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Improving experiences of hospital care for people living with dementia, their carers and the hospital staff who care for them

Briefing Paper **July 2020**

Currently about 40% of people admitted to hospital over the age of 70 have dementia, and this number is growing. Being in hospital can be particularly confusing and challenging not only for people living with dementia, but also for their carers and the staff that care for them. Negative experiences can influence long term health and decisions about the future for people living with dementia and their families. The need to improve the experience of care in hospital for people living with dementia is well recognised, but it's not clear how best to do this.

This is a summary of research project in which we undertook three linked systematic reviews to bring together the available information about the experience of care for people in hospital with dementia from the perspectives of those giving and receiving care.

We wanted to find out:

- What is it like for people living with dementia and their families when they are in hospital?
- What is it like for staff who are caring for people with dementia in hospital?
- What can we do to improve the experience of care in hospital for people with dementia, their families and the staff who care for them?

Please use this QR code to navigate to the project website

Throughout the project we worked with a group of current and prior carers, healthcare practitioners and researchers who helped us design the research and interpret the findings. We also discussed the findings with other healthcare practitioners and carers, and together we developed the DEMENTIA CARE pointers for service change (shown overleaf) —12 institutional and environment practices and processes that warrant consideration for those aiming to improve the experience of care in hospital for people living with dementia, their carers and staff.

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Dementia understanding

- Increase awareness and understanding amongst all hospital staff that responsive behaviours are most likely a communication of unmet needs
- Recognise that people living with dementia cannot always communicate their needs, and may be thirsty or in pain, or may not know where they are?

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

Modelling person centred care from leadership down

- Encourage senior staff to demonstrate their belief in and understanding of the importance of valuing psychological health of people living with dementia as this will encourage others to do likewise

Environment

- Undertake a 'Dementia-friendly' environment review and involve people living with dementia, carers and staff (from a variety of roles) in the review
- Avoid moving people living with dementia where possible and orientate often: clocks, newspapers, signage
- Organise staff rotas to maximise familiarity and consistency for people living with dementia
- Encourage personalisation of the space around people living with dementia (e.g. with photos, favourite throw/blanket)

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 people living with dementia

Time

- Spend time getting to know people 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

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 people living with dementia and helps reduce carer anxiety

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)

Raise the profile of dementia care

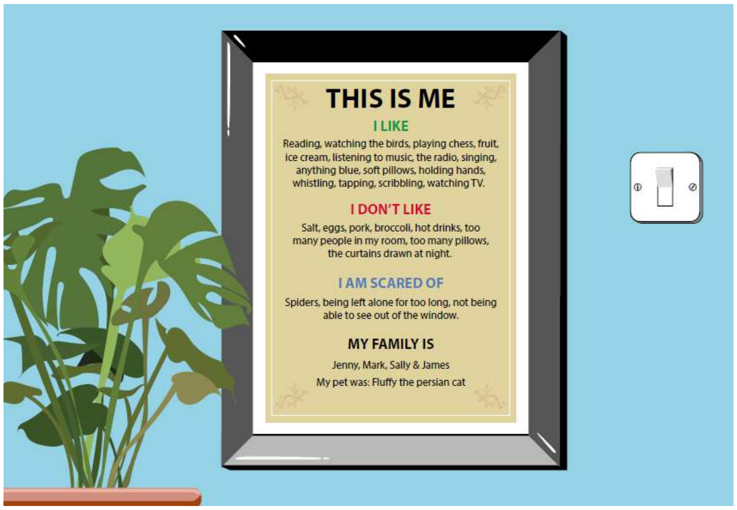
- Prioritise dementia care
- Motivate and reward staff to undertake roles and training that champion dementia care

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

What did we learn?

These reviews show that for people living with dementia being in hospital is dynamic and complex, and is impacted by a range of personal, institutional and environmental factors. Even though for many years person-centred care for people living with dementia has been supported as best practice in hospitals, the evidence we identified suggests that this is still not happening consistently. The effect of this is not only a poor experience of care for people living with dementia and their carers, but also a detrimental effect on staff emotional wellbeing as a result of staff not being able to give the care they want to provide.



This image depicts 'I – information sharing'.

The evidence in our reviews indicate that using simple systems to identify whether someone has dementia can help remind everyone to take more time with care.

The DEMENTIA CARE Pointers for Service Change highlight areas for consideration for those aiming to improve the experience of care in hospital for people living with dementia, their carers and staff.

How did we do this research?

Finding the literature: We searched 16 bibliographic databases, the references and citations of included sources, relevant reviews and websites, and contacted authors of relevant studies.

Eligibility criteria: We included qualitative studies on the experience of care, and qualitative and quantitative studies on the experiences, effectiveness and cost-effectiveness of approaches to improve care in hospital, from the perspective of people living with dementia, their carers or hospital staff.

Study selection, data extraction, study quality and synthesis: All stages were completed independently by two reviewers. Studies describing the experiences of people living with dementia, their families or hospital staff receiving or delivering care were brought together by comparing and synthesising study themes and concepts. Studies of effectiveness and cost effectiveness of interventions to improve experience of care were presented in tables and described narratively. The reviews were then mapped together in an overarching synthesis and the findings discussed with current and prior carers, healthcare practitioners and researchers.

Where was the evidence from?

We included 77 qualitative studies in the review but 35 studies were prioritised in order to manage the large number of studies. We identified 25 quantitative studies all of which were included in the review.

Overall, 41 studies were conducted in the UK, 19 in the rest of Europe, 17 in the USA and Canada, 19 in Australia and New Zealand, and 3 in Asia.

Contact Us

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This image depicts 'N – not alone'. The evidence in our reviews indicate that helping staff to know that they are not alone and supporting strategies for self-care can benefit staff and people living with dementia.

What do we mean by 'experience of care'? And 'carers'?

We defined 'carers' as family or friends who provide regular, informal care to people living with dementia

We defined 'experience of care' as "the extent to which a person perceives that their needs arising from physical and emotional aspects of being ill are met"

The project was conducted by Ruth Gwernan-Jones, Ilianna Lourida, Rebecca Abbott, Morwenna Rogers, Colin Green, Susan Ball, Linda Clare, Darren Moore, David Llewellyn and Jo Thompson Coon from the University of Exeter, Anthony Hemsley and Debbie Cheeseman from Royal Devon and Exeter NHS Foundation Trust, Julia Burton and Sue Lawrence from the Alzheimer's Society Research Network, Martyn Rogers from Age UK Exeter, Chrissy Hussey and Tina Naldrett from Hospiscare and George Coxon from Devon Care Kitemark. Our Project Advisory Group and contributed to all stages of the project.

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More information including a link to the full report can be found on the project webpage.