

## NEW HORIZONS

# New horizons for caring for people with dementia in hospital: the DEMENTIA CARE pointers for service change

REBECCA A. ABBOTT<sup>1</sup>, MORWENNA ROGERS<sup>1</sup>, ILIANNA LOURIDA<sup>1,9</sup>, COLIN GREEN<sup>2</sup>, SUSAN BALL<sup>3</sup>, ANTHONY HEMSLEY<sup>4</sup>, DEBBIE CHEESEMAN<sup>4</sup>, LINDA CLARE<sup>5</sup>, DARREN MOORE<sup>6</sup>, CHRISSEY HUSSEY<sup>7</sup>, GEORGE COXON<sup>8</sup>, DAVID J. LLEWELLYN<sup>9,10</sup>, TINA NALDRETT<sup>7</sup>, JO THOMPSON COON<sup>1</sup>

<sup>1</sup>Evidence Synthesis Team, NIHR ARC South West Peninsula (PenARC), University of Exeter Medical School, College of Medicine and Health, St Luke's Campus, University of Exeter, Exeter EX1 2LU, UK

<sup>2</sup>Health Economics Group, University of Exeter Medical School, St Luke's Campus, University of Exeter, Exeter EX1 2LU, UK

<sup>3</sup>Health Statistics Group, PenARC, University of Exeter Medical School, College of Medicine and Health, St Luke's Campus, University of Exeter, Exeter EX1 2LU, UK

<sup>4</sup>Royal Devon and Exeter NHS Foundation Trust, Exeter EX2 5DW, UK

<sup>5</sup>Centre for Research in Aging and Cognitive Health, PenARC, University of Exeter Medical School, St Luke's Campus, University of Exeter, Exeter EX1 2LU, UK

<sup>6</sup>Graduate School of Education, College of Social Sciences and International Studies, St Luke's Campus, University of Exeter, Exeter EX1 2LU, UK

<sup>7</sup>Hospiscare, Exeter EX2 5JJ, UK

<sup>8</sup>Pottles Court Care Home, Days-Pottles Lane, Exminster, Summercourt Care Home, Teignmouth, Exeter EX6 8DG, UK

<sup>9</sup>Mental Health Research Group, University of Exeter Medical School, St Luke's Campus, University of Exeter, Exeter EX1 2LU, UK

<sup>10</sup>The Alan Turing Institute, London, UK

Address correspondence to: Dr Rebecca Abbott, Evidence Synthesis Team, NIHR ARC South West Peninsula (PenARC), University of Exeter Medical School, College of Medicine and Health, St Luke's Campus, University of Exeter, Exeter EX1 2LU, UK. Email: [ra.abbott@exeter.ac.uk](mailto:ra.abbott@exeter.ac.uk)

## Abstract

Approximately two-thirds of hospital admissions are older adults and almost half of these are likely to have some form of dementia. People with dementia are not only at an increased risk of adverse outcomes once admitted, but the unfamiliar environment and routinised practices of the wards and acute care can be particularly challenging for them, heightening their confusion, agitation and distress further impacting the ability to optimise their care. It is well established that a person-centred care approach helps alleviate some of the unfamiliar stress but how to embed this in the acute-care setting remains a challenge. In this article, we highlight the challenges that have been recognised in this area and put forward a set of evidence-based 'pointers for service change' to help organisations in the delivery of person-centred care. The DEMENTIA CARE pointers cover areas of: dementia awareness and understanding, education and training, modelling of person-centred care by clinical leaders, adapting the environment, teamwork (not being alone), taking the time to 'get to know', information sharing, access to necessary resources, communication, involving family (ask family), raising the profile of dementia care, and engaging volunteers. The pointers extend previous guidance, by recognising the importance of ward cultures that prioritise dementia care and institutional support that actively seeks to raise the profile of dementia care. The pointers provide a range of simple to more complex actions or areas for hospitals to help implement person-centred care approaches; however, embedding them within the organisational cultures of hospitals is the next challenge.

**Keywords:** dementia, person-centred care, acute care, dementia-friendly environment, hospital, older people

## Key Points

- Hospitalisation for an older adult with dementia is very challenging.
- We propose 12 'DEMENTIA CARE' pointers for service change, developed from robust evidence and informed by stakeholders.
- The pointers for service change provide actionable strategies relating to personal, environmental and institutional practices.
- Implementing best practice in dementia care needs a hospital wide approach.

## Dementia in the acute care setting

There are over 55 million people worldwide with dementia, and this is expected to double in the next 30 years [1], with the global burden of serious health-related suffering in dementia projected to increase fourfold by 2060 [2]. In the UK, the last 5 years has seen an increase of 35% of unplanned hospital admissions for people with dementia and up to one in four hospital beds are reported to be occupied with someone with dementia [3]. A similar picture is seen in Europe, with studies reporting one in three older adults presenting in hospital emergency departments having some degree of cognitive impairment [4]. People with dementia are twice as likely to have an emergency admission compared to those without [5], and their risk of adverse outcomes once admitted, such as falls, delirium, new infections and physical and cognitive decline is also higher [6, 7]. People with dementia are more likely to spend longer in hospital once they are admitted and have higher rates of readmission once they are discharged [8].

### Challenges of the acute care environment for people living with dementia

The unfamiliar environment and routinised practices of the wards and acute care is particularly challenging for people living with dementia. The absence of family and familiar surroundings, on top of the physical issue leading to the admission, heightens anxieties, confusion and distress. Challenges in communication can impact effective pain medication, hydration, nutrition and all aspects of physical and emotional care. Whilst these challenges have long been recognised [9–11], it remains an ongoing issue [12, 13], and has been further impacted by the COVID-19 pandemic [14, 15]. It is well established that a person-centred care approach helps alleviate some of the unfamiliar stress from being in the acute care environment [13, 16–18]. To embed person-centred care across the hospital environment, the evidence suggests cultural changes are needed at organisational and ward levels [19, 20]. For this to happen, it has been suggested that there needs to be leadership that supports and advocates for workforce capacity to recognise and meet both psychological and physical needs of people with dementia, promotion of physical environments that support familiarisation and social interactions, and an inclusive approach to carers and the development of a culture of sharing knowledge and information across hierarchies and roles [19]. These points have been echoed by Chenoweth et al. [13] who concluded

that person centeredness of hospital care for persons with dementia depends very much on staff knowledge, skill and aptitude for dementia care work, on the hospital systems and work cultures, which shape staff's approach to this work, and staff's acknowledgement of the centrality of the person and their family/carer in healthcare decisions. Sanatinia et al. (2020) also highlighted the need for organisational change but suggested from their own observations that dementia-specific training to a wide range of staff, along with active hands-on support from senior staff, can promote the delivery of person-centred care.

