

Dementia Report

**The Experiences of Patients with Dementia and their Carers
at Southampton General Hospital**

October 2024

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Introduction

1. Healthwatch Southampton was approached by the Alzheimer's Society in September 2022, to highlight a few issues relating to the experience of some patients with dementia and their carers within Southampton General Hospital (SGH). Their examples included poor patient and carer experiences in hospital, which we felt warranted further exploration to understand better the perspectives of patients, family members, unpaid carers as well as other stakeholders including hospital staff. We therefore engaged in a combination of methods to explore this further, comprising case studies, interviews, and a workshop for stakeholders including hospital staff.
2. We would like to thank all of those that shared their stories with the desire to improve the experience of dementia patients, their families and carers in hospital. Please note that when we use the term 'carer' in this report, this refers to unpaid carers, not paid healthcare professionals.
3. While the initial report was drafted in 2023, due to staff vacancies over a 5-month period, we were not able to finalise the report until April 2024. Given the delay since the initial approach by the Alzheimer's Society, we agreed with SGH to conduct a visit in September 2024 so that our report and recommendations could accurately reflect current services for patients with dementia. Our observation is that the Basset Ward offers a high standard of care for patients with dementia and our recommendation is that should resources be available in the future, SGH should consider modifying their criteria to enable more patients to be given this standard of care.

Scope and Limitations

4. There were limitations to this work which was a small-scale project using the time and resources available to us:
 - We recognise that given the small sample; it does not represent how all dementia patients are treated at the hospital. SGH has many patients with dementia admitted over the course of a year and our work is a small snapshot of a few experiences during the last 3 months of 2022. Furthermore, we appreciate that NHS staff are under immense pressure, meaning some conversations were limited and some individuals did not have the capacity to engage in this work.
 - We acknowledge that there remain gaps in our knowledge. We wanted to speak to a larger number of carers to gain more perspectives and experiences through a wider survey or focus groups. However, we appreciate that many carers do not have the time nor capacity to be involved.
 - We also recognise the complexity that hospital staff have when identifying who is an unpaid carer for a patient, in terms of definition and responsibilities.
 - We recognise the challenging times that the hospital experienced in the post-Covid period. The case studies were during 2022 when the hospital staff were still under extreme pressure.
 - There was an unavoidable time delay between the evidence gathering period (2022/2023), writing the report (2023/2024). We acknowledge that there may have been many changes at SGH since the beginning of this piece of work.

5. Hence, following discussion with SGH, we considered it useful to undertake a follow up visit to the Dementia Ward in September 2024. Despite these limitations, we hope that this piece of work can contribute to an important discussion about the experience of dementia patients and their carers in hospital and helped to bring further awareness. It also highlights good practice, improvements, and changes at SGH as well as services that are available to dementia patients at the hospital, who meet the relevant criteria.

Definition of Dementia

6. Dementia refers to a set of symptoms that develop over time and affect behaviour, memory, language, and problem-solving, and is caused by a disease damaging nerve cells in the brain. Alzheimer's is the most common form of dementia.
7. Dementia gets progressively worse over time, and causes challenges such as memory loss, difficulty concentrating, problems with communication, confusion, and mood changes. Although there is no cure for dementia, appropriate care and treatment can help individuals to have the best quality of life for as long as possible¹.

Context

8. The World Health Organisation (WHO) states that the principal goals for dementia care includes optimising physical health, treating physical illness, understanding of behaviour changes, and providing support to carers. Visits to hospitals can be very difficult and/or traumatic for individuals with dementia. New environments, faces, and routines can lead to a range of adverse health and behavioural outcomes that can cause additional distress for them, their carers and staff². The WHO states that there is a need for dementia to be a public health priority, increased awareness, and creation of a dementia-inclusive society.³
9. In 2019, Healthwatch England published a report titled 'Why it's important to review the care of people with dementia', which looked at experiences of social care, and analysed council data about people's needs. This research found that accessing social care services is 'not always easy for people with dementia [and] information is not presented in a way that is accessible'⁴. Another Healthwatch England report found that people with dementia are not always getting the support they need, and carers face various challenges⁵.

