Learning and leading in advanced dementia care

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Paper 4: Learning and Leading in Advanced Dementia Care

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Abstract:	Paper four in this series explores learning and leadership in advanced dementia care. This outlines current learning opportunities about advanced dementia and what developments are needed. The need for strong leadership at all levels is explored, particularly in care settings.
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Paper 4: Learning and Leading in Advanced Dementia Care (word count 4370)

Rhoda Macrae, Raymond Duffy, Barbara Lawson

Abstract

Paper four in this series explores learning and leadership in advanced dementia care. This outlines current learning opportunities about advanced dementia and what developments are needed. The need for strong leadership at all levels and settings is explored.

Introduction

As Tolson and Brown (2019) have stated within the first article in this series on advanced dementia care, when practitioners lack knowledge, do not have access to expert nurse role models and leaders and work in impoverished care environments rather inevitably poor standards of care will continue. The Global Action Plan (WHO, 2017) and national dementia strategies worldwide all highlight the necessity for strong leadership when providing dementia care particularly at a local level.

Leadership involves a clearly formed idea of what you want to achieve and what that will look like when care practices are improved. Leadership does not rely on a title or position, indeed the Nursing and Midwifery Council (NMC) Code states that everyone has the potential to exercise leadership (Nursing and Midwifery Council, 2018) regardless of whether or not they occupy a formal leadership role. In Scotland, the Scottish Social Services Council (SSSC) in their "Step into Leadership" learning pathway (SSSC, 2018) suggest that leadership is a devolved responsibility and that all frontline care workers can and should lead by using their initiative to support individuals and families, inspiring colleagues to think differently and supporting others to learn and develop. It follows that those in leadership roles need educational and organisational support to develop and provide the leadership skills required to optimise their potential to lead and teach others.

This article rather than focusing on the difference between leadership and management, or leadership qualities, styles and generic toolkits will signpost resources and educational opportunities that can support practitioners to advance their practice and develop their leadership skills in relation to advanced dementia care. It is with this in mind that it explores the challenges of educating those people who care for the person with advanced dementia. It will also outline some educational opportunities and programmes before illustrating how one nurse leads advanced dementia care in practice.

Who cares for people with advanced dementia?

Advanced dementia can last many years, indeed often longer than the earlier part of the illness trajectory (Reisberg et al., 2006). People living with advanced dementia are often frail, physically diminished and heavily reliant on the support of others for their continued health and wellbeing. If they are over 65 years they are likely to have on average four comorbidities while people of a similar age without dementia, have on average two (Poblador-Plou et al 2014). A consequence is that people living with dementia are most likely to be admitted to hospital in the UK with avoidable conditions: a fall, fractured hip, urinary tract infection and chest infection (Scrutton and Brancati 2016). They are also over three times more likely to die during their first admission to hospital for an acute medical condition than those admitted without dementia (Scrutton and Brancati 2016). These complex physical healthcare needs must be addressed in tandem with their psychosocial and spiritual needs. The place of care for those living with advanced dementia may include the family home, care homes, hospitals and hospices and specialist NHS continuing care facilities. The place of care is also likely to change during the months or years they experience advanced dementia with some of these moves due to changing healthcare needs. It is also known that hospital admissions increase in the last few months of life (Gardiner et al, 2013) and that up to 55% of those with advanced dementia in their last years of life in England, will die in a care home (Sleeman et al, 2014).

This means that nurses working in all settings have an important role in providing good advanced dementia care. It is worthwhile highlighting that nurses working in care homes are in a pivotal position to lead advanced dementia care, as they are most likely to be supporting the frailest people in the most advanced stages. It is however essential to ensure all nurses are not only equipped with specialist knowledge and skills in advanced dementia care, but also the leadership skills to implement such care. This presents a challenge.

Workforce issues such as the shortage of registered nurses and the recruitment and retention challenges faced by care homes and care at home services continue to intensify (Scottish Care, 2018; Buchan et al 2017). Moreover current educational opportunities vary in availability, accessibility effectiveness and quality (Jack-Waugh and Brown, 2019). These challenges, coupled with a lack of investment in cultivating nurse leaders and a reduced investment in the post qualification education of nurses have created a perfect storm. The unfortunate reality for many nurses and dementia care staff is that they are trying to provide the best care they can, while facing feelings of helplessness and dissatisfaction at not being able to provide the most appropriate care consistently. So during a period where considerable economic and social pressures on services exist (Buchan et al, 2017), what resources are available to help develop the learning and leadership in advanced dementia care that is required?