### Caring for persons with dementia in the acute care setting

Whilst the issues of implementing person centred care in this environment are known and contributory factors that impact it are recognised, as highlighted above, practical solutions for addressing the issues are still found wanting. Person-centred care, and how to support it, is a key feature in international guidance for dementia care in the acute care setting (e.g. Alzheimer's Association [21], Alzheimer's Australia [22]). The recent position statement from the British Geriatrics Society Dementia and Related Disorders Special Interest Group sets out the principles of good person-centred care for older people with dementia admitted to acute hospitals [23]. The statement enumerates the expectations and requirements needed to ensure this, relating to leadership and governance, training, the hospital environment, mental health professional service provision, carer involvement and care processes more widely, building on existing organisational-level recommendations [24–26]. In the UK, in 2011 and updated in 2019, the Royal College of Nursing published the SPACE principles (standing for Staff, Partnership, Assessment, Care and Environment). The SPACE principles relate to the five areas considered essential to deliver appropriate care for people with dementia across health and social care settings: staff who are skilled and have time to care, partnership working with carers, assessment, early identification of dementia and post diagnostic support; care and support plans which are person-centred and individual, and environments that are dementia friendly [24]. In 2018, the UK National Dementia Action Alliance (NDAA) 'Hospital Friendly Charter' further built on the SPACE principles, including a checklist for hospitals to self-assess whether dementia-friendly principles were embedded within their organisations [25]. However, implementation

of changes that uphold such principles within hospitals and the acute care environments are not without issues [27, 28], and whilst the principles of best practice are established, little pragmatic guidance exists. We sought to develop a set of evidence-based and actionable pointers for service change to help organisations and staff implement and deliver person-centred care in the acute care setting.

### The DEMENTIA CARE pointers for service change

The pointers for service change were drawn from three linked systematic reviews that explored the experience of care in hospital for persons with dementia, their carers and the staff that care for them, and how it could be improved [17]. The pointers were based on the evidence from these reviews and were informed and shaped by extensive stakeholder involvement [17]. The evidence-based pointers relate to 12 areas of giving or receiving care for people with dementia in the acute care setting and were purposively organised to spell out the acronym DEMENTIA CARE to aid people in remembering them. The specific actionable pointers within each area are presented in Table 1 and described below along with the evidence that underpins them.

#### *Dementia understanding*

There is both a widespread lack of understanding of the reasons people with dementia demonstrate responsive behaviours and a feeling of being ill-equipped by training to respond to them [29–32]. Responsive behaviours are often observed and felt by hospital staff to be challenging and disruptive [30, 33, 34], rather than a form of communication by people with dementia resulting from unmet needs. Staff who have past experience of caring for people with dementia have shown they are able to draw on their skills to interpret non-verbal cues [32, 35], understand behaviours may reflect unmet needs and recognise the importance of ‘building a picture’ to inform their understanding of how to best care for that person [32, 36–39]. Appreciating and understanding the nature of responsive behaviours is crucial for hospital staff across all levels and roles to enable appropriate and compassionate care.

#### *Education and training*

Hospital staff at all levels and roles continue to perceive that they are not adequately trained for caring for people with dementia in the acute care setting [29, 30, 32, 40, 41]. In particular, skills and knowledge of de-escalation are needed [30, 42]. Carers also perceive a lack of training as an issue [43, 44]. Training has been shown to improve staff confidence in providing care [45–48]. Training should start early: care of people with dementia should be included in undergraduate, generic and specialist training of healthcare staff, including higher medical training, and post-registration nursing education programmes. Nursing and medical staff have spoken about the need for training to be face-to-face, dynamic and

delivered by experts; basic e-training is not thought to be sufficient [47].

Evidence indicates that all staff working in any role in the acute care setting should receive basic level dementia awareness training. This would be equivalent to Tier I in the UK Dementia Training Standards Framework [49]. For this to happen, senior management support is needed. Staff in nursing and medical roles on older adult wards need to be supported and resourced to attain more advanced training. In the UK, this would be equivalent to Tier 2 and 3 training of the Dementia Training Standards Framework, which focusses on basic skills and knowledge and leadership, respectively. Training needs to be seen as an essential priority, not a desirable one. Training that does not impact on ward staffing levels may be more achievable than external courses.

#### *Modelling of person-centred care from leadership down*

Improving the experience of dementia care requires more than processes and training programmes: it needs changes to culture, driven by strong and committed leadership. In the most recent national audit of dementia care in general hospitals in the UK, published July 2019 [50], dementia champion representation at directorate and ward level fell from the previous 2017 audit from 83 to 77%, and 94 to 89% respectively [51]. In addition, 23% of hospitals still had no dementia care pathway in place. Leaders, both managerial and clinical, are major influencers in supporting change in practice and role modelling of best practice [16, 42, 52, 53]. Furthermore, by valuing and supporting a person-centred culture, organisational leaders ensure resources are available to support care provision and staff education and training.

#### *Environment*

For people with dementia, the hospital experience can be very disorientating [32, 35, 43, 54–60]. Acute care hospital wards are by their very nature noisy and busy. While this can be stimulating, in the majority of cases, the evidence suggests it adds to the confusion about what is happening and in so doing, heightens fear, anxiety and insecurity [36, 56, 60, 61]. Evidence suggests that staff and carers alike recognise that acute care wards are not the best environment for people with dementia [29, 58, 62]. Changing ward layouts, such as removal of central nursing stations, creating home-like spaces and colours, and adding signage to the ward have all been shown to help improve the experience of care [63, 64]. Spaces that facilitate social engagement and provide opportunity for activity have been shown to help [65–67], but continue to be highlighted by people with dementia and carers as lacking.