¹ The Alzheimer's Society, What is Dementia <https://www.alzheimers.org.uk/about-dementia/types-dementia/what-is-dementia>

² Digby et al [The experience of people with dementia and nurses in hospital: an integrative review - Digby - 2017 - Journal of Clinical Nursing - Wiley Online Library](#)

³ WHO, Dementia [Dementia \(who.int\)](https://www.who.int/news-room/fact-sheets/detail/dementia)

⁴ Healthwatch England, Why it's important to review the care of people with dementia [20190628 - Why it's important to review the care of people with dementia.pdf \(healthwatch.co.uk\)](#)

⁵ Healthwatch England, Dementia carer: As a carer I get just 3 hours' sleep a day Dementia carer: [Dementia carer: As a carer I get just 3 hours' sleep a day | Healthwatch](#)

10. Southampton City Council estimates that the city's over 65 population is forecast to grow by 18% by 2030. It is estimated that by 2025 there will be an estimated one million people living with dementia in the UK⁶. Within this context of an ageing population and the projections about dementia by 2025, the piece of work undertaken by Healthwatch Southampton (even though it is based on two cases) is particularly relevant in increasing our understanding of the services that are on offer and the importance of extending them to more people.

Methods Used to Gain Insight

11. We used a combination of methods to gain the best understanding of the experience of dementia patients and their carers in Southampton General Hospital (SGH):

- Thirteen case studies provided by the Alzheimer's Society in October 2022 were used first to highlight some of the key issues and identify areas to explore.
- Unstructured interviews with two carers of patients completed in November 2022, with the help of the Alzheimer's Society. We invited all thirteen of the carers identified in the case studies for an unstructured interview of which two carers of patients with dementia accepted our invitation. This enables us to hear some first hand, detailed experiences.
- Workshop in March 2023 with stakeholders including hospital staff understand their perspective. The exercises used at the workshop were based on the information gathered through the case studies and interviews.

Case Studies and Interviews

12. The Alzheimer's Society provided us with examples of real case studies (13) regarding individuals with dementia and their carers, which highlighted a variety of issues and challenges, which we decided needed further exploration. We then established the following key aims:

- Identify where current plans at SGH do not meet people's needs.
- Understand the policies and procedures in place concerning care of dementia patients.
- Use our findings to make recommendations that may help improve health outcomes for people with dementia in Southampton General

⁶ 2 NHS, About Dementia About dementia - NHS (www.nhs.uk)

Hospital.

- To explore our first aim further, we decided that it was important to gain additional insight into the first-hand experiences of patients with dementia and their carers.
13. Therefore, with the help of the Alzheimer's Society, we arranged two virtual unstructured interviews with carers of people with dementia so that the carers could share what was significant to them, and alert us to issues we were not previously aware of. These two conversations and analysis of the thirteen case studies highlighted common themes relating to communication with carers, inadequate understanding of dementia and how best to support patients with dementia. We recognise that these themes may not be representative of the experiences of all patients with dementia, but they give some insight to carer perspectives.

Workshop Activity

14. After gathering these limited first-hand experiences, we used the theory of change model⁷ to identify gaps in our knowledge and planned a workshop exercise so that local stakeholders and hospital staff could help shape the recommendations for improvement. We invited 28 stakeholders including hospital staff, community organisations, and one member of the public. Eleven participants attended the workshop. At the workshop, we explored the following issues in three task groups:
- Current structures in place to support patients with dementia and their carers.
 - The issues, barriers and challenges faced by hospitals.
 - Recommendations for improvement.

Issues raised in the case studies and interviews, from carer experiences

15. Communication with carers
- There was poor communication between SGH and carers, specifically regarding what treatment has been given or planned.
 - Some staff had made decisions about treatment by discussing it with the patient with dementia, without involving the carers.
 - Some carers reported that they were unable to see positive change or get answers regarding their concerns, leaving them feeling

⁷ Theory of change is a way of planning and evaluating social change efforts by **mapping out the steps and assumptions** involved.

disheartened and alone.

- The discharge process can often be confusing and challenging with some pressure on carers to arrange further care (whether that be arranging a home care provider or residential care).