Dementia knowledge and skills frameworks

The national education and development frameworks of all four nations set out the core skills and knowledge that, not just nurses, but all health and social care staff should aspire to achieve. Not only are they not specific to particular professions they also apply regardless of the care setting (Skills for Health, Health Education England and Skills for Care, 2018; Scottish Government, 2010; Care Council for Wales, NHS Wales, NHS Public Health Wales and the Welsh Government, 2016; Health and Social Care Board, 2016).

However, none of these frameworks are mandatory, which means that some organisations will adopt and implement them and others will not. Moreover, the application and monitoring of these frameworks in both pre and post-qualification health professional training is inconsistent across the UK (Jack-Waugh and Brown, 2019). This situation led the Higher Education for Dementia Network (HEDN) arguing that this is a task that needs to be taken up by the Professional Regulatory Bodies both at undergraduate and post-graduate levels. They recommend that reference to such frameworks would ensure a more consistent and rigorous approach to dementia education nationally (Knifton et al, in press).

The 2016, Making a difference in Dementia: Nursing Vision and Strategy, set out how nursing could maximise its unique contribution to high quality compassionate care and support for people with dementia and their family carers (Department of Health, 2016). The National Institute of Health and Care Excellence (NICE) Guidance (NICE, 2018) also includes useful guidance including helpful sections on advanced care planning and palliative care, however NICE (2018) fails to identify the complex skills and knowledge required to deliver and lead high quality advanced dementia care.

The challenge posed by the complex needs of people living with advanced dementia needs to be addressed within the education of both current and future nurses and other allied health and social care professionals. This has direct repercussions for Universities and other education providers who are required to adjust their curriculae to address future demand. The curriculum framework developed by the Higher Education Dementia Network (2012) (See https://www.dementiauk.org/for-professionals/hedn-and-curriculum-for-dementia-education/) was designed to inform the various higher education courses in dementia care, principally at post-graduate level. However, is it difficult to know the extent to which the framework is applied (Banarjee et al., 2017). Even less is known about how much of the dementia education provided, focusses on advanced dementia care (Hvalič-Touzery, et al., 2018).

Positive learning and leading in advanced dementia care

There are specific competencies for nurses who have specialised in dementia care. However, the skills and knowledge required to support not only the person, but also their family and friends is still largely unexamined and such work needs to be undertaken urgently. Despite the need for a closer inspection of workforce preparedness for learning and leading good advanced dementia care, there are some areas where positive educational practice exists. Two of the best developed approaches are the Admiral Nursing Service in England and the National Dementia Champions Programme in Scotland.

There are currently approximately 270 Admiral Nurses in the UK. The Admiral Nurse Competency Framework (Dementia UK, 2018) facilitates professional development and draws upon a range of guidance including that from the NMC (2018). The framework has three levels and six competency areas to allow Admiral Nurses to develop practice and maintain a professional portfolio of their practice across each level and is available at https://www.dementiauk.org/for-professionals/admiral-nurse-competency-framework/.

A recent small scale study identified that a large part of the Admiral Nurse role is supporting the wellbeing and positive relationships between the person living with dementia and their principal carer (Evans et al., 2018). The case management approach that the Admiral Nurse approach advocates, enables the facilitation of a holistic assessment using the Admiral Nurse Assessment Framework in order to identify and predict which services and supports might be needed next, in what is recognised as an ever changing, complex and sensitive situation (Dening et al, 2017). Admiral Nurses also have to be able to engage in advanced care planning and sensitively facilitate exploration of the carers' understanding and emotional needs in relation to the condition and its effects. The skills that Admiral Nurses called on time and time again were:

- advanced communication skills
- reflective practice
- emotional self-awareness

Although the Admiral Nurse education does not have a specific advanced dementia care focus, it does include education on advanced dementia and end of life care, with some Admiral Nurses currently based in hospices. Evans et al. (2018) concluded that comprehensive training in all these areas together with effective clinical supervision were essential to underpin effective and sustainable advanced dementia care practice.