Making the personal and physical environment more familiar combats disorientation and lessens the fear and anxiety for people with dementia [60, 63, 68]. This can be helped by (i) limiting staff rotations across wards [37], (ii) fostering an environment that encourages staff, people with dementia and carers to get to know each other [16, 66, 67, 69], (iii) minimising moving people with dementia within and between wards [29, 58] and (iv) encouraging families

**Table 1.** The DEMENTIA CARE pointers for service change

Dementia Understanding	Increase awareness and understanding amongst all hospital staff that responsive behaviours are most likely a communication of unmet needs. Recognise that persons living with dementia cannot always communicate their needs, and may be thirsty or in pain, or may not know where they are?	Communication	Create shared places on the ward for communicating: handovers that contain personal information, not just physical information or safety briefings are likely to help. Reintroduce oneself, remind (who, where, why) and reassure. Involve carers early in discharge planning: beneficial for the persons living with dementia and helps reduce carer anxiety.
Education and training	Basic dementia training needs to be part of routine induction training for all clinical and non-clinical staff. Provide advanced training for staff working on older adult wards, to further their understanding of dementia and give confidence in delivering care. Explore ward-based options for training, including staff across disciplines.	Ask family	Extend visiting hours for family and carers to help improve the experience of care for all. Involve family and carers in decisions about care. Keep family informed. Invite family who are interested in helping to be involved in assisting with care practices (e.g. help with eating, drinking, washing).
Modelling of PCC from leadership down	Encourage senior staff to demonstrate their belief in and understanding of the importance of valuing psychological health of persons living with dementia as this will encourage others to do likewise.	Raise the profile of dementia care.	Prioritise dementia care. Motivate and reward staff to undertake roles and training that champion dementia care.
Environment	Undertake a 'dementia-friendly' environment review and involve persons living with dementia, carers and staff (from a variety of roles) in the review. Avoid moving persons living with dementia where possible and orientate often: clocks, newspapers, signage. Organise staff rotas to maximise familiarity and consistency for persons living with dementia. Encourage personalisation of the space around persons living with dementia (e.g. with photos, favourite throw/blanket).	Engage volunteers	Explore volunteer opportunities with local agencies. Consider having a formal volunteer strategy to maximise the volunteer potential. Manage staff and volunteer expectations regarding the presence and role of volunteers on the ward.
Not alone	Help staff to know they are not alone and support strategies for self-care Create ward cultures that supports staff and encourages them to look after themselves as this will benefit staff and persons living with dementia		
Time	Spend time getting to know persons living with dementia. This will save time across many areas of care		
Information sharing	Make space to document psychological wellbeing and/or distress Use simple systems to identify whether someone has dementia: this can help remind everyone to take more time with care Share personal likes and dislikes, and individual behaviours (preferred name, family situation)		
Access to resources	Tailor activities to the individual to help reduce responsive behaviours Provide access to simple and inexpensive activity resources such as playing cards, newspapers and magazines, as these are easy to replace when thinking about infection control Explore opportunities to access specialist advice		

to personalise the space [68]. Orientation is particularly important for people with dementia arriving on the ward but also throughout their stay.

**Not alone**

Staff often feel challenged and conflicted by their perceived inability to provide optimal care [29, 30, 32, 36, 59, 70]. This can be for a number of reasons, such as the need to focus on tasks or a lack of knowledge, and is perceived as being beyond their control [17]. Although there was

limited evidence on interventions targeted at improving staff wellbeing, working as a team to communicate about specific caring issues and negative experiences, sharing concerns and learning from others have all been shown to help relieve the burden of care [30, 32, 71]. Learning strategies from those in the team who have experience in working with people with dementia about the subtleties of engaging and disengaging is critical for staff emotional wellbeing [59]. Changes to the ward and institutional policies that hamper care will take time, but evidence suggests that small steps to improve care practices will improve the experience of

caring. When staff are able to provide person centred care, this increases experiences of job satisfaction and emotional well-being [17].

### *Time*

Staff perceive 'a lack of time' to be a key reason why optimal care does not always happen [29, 30, 35, 41, 62, 70, 72]. Lack of time can be a result of insufficient staffing or the perceived need to prioritise physical care and hospital routines over time spent on delivering a more person-centred care. People with dementia and their carers also perceive this as an important barrier preventing staff from delivering the best care. Spending a few extra moments with a person with dementia or engaging them in conversation when walking past and acknowledging their presence is important for everyone, but particularly for someone with dementia in an unfamiliar environment [33, 37, 39]. The current evidence suggests that if more time was spent getting to know and understand the people with dementia, time could be saved across many areas of care [17].

### *Information sharing*

Whilst individual staff recognise that sharing information about psychological well-being and distress is as important as medical information, hospital and ward processes often do not facilitate this [29, 30, 40, 41, 57]. If psychological well-being of people with dementia is not routinely recorded, assessing whether there has been a change or whether action is needed is not possible. A lack of documentation about personal preferences and circumstances hampers the ability to deliver person-centred care. Personal information can often be sought several times by a range of different staff, or alternatively not sought at all, both resulting in frustration for carers and the person with dementia [43, 57, 61].

Systems of documentation that encourage families and staff in any role or level to record personal 'likes and dislikes' and make information accessible between staff members are pivotal to good care [16, 62, 63, 73, 74]. Several examples are currently in practice in hospitals throughout the UK, such as 'This is me', 'Who am I' and 'Getting to know me'. Similar examples in other countries, include the 'TOP 5' resource used in Australia and 'All about me' in Canada. Volunteers can also find it useful to have information to hand to help facilitate rapport with individuals [42]. Having systems in place on wards that help staff across all roles and levels identify whether a person has dementia helps foster person-centred care [63]. Examples of current practice in UK hospitals include bed-side symbols in the form of butterflies or small blue forget-me-not flowers and in Australia, a small blue circular 'cognitive impairment identifier': something simple by the bed, which alerts staff to the need to take more time with the person. This is also important as it can help remind staff that they need to (re)introduce themselves each time and remind the person with dementia about the 'who, where and why'.