16. Lack of understanding of dementia

- Not all staff have understanding, knowledge, and awareness of dementia.
- There was no clear signage to identify the patient as having dementia, and the "This is Me booklet" was not consistently used.

17. How best to support patients with dementia and improve care

Exploring further on how widespread the following support issues are could lead to improvements. Experiences of some carers on support issues in the thirteen cases explored included:

- Patients were not always treated holistically, that their physical health was being treated whilst being mindful of their dementia status.
- Patients with dementia labelled as difficult or aggressive when their specific needs were not met.
- Patients finding procedures such as catheter change traumatic due to the environment, change in routine, and lack of familiarity with staff.
- The hospital environment can be highly stressful for patients with dementia, for example, due to the overstimulation and noise generated on general wards.
- Patients are not always given the support or encouragement by staff to eat or drink at mealtimes, leading to other problems such as weight loss.

Findings from the workshop and case studies

18. The workshop discussion on the carer perspective from the case studies and the interviews are summarised below:

19. Issues with the quality of communication with carers

In response to the issues that had been raised:

- Hospital staff who attended the workshop acknowledged that there had been some communication issues between staff and patients/ carers, particularly during the COVID-19 pandemic. For example, this included miscommunication from staff resulting in some visitors believing they could only see their loved ones for one hour a day.
- It was recognised that from a hospital perspective it is complex to

identify who is an unpaid carer for a patient.

- Participants reiterated experiences from the case studies which highlighted that carers often feel like they are not listened to, including in discharge processes.
- It was agreed that there is a need to emphasise improved support for carers, and consideration that carers often have their own needs to consider.

20. Lack of understanding of Dementia

The discussions covered:

- Hospital staff who attended the workshop emphasised their commitment to improve their practice with support of external organisations. They noted that relationships with the third sector are improving and that this will help facilitate positive changes.
- Extending dementia training to all staff so that there is overall understanding of the needs of patients with dementia across the hospital.
- Communication between the third sector and SGH had been improving, and it was noted that SGH staff were open to suggestions for improvement through support and advice from external organisations.

21. How best to support patients with Dementia

Using a symbol to enable the patient's dementia status to be more visible so that they can be better supported was discussed. While greater use of SGH's dragonfly symbol, to identify patients with dementia was an option, some participants highlighted that the dragonfly imagery can be confusing as it is not a nationally recognised symbol, and often alternative symbols such as the forget-me-not flower are associated more often with dementia.

Various barriers to improving dementia awareness were discussed, including increasing awareness of SGH policies. The Alzheimer's Society highlighted increasing demand on them and Dementia Navigators to help support patients and raise awareness in hospital. Extending training would address this and also help with patients with dementia being treated holistically, with their individual needs taken into consideration.

22. Avoidable distress situations and improving care

SGH conduct ward audits and spot checks with the help of volunteers. It was acknowledged that hospital staff have been and continue to be under immense pressure. Stakeholders at the workshop gave examples of concerns that could lead to distressing situations. These included:

- Changes to routines
- Patients needing to be restrained during procedures
- Patients with dementia leaving the hospital on their own accord and without supervision
- Patients being labelled as 'aggressive,' as their frustration or fear was misinterpreted when their dementia status was not considered. One workshop participant referred to this as a 'lose-lose' situation, as if an individual is quiet their issues are ignored, but if they display frustration they are labelled as difficult.
- Inadequate crisis response, and the consideration of respite needs for carers.
- Overall, participants felt that to improve care and prevent avoidable harm for patients with dementia, a consistently more holistic approach to care is necessary. This would involve assessing needs in relation to patient's physical health and dementia status. Participants highlighted that considering the wellbeing of the carers must also be a priority.

23. Workshop suggestions for maintaining or improving good practice

The following suggestions emerged from discussions at the workshop. Note: suggestions in italics are actions that have been implemented or being implemented by SGH.

24. Improving the quality of communication with carers

- Establish digital access to information on patient's care for carers - access to My Medical Record.
- Improve communication with carers regarding discharge.
- *Effective complex discharge process.*
- Improve connections with community organisations - such as referrals at discharge.