Scotland's Dementia Champions Programme is another example of how to educate health and social professionals to lead change and improve care experience for people with dementia, their families

and carers (Jack-Waugh et al, 2018). This blended learning programme with 5 days of face to face teaching and learning contains all the features and more that have been identified as being effective (Surr and Gates, 2017). People living with dementia their family and carers are partners in the development and teaching. It includes an experiential, interactive rights-based approach that uses simulation, skills and practice-based learning to boost participants' values, attitudes and knowledge. The programme is underpinned by appreciative enquiry and a blended learning approach. Practice based assignments are designed to support participants to collaboratively identify care practices and or processes that would improve the care experience for people living with dementia and their supporters. Assignments also ask participants to design an action plan to implement these changes over time. Participation before during and after the programme, is supported by personal tutors, Alzheimer Scotland Nurse/Allied Health Professional consultants and Scottish Social Services Council staff, this means that the programme sits within an infrastructure of policy, education and practice support. (Brown et al., 2017).

It is difficult to know how widespread specially commissioned programmes on advanced dementia are. One example is the Dementia Specialist Improvement Leads educational programme commissioned by NHS Education for Scotland. This training for trainer's programme was specifically designed to support development of the workforce in areas that specialise in dementia care in Scotland. This immersive learning course was designed for care staff in senior positions to increase their knowledge and skills about how to provide care to people with dementia and complex co-morbidities, provide fundamental nursing care and promote emotional security, physical safety and well-being that they could then share with their staff (NHS Education for Scotland, 2018). Like the Admiral Nurse competency framework it was created for professionals with a specialist role leading and improving dementia care and is accessed increasingly by senior care home staff as well as its target audience which was initially the NHS. For more information see http://www.knowledge.scot.nhs.uk/dementia/organisations/specialist-dementia-unit-network.aspx

There is a clear need to examine both pre and postgraduate development of learning in advanced dementia care. The lack of attention in current accredited provision inspired the Erasmus+ funded project 'Dementia Palliare' (Tolson et al, 2017). This European project involving seven partner countries led to a number evidence informed educational outputs including a Best Practice Statement, a virtual Community of Practice and four modules that now feature in the MSc in Gerontology with Dementia Care offered at the University of the West of Scotland. See

https://www.uws.ac.uk/research/research-areas/health/alzheimer-scotland-centre-for-policy-and-practice/ https://www.uws.ac.uk/study/postgraduate/postgraduate-course-search/gerontology-with-dementia-care/

The Best Practice Statement provides a learning framework with six sections detailing the 'what, why and how' of best practice in advanced dementia care. While there is a need for more focussed learning programmes in advanced dementia care, there is a growing body of evidenced based interventions and approaches to theoretically support and empower leaders in the field. All provide principles and theories to inform care, practical tools, frameworks, guides and education enabling staff to support people living with advanced dementia in their activities of living and intimate personal care [figure two]

Orellana, Manthorpe and Moriarty (2017) looking at leadership in care homes highlighted the gap in knowledge about care home managers leadership attributes despite them being of critical importance to the management and leadership of care homes. One of the few large studies looking at the role involving over 3,000 caregivers in Sweden, found that good leadership was vital both in ensuring person-centred care and in creating a positive culture of psychosocial support (Backman et al., 2016). The use of regular supervision by leaders and managers has also been identified as an important way to support staff in providing person-centred care (Kirkley at al., 2011).

Positive leadership in care settings was also identified by Jakobsen and Sørlie (2016) as one based on the principles of trust and mistrust. Caregivers in their study reported feeling supported where the leader was both trusted and showed trust in them. Their expectation was that leaders set the standard of care, are role models and listen to the challenges staff face. In their literature review Orellana, Manthorpe and Moriarty (2017) also reported that leaders who are trusted and supported reported benefits to themselves, their staff and residents and felt better motivated if they had some independence and autonomy particularly if they worked in the commercial sector. A very recent study by Dever` (2018), who interviewed at Nurse Managers in the USA identified the following themes as those that that accompanied their role. Their visibility on the unit, the use of trial and error learning, a sense of "aloneness" due to the absence of other registered nurses to consult, the need for peer support, role modelling, and importance of supporting the resident through their "final journey making the Nurse Managers position "a tough job". While there are significant gaps in our knowledge of leadership in care homes there are even fewer studies reflecting leadership skills specifically in advanced dementia care. Yet the key to successful care interventions for advanced dementia clearly include positive leadership (Stacpoole et al, 2017)

Leadership in action

This final section will examine the impact of positive leadership using an example from practice of leadership in action. Using Loveday's (2012) model of leadership (See figure three), Barbara Lawson, an award winning care home manager, reflects on the impact of positive and dynamic leadership on the care home setting.