### *Access to resources*

Adding resources and capacity to acute wards helps to improve the experience of care [16, 65]. Capacity can be in the form of specialist advice, having better access to specialist support such as dementia specialist nurses, liaison psychiatry and geriatricians. Resources and extra capacity can also be provided by therapists and volunteers helping with occupation and activities [42, 74, 75]. The evidence suggests that the change of routine and perception of having nothing to do is disrupting for the person with dementia [43, 60–62]. Activities tailored to individual likes can help reduce responsive behaviours. Having access to simple resources on the ward can help with increasing opportunities for occupation [76, 77].

### *Communication*

People with dementia, carers and staff believe that better communication is key to improving the experience of care [16]. For the person with dementia, this means being aware of where they are and who they are talking to, and more importantly being treated as a person. For the carer, this means being involved and informed about decisions relating to the care of the person with dementia and being respected for the information they hold about them. For carers, evidence suggests that communication about the process of discharge is particularly important [43, 56].

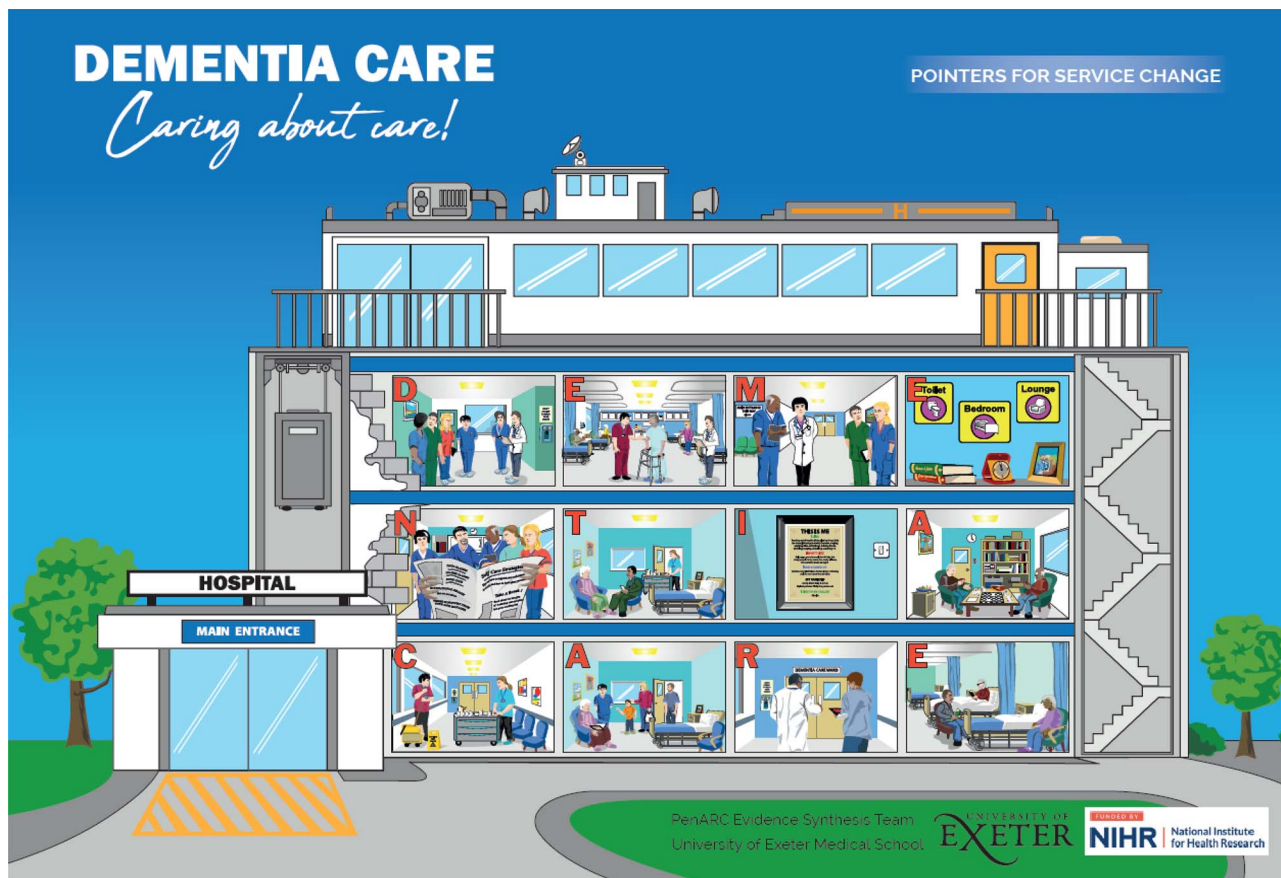
For staff, this means two-way communication across staff roles and levels without the boundaries of hierarchy. The person who gets to know the most about the person with dementia might be the person who makes their tea, the porter who takes them from test to test, or the senior matron who has made a point of getting to know them; and the ward culture needs to foster an approach that encourages and enables all to share useful personal information when they hear it.

### *Ask family*

Presence of family on the ward not only helps people with dementia to feel more secure and less isolated, but also helps reduce the perception of disruption to their usual routine [34, 43, 61, 62]. Family also hold personal knowledge that can help staff deliver person-centred care [35, 61]. For many family members, being able to be with the person with dementia (and feel welcome on the ward) and continue to be part of the care is important for their own health and well-being [16, 29, 43, 56, 61]. For some carers, however, it should also be recognised that this may be a time for respite, or there might be reasons they cannot be involved more [43, 61]. It is particularly important for the family member to be included in decision-making and be kept informed about how the person with dementia is doing [16, 43, 61].