25. Improve understanding of dementia so that staff have more knowledge on how best to support patients

- *Raise staff awareness of dementia and understanding of the different forms of dementia.*
- *Use the 'This is Me' booklet consistently.*

- Develop a hospital passport.
- *Ensure the full implementation of mandatory staff training on dementia care and awareness.*
- *Develop a Dementia Working Group involving community mentors.*
- Effective use of Carer Champion roles.

26. Prevention of avoidable distress to patients and carers, and improving care

- Improve signposting to community organisations to prevent distress after discharge.
- Conduct more audits on patient safety, safeguarding and Adverse Event Records (AERs).
- Use risk registers for recurrent issues.
- Meet essential needs of all patients.
- *Improve understanding of carer stress – Triangle of Care⁸.*

SGH: Continuing Good Practice and Implementing Improvements

27. Healthwatch Southampton has been working with Southampton General Hospital since the end of 2023 to share the findings of the case studies, interviews and workshop. This led to discussions about continuing good practice as well as implementing improvements. This has meant that many of the recommendations from the workshop have been taken on board by SGH.

28. Southampton General Hospital has been transparent and responsive to the dementia work and is committed to improving the patient and carer experience whilst in hospital and have committed to continue with the following measures to ensure ongoing good practice:

- Continue to run a regular Dementia Champions Day.
- Continue to ensure Dementia Awareness Level 1 is mandatory and statutory for all UHS staff.
- Continue to make staff aware of the “This is Me” national document created in partnership with the Alzheimer’s Society and Royal College of Nursing and is utilised across SGH.
- Continue to offer support to carers of all ages and conditions through the Carers Lead and Carers Support Service.
- Promote and raise awareness of dementia in Dementia Action Week in May every year.

⁸ Triangle of Care - [case-study-supporting-well-carers-included.pdf \(england.nhs.uk\)](https://www.england.nhs.uk/case-study-supporting-well-carers-included.pdf)

29. During 2023/2024 SGH have also taken the following additional steps to ensure improvements in all areas below:
- Issue an Organisational Wide Learning request to ensure the Trust Guidance on visiting patients with dementia is widely understood and implemented.
 - Restart the Dementia Working Group which meets quarterly.
 - In 2023 The Alzheimer Society were able to start bimonthly Carers Drop Ins to help support carers of patients living with dementia. These Drop Ins have been running for a year now.
 - A Hospital Discharge Navigator now sits in the Discharge Hub to support signposting to community support.
 - SGH is promoting Fundamentals of Care and has publicised 8 Care Commitments that promote a person-centred approach to patient's care.

Enhanced Dementia Care Ward (Bassett Ward)

30. In order to ensure this report reflected current practice at SGH, the Healthwatch Southampton were invited to visit the Enhanced Dementia Ward in September 2024. The Healthwatch Team met with the Chief Nursing Officer, the Dementia and Delirium Specialist Nurse, Lead Matron of Mental Health and the Older Persons Team Matron.
31. SGH opened a specialised Dementia Ward in 2012. In 2021 this ward was moved to the Princess Anne Hospital due to the Covid-19 Pandemic. It was developed as an Enhanced Dementia Care ward (Basset Ward) for 26 patients with dementia. Whilst the Bassett Ward can offer specialised enhanced care to patients with dementia there are limited bed spaces (26) and staffing resources available. Therefore, staff must assess patient suitability to join the ward. A patient must meet certain criteria to be admitted including being aged 80+ (under 80 in exceptional circumstances only) and the patient must have a Do Not Resuscitate Order or Directive (DNR).
32. The Dementia and Delirium Team aim to visit all patients presenting signs of dementia and/or delirium at SGH. They visit patients who may have an existing condition or may have delirium related to a Urinary Tract Infection (UTI) or any other conditions. The patient is always treated for their primary physical illness first.