Barbara's reflections

"Recent policy direction means that people with dementia tend only to be admitted to a care home when they are living with advanced dementia and other comorbidities. Getting to know the person and the family at a time when, often palliative dementia care is required, offers both challenges and rewards. Staff have to learn quickly what is important to the person and their family during an unpredictable palliative phase. Supporting staff to support the person to live the best life possible is a key part of my role, building on what works well is my starting point. Working in partnership with staff, families and the liaison nursing service makes a positive difference to care. This partnership has helped us identify the root causes of stress and distress and reduced hospital admissions.

Even when you have made great strides in care practices, sustaining and building on those will always pose ongoing challenges. Leading dementia care takes energy, skill, determination, passion and a strong belief that every person with dementia can be supported to live well, feel valued, accepted and secure. It also means supporting, educating, nurturing, guiding and modelling good practice to both staff and informal care givers. Being prepared to empower others will also have a positive impact on their quality of work, satisfaction, collaboration and productivity."

Loveday's (2012) ideas draw upon the work of both Kitwood (1997) and Nolan et al (2006) who emphasise that a service, organisation or care setting must be committed not just to the personhood of people living with dementia but also the personhood of the staff. The Senses Framework (Nolan et al, 2006) clearly identifies the importance of relationships among residents, family, staff and others involved in the care setting. Leadership is possible in all these groups and should be recognised and nurtured.

Conclusion

Loveday (2012) makes it clear that leadership is about holding a vision and inspiring and guiding movement towards it. Leading a team requires trust and respect requiring you to be able to 'walk the walk' as well as 'talk the talk'. Yet leadership is more than managing a team; nurturing staff who might develop into the leaders of the future is crucial. Reflective practice, supervision and continuing professional development should be integral and routine for all staff. Devolved leadership is also an

important consideration as that is one of the few steps known to improve person-centred care (SSSC, 2018; Orellana, Manthorpe and Moriarty, 2017). More needs to be known about how to encourage this in all settings. Evidence about the required leadership skills and competencies needed to bring about improvement to advanced dementia care management remains scant and while expert opinion and commentary such as this is valuable, much more research into leadership is required soon, as the need for skills in advanced dementia care grows.

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Figure 1: Evidence informed resources to support advanced dementia care

Tom Kitwood pioneered the idea of person centred care, maintenance of personhood and malignant social psychology. His ideas in the seminal 1997 text have been the subject of numerous studies and articles and have been developed by others into frameworks and models of care.

Jackie Pool developed the Pool Activity Level (PAL) Instrument: a reliable and valid cognitive tool for assessing activities of daily living and support engagement in activity. To find out more go to http://jackiepoolassociates.org