### *Raise the profile of dementia care*

The evidence suggests that through a combination of a lack of confidence, knowledge, and experience and a ward culture



**Figure 1.** The ‘Pointers for Service Change’ in context

that prioritises routine physical care, people with dementia can end up being regarded as low priority compared to others on the ward and not offered the same level or aspects of care [37, 60, 72, 78]. There is evidence that shows that the more rewarding the roles in dementia care are, the more hospital staff will feel encouraged to become involved: staff acting as dementia champions report how the role elicits a sense of achievement [73]. Increased skills, knowledge and status in staff can build to create a culture that values and prioritises the psychological needs of people with dementia alongside their routine-focussed physical needs.

#### Engage volunteers

Volunteers can have a significant impact for the person with dementia in the acute care environment. The evidence suggests that volunteers can help by providing companionship and a sense of comfort, and by assisting people with dementia to engage in social activities [53, 74, 79, 80]. However, it is important to manage expectations of both volunteers and staff when volunteers are introduced on a ward [53]; for volunteers to understand how to evaluate meaningful interactions with people with dementia and feel satisfied in that role, and for staff to be clear about the role of volunteers and be prepared to welcome them on the ward.

An illustration (<https://ink-pot-graphics.com/>) of the overall summary of the pointers for service change is shown

in Figure 1, and an example of an individual pointer for service change is shown in Supplementary File 1.

The DEMENTIA CARE pointers for service change serve to provide a range of simple to more complex actions or areas for hospitals to focus on to foster a good experience of care for people with dementia, from all perspectives. The pointers highlight the importance of staff dementia understanding and staff training, information sharing and communication with people with dementia and carers and the involvement of both in care decisions and practices, ward environment adaptations to meet the needs of people with dementia, and the potential role of volunteers in complementing care by paid staff. Staff training, clear communication and involvement of carers were identified as key factors for ensuring the delivery of high-quality care in a recent UK study exploring organisation and delivery of acute inpatient services for people with dementia [20]. The pointers for service change are particularly pertinent in light of the negative impact of the COVID-19 pandemic on dementia care and provision of nursing care more generally [14, 81, 82]. Hospital leads and carers have reported how ward reorganisations, staff shortages, staff redeployment and visitor restriction policies have inevitably impacted the quality of care for people with dementia in hospital [14].

The pointers for service change cover similar areas of practice to existing UK recommendations (such as the Dementia Action Alliance Dementia Friendly Hospital Charter [25]

and the UK Royal College of Nursing SPACE principles [24]), but extend these to provide practical ideas for service change and are underpinned by substantive evidence from 89 studies [83], guided by extensive stakeholder input. In addition, the pointers address two new areas for organisations to consider not previously covered by the above recommendations: (i) the benefits that a ward culture promoting person-centred care can bring in terms of staff time, well-being and improved care for people with dementia, and (ii) the decisive role of institutional support for such a culture change to materialise. The importance of these are highlighted in two recent implementation studies. Implementation of a programme, which aimed to improve the care of people with dementia in hospital across nine NHS trusts in the UK, found the outcomes were most positive when the senior management were fully in support of the programme [84]. Implementation of a ‘Dementia Care Hospital Programme’ trialled across three metropolitan and one regional Australian hospitals, which focussed on alerting staff to those with dementia and equipping staff with key communication strategies, resulted in an improvement in staff confidence, comfort and job satisfaction when caring for patients with dementia [85].

Both the programme implementation studies above and the findings from the systematic reviews that informed the DEMENTIA CARE pointers for service change indicate that significant improvements in hospital dementia care are possible through simple changes but that successful implementation is likely to require organisational support. Whilst the involvement of clinical and non-clinical staff is important for driving cultural change, high-level organisational commitment and support is essential for sustaining and supporting change [20, 21, 85]. Recognition that for priorities of care to change there needs to be a change in the ‘culture’ within organisations and at the ward level is well documented in the literature [7, 31, 86, 87]. Handley et al. [88] suggest that cultural change in this area needs organisations and leaders to legitimise the priority of dementia care [88]. This is recognised in the pointers that we present as ‘raising the profile of dementia care’.

### Final thoughts

Hospitalisation for an older adult with dementia remains very challenging. Implementing best practice in dementia care needs a hospital wide approach. Increase in workforce capacity, physical environments that support familiarisation, social interaction and activities, inclusive carer policies and cultures of sharing knowledge have all shown promise in improving dementia care in the acute-care setting. The evidence-based DEMENTIA CARE pointers for service change presented here provide a range of simple to more complex actions or areas for hospitals to help implement such approaches. How to share and embed them within the organisational cultures of hospitals is the next challenge.

**Supplementary Data:** Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

**Declaration of Conflicts of Interest:** None.

**Declaration of Sources of Funding:** This article presents independent research funded by the National Institute for Health Research (NIHR) Applied Research Collaboration (ARC) South West Peninsula. The views expressed in this publication are those of the author(s) and not necessarily those of the National Health Service, the NIHR or the Department of Health and Social Care. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

**Acknowledgements:** The authors would like to acknowledge the work and support during the original project of Ruth Gwernan-Jones, Martin James, Julia Burton and Sue Lawrence.

