of costs and improvement.

For the financial evaluation we performed detailed analysis through mapping the lifecycle of the pathways. Through this process we were able to identify the cost drivers that would be incurred in primary, community and hospital care, using NHS reference costs and, where there is a hospital stay, average cost per bed day²³. We have included the wider social impacts and economic impacts but we have not attempted to cost financially outside of the health remit or the social, emotional, physical and financial costs to Tom himself.

The tables on the following page represent a summary estimation the different impacts of the two pen portrait journeys from a financial perspective:

²¹ NB the time recorded (for finance calculations) in the care home in the optimal scenario is the same as in the sub optimal scenario i.e. 3 months in each.

²² https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=101

²³ An overnight stay in hospital varies according to location and the type of services needed. Data on NHS costs is not collected by bed day but according to the treatment required. However a hospital stay is estimated to cost £400 per day Data.Gov.uk <https://data.gov.uk/data-request/nhs-hospital-stay> Edbrooke and colleagues estimated the average cost per patient day in 11 ICUs was £1,000

www.ics.ac.uk/EasySiteWeb/GatewayLink.aspx?allid=441

Costs have been calculated as at 2015/16 prices.

The excel spreadsheet designed to cost these scenarios includes full details of cost data sources and is available upon request.

Table 1: Summary of financial costs for both pathways by provider

Analysis by provider	Sub-optimal	Optimal
Acute	£17,428	£600
Ambulance service	£233	£233
Care Home	£7,670	£7,670
Primary care	£7,119	£8,136
Third Sector	£0	£1,675
Grand total	£32,450	£18,315

Not only is Tom’s (and his wife’s) health and quality of life significantly better in the optimal scenario, but the costs to the health economy are reduced by 43%.

Table 2: Summary of financial costs for both pathways by cost category

Analysis by cost category	Sub-optimal	Optimal
Primary care management	£7,075	£8,136
Urgent & Emergency Care	£461	£233
Secondary Care Management	£17,200	£600
Intermediate Care	£7,670	£7,670
Community Care	£0	£1,675
Grand total	£32,450	£18,315

Finance key variances

Primary care expenditure is 15% more in the optimal scenario. Most of this investment is centred on: a) a dedicated dementia advisor (£7.4k) and b) early diagnosis and earlier prescriptions for inhibitor drugs. The % increase is relatively small because there are significant cost savings associated with incontinence products (£6.9k variance between the two scenarios).

Secondary care expenditure is radically different, ranging from three hospital admissions totalling 43 days as an inpatient (£17k) compared to one day’s stay in the optimal scenario (£1k).

The third sector also makes a significant contribution in the optimal case with the provision of the 'singing for the brain' programme (£1.7k)

Financial summary:

In the sub-optimal pathway Tom receives very little / inappropriate support during the early years of his dementia symptoms. Initially, there are only the health costs associated with the first A&E and hospital admittance but the time-bomb is ticking loudly without the appropriate diagnosis and treatment. Strategically, these early years are the most important to Tom and Barbara's long-term health. As shown in the optimal scenario, preventative care has a huge impact and the later complications are then largely avoided / delayed.

The impact is significant on outcomes, quality and finance

NB: Police costs (to locate a lost Tom) and dental costs have not been factored in to the financial analysis, but these would (in addition) be in excess of £2,000 to the tax payer.

Think change, Think NHS RightCare

This optimal pathway was understood, tested and created using the proven NHS RightCare approach.