33. The Healthwatch Team were given a guided tour of Bassett Ward. There was a mixture of wards with four beds to a room and single occupancy rooms for one-to-one care and end of life care. The rooms were spacious, light, and airy with great views across the city. The Ward was in a good clean condition, tidy and no visible sign of broken furniture/equipment. We observed good dementia friendly practice in both staff protocol and the ward environment. Each ward is named after a colour and there are colour coded signs e.g. purple ward, green ward, etc. All wards have access to their own bathrooms.
34. We observed the 'This is Me' booklet available on the ward for staff to understand more about patients' needs. There were whiteboards next to each bed with the patient's preferences e.g. activities they like, how they like their drinks etc. On the wall a bird bath was projected with gentle birdsong (one of the patient's loved birds and watching them on the wall kept him calm).
35. There was a small dining/day room (a converted ward) with tables and chairs in the centre. It had a TV which was showing an old film. Other DVDs were available and there was a choice of other activities including a jigsaw on the table, old radios, and a keyboard in the room. No patients were using the room at the time we visited however the room was available and inviting to patients.
36. Bassett Ward staff informed the Healthwatch Southampton team that they have identified funds to refurbish the Day Room (decor, furniture, and activities, etc) soon. Displays around the ward included holiday memories, coloured in shells and memorabilia to Southampton Football Club, etc. During the time of our visit, around 12 noon, many of the patients were in bed asleep, a few were sat in chairs, a few were up and standing.
37. Bassett Ward has high staff ratios and there is always a member of staff in each ward with the four patients. The nurse in charge and all staff we met clearly enjoyed the work with patients with dementia and were kind and compassionate. Bassett Ward has two dedicated doctors on duty that can see patients and family/carers from Monday – Friday. This ensures continuity of care. The patients seemed well cared for with their needs met. The Ward supports patients with a high level of need, and we observed one patient whose needs were met quickly by ward staff when they were crying out for help.

38. We observed many examples of good practice and positive interaction during our visit included a Health Care Assistant (HCA) who was reading the local newspaper to a patient and another staff member sat chatting with a patient. We spoke to a volunteer who donates his time twice a week on the Ward. He helps on the Ward to provide additional support for the patients and has been involved in fundraising for resources including arranging for 50 free copies of the Daily Echo (local newspaper) to be delivered to the ward 6 days a week, and has donated an amazing touchscreen, portable TV screen which has access to games, videos.
39. Family and Carers of patients admitted to Basset Ward are encouraged to visit during visiting hours which are every day from 2 to 8pm, but these can be flexible if needed and arranged with Ward staff.
40. Bassett Ward staff agreed that there are some challenges when discharging patients with dementia including finding appropriate care in the community both home care services and residential care. The Ward links with community services to ensure appropriate care on discharge. One benefit is that the environment that Bassett Ward provides care home providers the opportunity to see how patients would respond in a residential setting.
41. The Basset Ward offers a high standard of care for patients with dementia, and should resources be available in the future, we would like the criteria to be modified to allow more patients to be given this standard of care.

Key Recommendations

42. When identifying these key recommendations, we have considered both the available resources and the current pressures facing the NHS. We believe the following recommendations can be implemented effectively using resources that are obtainable or already available to the hospital.

1) Improve communication with carers regarding discharge

Providing carers with more information regarding discharge, including timings, and any follow up needed to support the patient with dementia. SGH should ensure that support available to carers of patients with dementia is widely publicised.

2) Improve collaboration and partnership working with community organisations

Continuing to develop existing relationships with local community organisations who have knowledge of dementia and the needs of patients with dementia. This could encourage knowledge and resource sharing and helping patients with dementia and their families to access seamless care on discharge from hospital.

3) Monitor the use of the 'This is me' booklet across all wards at Southampton General Hospital and continue to increase staff awareness of its existence

This is a resource that is widely available, however needs to be consistently utilised to improve outcomes for both patients with dementia and carers. All staff should be aware of this resource and encouraged to use the 'This is Me' booklet to better understand the needs and characteristics of the patient.

Conclusion

44. We would like to thank everyone who participated in this work and helped us learn more about the experiences of some patients with dementia and their carers at SGH. Through case studies, interviews, and workshop discussions we found that there are various challenges relating to supporting patients with dementia within a hospital setting. We also recognise that Southampton General Hospital works hard to improve patient and carer experience. We look forward to continuing to collaborate with them on the key recommendations.



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