### References

1. Alzheimer’s Disease International. *Dementia* Stat 2022 [cited 12 January 2022 ] Available at: <https://www.alzint.org/about/dementia-facts-figures/dementia-statistics/>.
2. Sleeman KE, de Brito M, Etkind S *et al*. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. *Lancet Glob Health* 2019; 7: e883–92.
3. Torjesen I. Figures show big increase in emergency admissions for dementia patients. *BMJ* 2020; 368: m249. <https://doi.org/10.1136/bmj.m249>.
4. Mickelson Welding N, Kirkevold M. What older people and their relatives say is important during acute hospitalisation: a qualitative study. *BMC Health Serv Res* 2022; 22: 578. <https://doi.org/10.1186/s12913-022-07981-9>.
5. Sommerlad A, Perera G, Mueller C *et al*. Hospitalisation of people with dementia: evidence from English electronic health records from 2008 to 2016. *Eur J Epidemiol*. 2019; 34: 567–77.
6. Fogg C, Griffiths P, Meredith P, Bridges J. Hospital outcomes of older people with cognitive impairment: an integrative review. *Int J Geriatr Psychiatry* 2018; 33: 1177–97.
7. Dewing J, Dijk S. What is the current state of care for older people with dementia in general hospitals? A literature review *Dementia* 2016; 15: 106–24.
8. Fogg C, Meredith P, Culliford D, Bridges J, Spice C, Griffiths P. Cognitive impairment is independently associated with mortality, extended hospital stays and early readmission of older people with emergency hospital admissions: A retrospective cohort study. *Int J Nurs Stud* 2019; 96: 1–8. <https://doi.org/10.1016/j.ijnurstu.2019.02.005>.
9. Confederation NHS. *Acute awareness: improving hospital care for people with dementia*. London: NHS Confederation, 2010.
10. Tadd W, Hillman A, Calnan M, Calnan S, Read S, Bayer A. From Right place–Wrong person, to Right place–Right person: dignified care for older people. *J Health Serv Res Policy* 2012; 17: 30–6.
11. Harwood RH. Dementia for hospital physicians. *Clin Med* 2012; 12: 35–9.
12. Scerri A, Scerri C, Innes A. The perceived and observed needs of patients with dementia admitted to acute medical wards. *Dementia (London)* 2020; 19: 1997–2017.

13. Chenoweth L, Cook J, Williams A. Perceptions of care quality during an acute hospital stay for persons with dementia and family/carers. *Healthcare* 2021; 9: 1176. <https://doi.org/10.3390/healthcare9091176>.
14. Royal College of Psychiatrists. Impact of the COVID-19 pandemic on hospital care for people with dementia: feedback from carers/families and hospital leads for dementia. London: Royal College of Psychiatrists, 2021.
15. Burns A, Lobo A, Olde Rikkert M *et al.* COVID-19 and dementia: experience from six European countries. *Int J Geriatr Psychiatry* 2021; 36: 943–9.
16. Spencer K, Foster P, Whittamore KH, Goldberg SE, Harwood RH. Delivering dementia care differently—evaluating the differences and similarities between a specialist medical and mental health unit and standard acute care wards: a qualitative study of family carers' perceptions of quality of care. *BMJ Open* 2013; 3: e004198. <https://doi.org/10.1136/bmjopen-2013-004198>.
17. Gwernan-Jones R, Abbott R, Lourida I *et al.* The experiences of hospital staff who provide care for people living with dementia: a systematic review and synthesis of qualitative studies. *Int J Older People Nurs* 2020; 15: e12325. <https://doi.org/10.1111/opn.12325>.
18. Fazio S, Pace D, Flinner J, Kallmyer B. The fundamentals of person-centered care for individuals with dementia. *Gerontologist* 2018; 58: S10–9.
19. Abbott RA, Cheeseman D, Hemsley A, Thompson Coon J. Can person-centred care for people living with dementia be delivered in the acute care setting? *Age Ageing* 2021; 50: 1077–80.
20. Sanatinia R, Crawford MJ, Quirk A *et al.* Identifying features associated with higher-quality hospital care and shorter length of admission for people with dementia: a mixed-methods study. 2020. Southampton (UK): NIHR Journals Library; 2020. <https://doi.org/10.3310/hsdr08220>.
21. Fazio S, Pace D, Maslow K, Zimmerman S, Kallmyer B. Alzheimer's association dementia care practice recommendations. *Gerontologist* 2018; 58: S1–9.
22. Alzheimer's Australia. Dementia Care in the Acute Hospital Setting. Issues and Strategies 2014. [https://www.dementia.org.au/sites/default/files/Alzheimers\\_Australia\\_Numbered\\_Publication\\_40.PDF](https://www.dementia.org.au/sites/default/files/Alzheimers_Australia_Numbered_Publication_40.PDF).
23. British Geriatric Society Dementia and Related Disorders Special Interest Group, H., R., BGS Position Statement: Person-centred acute hospital care for people with dementia. 2022 [cited 9 January 2022] Available at: <https://www.bgs.org.uk/resources/bgs-position-statement-person-centred-acute-hospital-care-for-people-with-dementia>.
24. Royal College of Nursing. Commitment to the care of people with dementia in general hospitals (SPACE principles). 2011 [cited August 2019] Available at: <https://www.rcn.org.uk/professional-development/publications/pub-004176>.
25. National Dementia Action Alliance, N. Dementia-Friendly Hospital Charter. London: Dementia Action Alliance, 2018.
26. Dementia: assessment, management and support for people living with dementia and their carers; NG97. London: National Institute for Health and Care Excellence (NICE); 2018.
27. Cheong CY, Tay FHE, Choo J, Yap PLK. Person-centred dementia care in an acute hospital: experiences from nurses working in a specialized dementia unit. *Dement Geriatr Cogn Disord* 2021; 50: 250–7.
28. Røsvik J, Rokstad AMM. What are the needs of people with dementia in acute hospital settings, and what interventions are made to meet these needs? A systematic integrative review of the literature. *BMC Health Serv Res* 2020; 20: 723. <https://doi.org/10.1186/s12913-020-05618-3>.
29. Nilsson A, Rasmussen BH, Edvardsson D. Falling behind: a substantive theory of care for older people with cognitive impairment in acute settings. *J Clin Nurs* 2013; 22: 1682–91.
30. Nilsson A, Rasmussen BH, Edvardsson D. A threat to our integrity—Meanings of providing nursing care for older patients with cognitive impairment in acute care settings. *Scand J Caring Sci* 2016; 30: 48–56.
31. Turner A, Eccles FJR, Elvish R, Simpson J, Keady J. The experience of caring for patients with dementia within a general hospital setting: a meta-synthesis of the qualitative literature. *Aging Ment Health* 2017; 21: 66–76.
32. Berg A, Hallberg IR, Norberg A. Nurses' reflections about dementia care, the patients, the care and themselves in their daily caregiving. *Int J Nurs Stud* 1998; 35: 271–82.
33. Edvardsson D, Sandman P-O, Rasmussen B. Forecasting the ward climate: a study from a dementia care unit. *J Clin Nurs* 2012; 21: 1136–14.
34. Porock D *et al.* Disruption, control and coping: responses of and to the person with dementia in hospital. *Ageing & Society* 2015; 35: 37–63.
35. Lichtner V, Dowding D, Allcock N *et al.* The assessment and management of pain in patients with dementia in hospital settings: a multi-case exploratory study from a decision making perspective. *BMC Health Serv Res* 2016; 16: 427. <https://doi.org/10.1186/s12913-016-1690-1>.
36. Bryon E, Gastmans C, Dierckx de Casterle B. Involvement of hospital nurses in care decisions related to administration of artificial nutrition or hydration (ANH) in patients with dementia: a qualitative study. *Int J Nurs Stud* 2010; 47: 1105–16.
37. Carr TJ, Hicks-Moore S, Montgomery P. What's so big about the 'little things'. *Dementia: the international journal of social research and practice* 2011; 10: 399–414.
38. Norman R. Observations of the experiences of people with dementia on general hospital wards. *Journal of Research in Nursing* 2006; 11: 453–65.
39. Clissett P, Porock D, Harwood RH, Gladman JRF. The challenges of achieving person-centred care in acute hospitals: a qualitative study of people with dementia and their families. *Int J Nurs Stud* 2013; 50: 1495–503.
40. Dowding D, Lichtner V, Allcock N *et al.* Using sense-making theory to aid understanding of the recognition, assessment and management of pain in patients with dementia in acute hospital settings. *Int J Nurs Stud* 2016; 53: 152–62.
41. Turner A, Eccles F, Keady J, Simpson J, Elvish R. The use of the truth and deception in dementia care amongst general hospital staff. *Aging Ment Health* 2017; 21: 862–9.
42. Naughton C, Beard C, Tzouvara V *et al.* A feasibility study of dementia communication training based on the VERA framework for pre-registration nurses: Part II impact on student experience. *Nurse Educ Today* 2018; 63: 87–93.
43. Jurgens FJ, Clissett P, Gladman JRF, Harwood RH. Why are family carers of people with dementia dissatisfied with general hospital care? A qualitative study *BMC Geriatrics* 2012; 12: 57. <https://doi.org/10.1186/1471-2318-12-57>.
44. Kelley RS. Knowing the Person': The Use of Families' Knowledge and Expertise in Delivering Care and Valued Outcomes