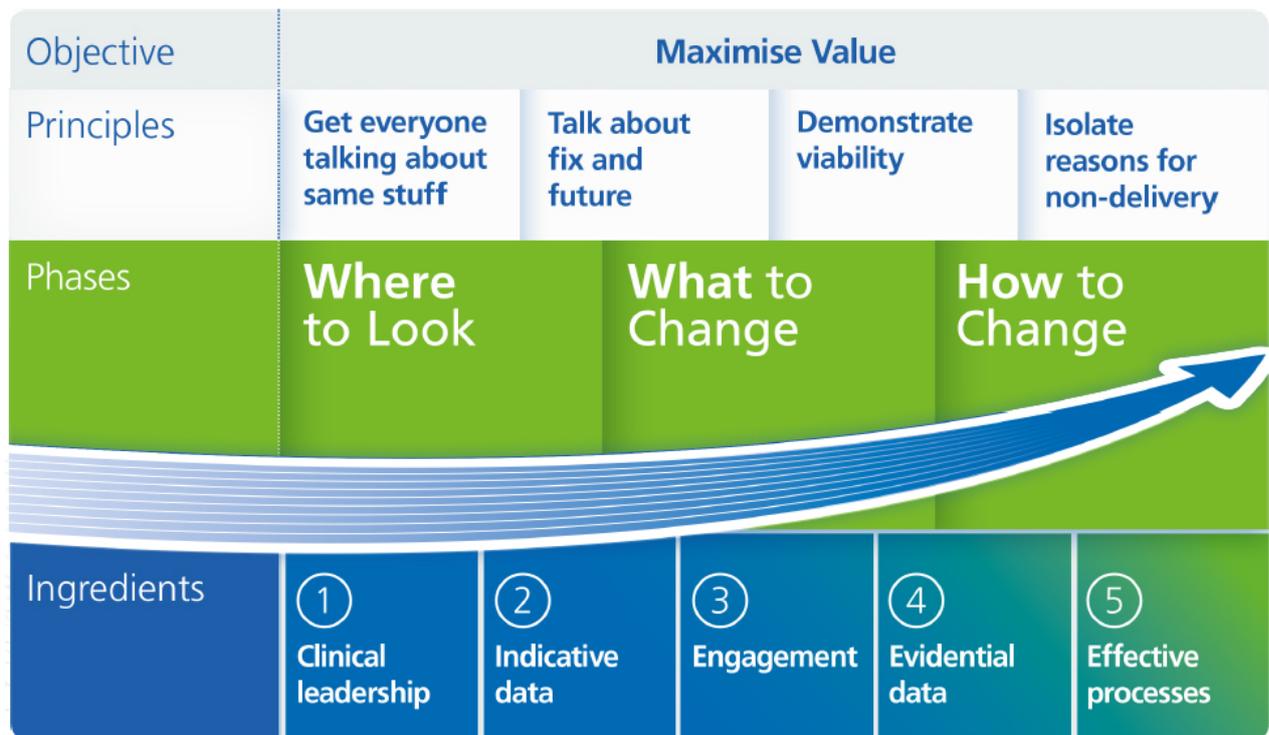
NHS RightCare is a methodology that focuses relentlessly on increasing value in healthcare and tackling unwarranted variation. It is underpinned by intelligence and robust evidence, showing commissioners and local health economies 'Where to Look' i.e. where variation and low value exists. The approach then goes on to support health economies through 'what to change' and 'how to change'. The diagram showing all three key phases is shown on the following page.

NHS RightCare offers facilitation and support to all CCGs and their health economies in implementing the RightCare approach and the developmental thinking, tools and data that enhance population healthcare improvement.

NHS RightCare is a proven approach that delivers better outcomes and frees up funds for further innovation. Please explore our latest [Commissioning for Value publications](#) and for more details about our programme visit www.england.nhs.uk/rightcare

You can also contact the NHS RightCare team via email at rightcare@nhs.net

Figure 3: The NHS RightCare approach



- For a toolkit for general practice in supporting older people and achieving the requirements of the Unplanned Admissions Enhanced Service please visit: http://www.nhs.uk/media/2630779/toolkit_for_general_practice_in_supporting_older_people.pdf
- For more information about the Long Term Conditions work at NHS England please contact england.longtermconditions@nhs.net
- The [Dementia Well Pathway](#) PDF
- The Dementia Pathway online tool can be found [here](#) to easily research data such as this.

Two slide packs to summarise this scenario – a full length pack and a shorter summary pack – are included as appendices.

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. Please contact 0300 311 22 33 or email england.contactus@nhs.net