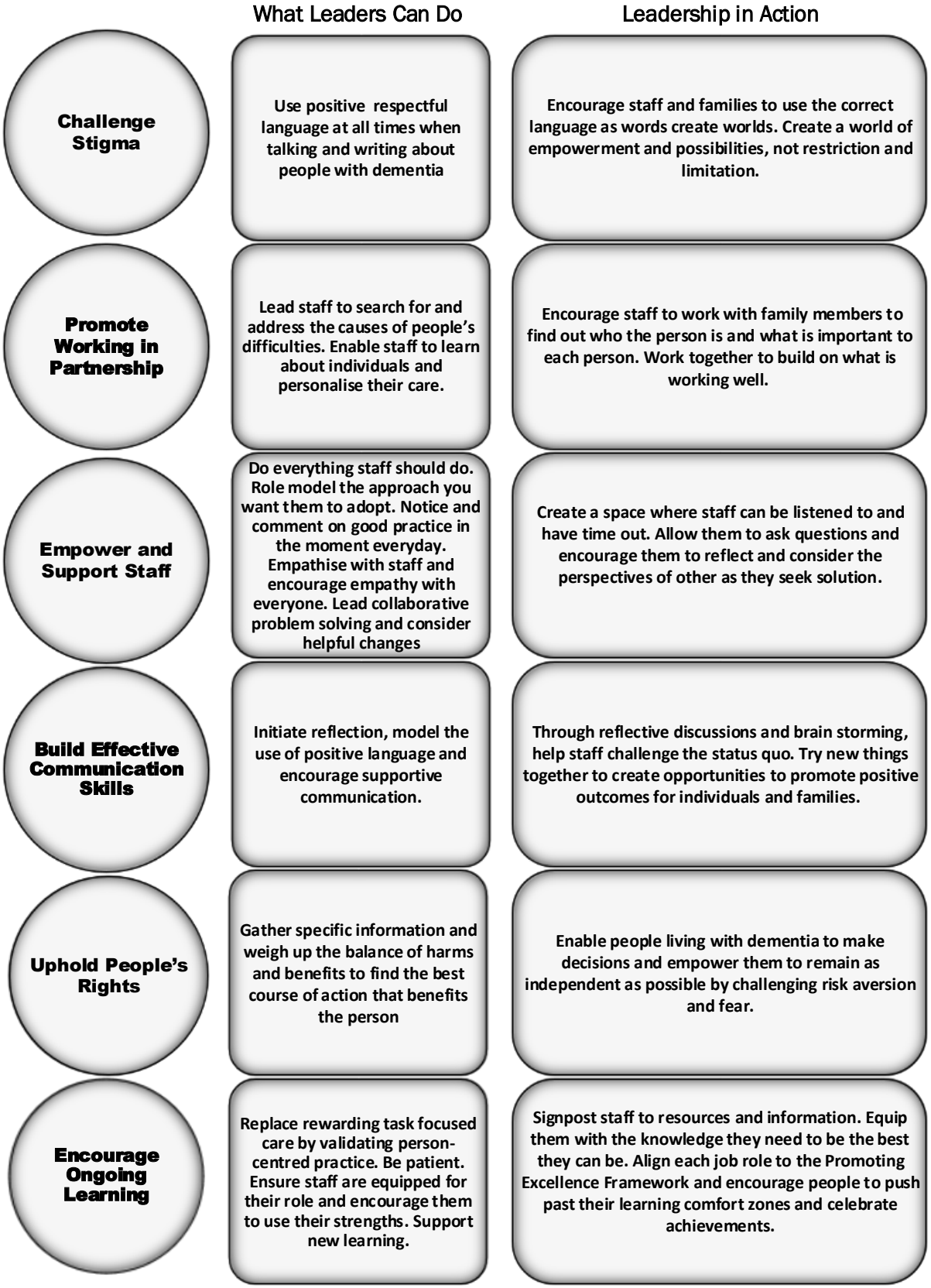
David Sheard builds on the work of Kitwood through emphasising working with emotions. For videos and information on the Butterfly Model of Care go to http://www.dementiacarematters.com/

Christine Kovach has led research into advanced dementia care (1997). You can hear about some of her work on pain here https://www.youtube.com/watch?v=tO-rU2wYPZc

Teepa Snow has developed a Positive Approach to Care. You can learn more about her practical approaches to working with brain changes by watching her videos here https://teepasnow.com/

Joanne Rader has led research and culture change into reducing distress, meetings emotional needs and compassionate approaches. Her research on bathing has informed bathing practices internationally. To find out more go to http://bathingwithoutabattle.unc.edu/about-bathing

Figure 2: What Leadership in action in dementia care looks like (Based on Loveday 2012, and Barbara Lawson's reflections, Care Home Manager at Kincaid Care Home, Greenock and Sue Pembrey Nurse Leader 2017).



Revisions made to paper NOP 1189

Revisions made in response to general comments made by reviewer 1 and 2

Additional section headings to signpost the reader added

Introduction re written to be more concise and clear

In 'who care for people with advanced dementia?' the paragraph on advanced dementia, co-morbidities, acute hospital admissions, deaths and place of care rewritten

Skills and education frameworks cited rather than in figure, dates checked and are correct

In 'positive learning and leading in advanced dementia care' enhancing edits and detail added to Admiral nurse approach, dementia champions and example of commissioned programme. Two new paragraphs added exploring evidence on how all staff can lead change and what positive leadership can look like.

An exploration and critique of how leadership and learning and the effect it can have on people living with advanced dementia added

Literature including that by Karen Harrison Denning and others at Dementia UK added

Conclusion re written to be more concise and clear

Reference list updated, referencing made clear

Revisions made in response to comments made via track change by reviewer 1

In text suggested edits accepted and suggested changes re wording addressed

Added literature and references as requested

Added content where suggested and conclusion re written