- for People with Dementia on Acute Wards. Ann Arbor: University of Leeds (United Kingdom), 2017.
45. Palmer JL, Lach HW, McGillick J, Murphy-White M, Carroll MB, Armstrong JL. The dementia friendly hospital initiative education program for acute care nurses and staff. *J Contin Educ Nurs* 2014; 45: 416–24.
  46. Sampson EL, Vickerstaff V, Lietz S, Orrell M. Improving the care of people with dementia in general hospitals: evaluation of a whole-system train-the-trainer model. *Int Psychogeriatr* 2017; 29: 605–14.
  47. Surr CA, Smith SJ, Crossland J, Robins J. Impact of a person-centred dementia care training programme on hospital staff attitudes, role efficacy and perceptions of caring for people with dementia: A repeated measures study. *Int J Nurs Stud* 2016; 53: 144–51.
  48. Luxford K, Axam A, Hasnip F *et al.* Improving clinician-carer communication for safer hospital care: a study of the 'TOP 5' strategy in patients with dementia. *International J Qual Health Care* 2015; 27: 175–82.
  49. Skills for Health; Health Education England; Skills for Care. Dementia Training Standards Framework. vol. 1-95. Health Education England and Skills for Care: Skills for Health, 2018.
  50. Royal College of Psychiatrists. National Audit of Dementia Care in General Hospitals 2018–19: Round Four Audit Report 2019. London: Royal College of Psychiatrists.
  51. Royal College of Psychiatrists. National Audit of Dementia Care in General Hospitals 2016–2017: Third Round of Audit Report. London: Royal College of Psychiatrists London, 2017.
  52. Schindel Martin L, Gillies L, Coker E *et al.* An Education Intervention to Enhance Staff Self-Efficacy to Provide Dementia Care in an Acute Care Hospital in Canada. *Am J Alzheimers Dis Other Demen* 2016; 31: 664–77.
  53. McDonnell A, McKeown J, Keen C, Palfreyman J, Bennett N. Introducing on-ward volunteers to work with patients with dementia. *Nurs Older People* 2014; 26: 28–33.
  54. Edvardsson D, Nordvall K. Lost in the present but confident of the past: experiences of being in a psycho-geriatric unit as narrated by persons with dementia. *J Clin Nurs* 2008; 17: 491–8.
  55. Emmett C, Poole M, Bond J, Hughes JC. Homeward bound or bound for a home? Assessing the capacity of dementia patients to make decisions about hospital discharge: comparing practice with legal standards. *Int J Law Psychiatry* 2013; 36: 73–82.
  56. Gilmour JA. Dis/integrated care: family caregivers and in-hospital respite care. *J Adv Nurs* 2002; 39: 546–53.
  57. Jensen AM, Pedersen BD, Olsen RB, Hounsgaard L. Medication and care in Alzheimer's patients in the acute care setting: a qualitative analysis. *Dementia (London)*. 2019; 18: 2173–88. <https://doi.org/10.1177/1471301217743306>.
  58. Teodorczuk A, Mukaetova-Ladinska E, Corbett S, Welfare M. Deconstructing dementia and delirium hospital practice: using cultural historical activity theory to inform education approaches. *Advances in Health Sciences Education* 2015; 20: 745–64.
  59. Bailey S *et al.* The emotional labour of health-care assistants in inpatient dementia care. *Ageing and Society* 2015; 35: 246–69.
  60. Digby R, Lee S, Williams A. The liminality of the patient with dementia in hospital. *J Clin Nurs* 2018; 27: e70–9.
  61. Kelley RS, Godfrey M, Young J. The impacts of family involvement on general hospital care experiences for people living with dementia: an ethnographic study. *Int J Nurs Stud* 2019; 96: 72–81.
  62. Goldberg SE, Whittamore KH, Pollock K, Harwood RH, Gladman JRF. Caring for cognitively impaired older patients in the general hospital: a qualitative analysis of similarities and differences between a specialist Medical and Mental Health Unit and standard care wards. *Int J Nurs Stud* 2014; 51: 1332–43.
  63. Brooke J, Semlyen J. Exploring the impact of dementia-friendly ward environments on the provision of care: a qualitative thematic analysis *Dementia (London)*. 2019; 18: 685–700.
  64. Margot-Cattin I, Nygård L. Access technology and dementia care: influences on residents' everyday lives in a secure unit. *Scand J Occup Ther* 2006; 13: 113–24.
  65. Goldberg SE, Bradshaw LE, Kearney FC *et al.* Care in specialist medical and mental health unit compared with standard care for older people with cognitive impairment admitted to general hospital: Randomised controlled trial (NIHR TEAM trial). *BMJ (Online)* 2013; 347:1–13. <https://doi.org/10.1136/bmj.f4132>.
  66. St John K, Koffman J. Introducing Namaste Care to The Hospital Environment: A Pilot Study. *Annals of Palliat Med* 2017; 6: 354–64.
  67. Daykin N, Parry B, Ball K *et al.* The role of participatory music making in supporting people with dementia in hospital environments. *Dementia* 2017; 17: 686–701.
  68. Edvardsson D, Winblad B, Sandman P-O. Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *The Lancet Neurology* 2008; 7: 362–7.
  69. Brooke J, Stiell M. Development of clinical and inter-personal skills to support people living with dementia. *Journal of Paramedic Practice* 2017; 9: 348–53.
  70. Byers DC, France NEM. The lived experience of registered nurses providing care to patients with dementia in the acute care setting: a phenomenological study. *Int J Hum Caring* 2008; 12: 44–9.
  71. Bryon E, Dierckx de Casterle B, Gastmans C. Because we see them naked' - nurses' experiences in caring for hospitalized patients with dementia: considering artificial nutrition or hydration (ANH). *Bioethics* 2012; 26: 285–95.
  72. Moyle W, Borbasi S, Wallis M, Olorenshaw R, Gracia N. Acute care management of older people with dementia: a qualitative perspective. *J Clin Nurs* 2011; 20: 420–8.
  73. Wilkinson I, Coates A, Merrick S, Lee C. Junior doctor dementia champions in a district general hospital (innovative practice). *Dementia* 2016; 15: 263–72.
  74. Wong Shee A, Phillips B, Hill K, Dodd K. Feasibility and acceptability of a volunteer-mediated diversionary therapy program for older patients with cognitive impairment. *Geriatr Nurs* 2014; 35: 300–5.
  75. Bateman C, Anderson K, Bird M, Hungerford C. Volunteers improving person-centred dementia and delirium care in a rural Australian hospital. *Rural Remote Health* 2016; 16: 3667. <https://doi.org/10.22605/RRH3667>.
  76. DiNapoli E, Scogin F, Bryant AN, Sebastian S, Mundy MJ. Effect of individualized social activities on quality of life among older adults with mild to moderate cognitive impairment in a geriatric psychiatry facility. *Aging Ment Health* 2016; 20: 262–70.

77. Gitlin LN *et al.* Feasibility of the tailored activity program for hospitalized (TAP-H) patients with behavioral symptoms. *Gerontologist* 2016; 13: 13.
78. Clissett P, Porock D, Harwood RH, Gladman JRF. The responses of healthcare professionals to the admission of people with cognitive impairment to acute hospital settings: an observational and interview study. *J Clin Nurs* 2014; 23: 1820–9.
79. Simpson K. Improving acute care for patients with dementia. *Nurs Times* 2016; 112: 22–4.
80. Tay FHE, Thompson CL, Nieh CM *et al.* Person-centered care for older people with dementia in the acute hospital. *Alzheimer's and Dementia: Translational Research and Clinical Interventions* 2018; 4: 19–27.
81. Whear R, Abbott RA, Bethel A *et al.* Impact of COVID-19 and other infectious conditions requiring isolation on the provision of and adaptations to fundamental nursing care in hospital in terms of overall patient experience, care quality, functional ability, and treatment outcomes: systematic review. *J Adv Nurs* 2022; 78: 78–108.
82. Masterson-Algar P, Allen MC, Hyde M, Keating N, Windle G. Exploring the impact of Covid-19 on the care and quality of life of people with dementia and their carers: A scoping review. *Dementia* 2022; 21: 648–76.
83. Gwernan-Jones RLI, Abbott RA *et al.* Understanding and improving experiences of care in hospital for people living with dementia, their carers and staff: three systematic reviews. *sHealth Services and Delivery Research*, Southampton. vol. 8. UK: NIHR Journals Library, 2020.
84. Evans S, Brooker D, Thompson R *et al.* Introduction to the transforming dementia care in hospitals series. *Nurs Older People* 2015; 27: 18–24.
85. Murray ME, Wong Shee A, West E *et al.* Impact of the dementia care in hospitals program on acute hospital staff satisfaction. *BMC Health Serv Res* 2019; 19: 680. <https://doi.org/10.1186/s12913-019-4489-z>.
86. Digby R, Lee S, Williams A. The experience of people with dementia and nurses in hospital: an integrative review. *J Clin Nurs* 2017; 26: 1152–71.
87. Reilly JC, Houghton C. The experiences and perceptions of care in acute settings for patients living with dementia: A qualitative evidence synthesis. *Int J Nurs Stud* 2019; 96: 82–90.
88. Handley M, Bunn F, Goodman C. Supporting general hospital staff to provide dementia sensitive care: a realist evaluation. *Int J Nurs Stud* 2019; 96: 61–71.

**Received 21 February 2022; editorial decision 14 June 2022**