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### Delivering personal care for people with advanced dementia

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## Paper 2: Delivering personal care for people with advanced dementia

### **Abstract**

This article considers the complexity of providing personal care for people with advanced dementia, including the need for expert nursing practice to assess and lead washing, dressing, continence care, nutrition and hydration. The contemporary evidence base for effective assessment, care planning, partnership working and evaluation of personal care for people with advanced dementia is presented, supported by sources of further information.

### **Introduction**

Advanced dementia is,

“.....associated with the later stages of illness when the complexity and severity of dementia-related changes in the brain lead to recognisable symptoms associated with dependency and an escalation of health care needs and risks.....” (The Fair Dementia Care Commission, 2019 p14).

People living with advanced dementia experience intersecting biological, psychological and social challenges which require the knowledge and skill level of staff working with them to be evidence-based and responsive to rapid change (Hanson et al., 2016, Holmerova et al., 2016). Meeting the increasing fundamental care needs for people with advanced dementia is essential to their wellbeing. The Nursing and Midwifery Council (NMC) (2018) states:

“the fundamentals of care include, but are not limited to, nutrition, hydration, bladder and bowel care, physical handling, and making sure that those receiving care are kept in clean and hygienic conditions. It includes making sure that those receiving care have adequate access to nutrition and hydration, and making sure that you provide help to those who are not able to feed themselves or drink fluid unaided.” (NMC 2018 ).

While these activities could be described as ‘basic’ the converse is true, especially for people with advanced dementia when such interventions may be distressing and unwelcome. Under detected and poorly managed pain, recurrent infections, increased risk of delirium, reduced ability to communicate needs, neuropsychiatric symptoms, depression and the increasing support needs of family members are all shared experiences of people living with advanced dementia (Hanson et al., 2016). The introductory article in this series identified that staff working across health and social care settings

often lack the skills and knowledge required to assess and respond to complex care needs. Additionally, challenges about the quality and leadership in the fundamentals of care have been expressed and rehearsed fully by Kitson et al., (2013). Inspired by much of this work, it is clear that people living with advanced dementia in particular, require nurses with specialised knowledge and skills to meet their complex health needs including fundamental and personal care (Holmerova et al., 2016, The Fair Dementia Care Commission, 2019).

### **Understanding the complex personal care needs of people with advanced dementia**

Personal care is considered simple and part of everyday life; it maintains health, personal appearance, skin integrity, supports bodily functions and increases wellbeing. In advanced dementia, the individual may be wholly dependent on others to fulfil their personal care needs and may find it confusing, unwelcome and a possible trigger for distressed responses and behaviour (Holmerova et al., 2016).

The overriding goals of supporting personal care for people with advanced dementia are to:

- Promote and maintain health, independence, identity and personal expression.
- Provide choice, comfort, dignity and a sense of wellbeing.
- Reduce the likelihood of stress and distress for the person living with dementia, families and staff (Holmerova et al., 2016).

Rights-based, biopsychosocial, multi-professional, and person-centred approaches are the foundation on which all interventions for people with advanced dementia should be based (Scottish Parliament's Cross Party Group on Alzheimer's, 2009; van der Steen, 2010; Spector and Orrell, 2010; Holmerova et al., 2016) Box 1 below outlines a range of psychosocial approaches to care which can be transferred to all aspects of personal care delivery.

[Box 1]

Irrespective of the care required, multi-professional assessments should inform care plans, which should be frequently reviewed and evaluated. The person's life story should be included together with a description of their strengths and needs, their experience of trauma, the type of dementia they have and their experience and individual signs of pain (Holmerova et al., 2016). If the person has an Advance Care Plan or has expressed wishes for their care in the advanced stages and end of life, these should inform care plans. Each area of personal care delivery needs specific assessment strategies and tools that require interpretation and integration to inform ethical, legal and evidence-based assessment

and care planning processes. Nurses have a responsibility to ensure that appropriately educated staff know how to undertake assessments, interpret the results and know when to raise any concerns with the nursing staff (NMC, 2018).

### **Nursing care for people with advanced dementia**

Awareness of the need for nursing leadership and interventions to respond to the needs of people living with advanced dementia has grown over the last ten years, culminating in the Fair Dementia Care Commission members stating,

“.....Addressing advanced dementia related health needs requires expert health care, nursing and palliative care assessments together with insights provided by family carers and others, particularly when the person has difficulty communicating their own needs and emotions.....”

(The Fair Dementia Care Commission, 2019 p14)

Addressing the complexities faced by people living with advanced dementia requires working in partnership with people living with dementia and their families and includes understanding and taking into account their previous experiences and preferences (National Institute for Health and Care Excellence (NICE) [NG97] 2018). There are several tools to support partnership working in care planning, implementation and evaluation. In Scotland, the Getting to Know Me document was developed with people living with dementia, their families and expert Dementia Nurse Consultants (Alzheimer Scotland's network of Dementia Nurse Consultants & the Scottish Government, 2013). The Alzheimer's Society has a similar published document called 'This is Me' (Alzheimer's Society, 2017). Ideally, these documents are completed before transitions to the hospital or care setting and nurses have an essential role in introducing people to the document, supporting completion and revisiting it when care needs change.

Families and friends can become uncertain of their role when the person is not cared for at home, yet they often have experience, knowledge and strategies to ensure that effective personal care is achieved. Alternatively, they may become anxious and critical if they feel the care is inadequate at these crucial transitions (Hanson et al., 2016; Jurgens et al. 2012). The Senses framework (Nolan et al., 2006) outlines the importance of relationships in care; these include the person, family and staff. van Lieshout et al. (2015) have used this concept for care settings where families are supported to

continue to care as far as possible with support from staff. By finding out how families currently provide care, including their degree of involvement, methods and timing of interventions nurses can foster feelings of security through replication of home routines, where possible. Partnership working supports transitions between home and other care provision and provides additional support to families caring at home (Johnson and Steel, 2019).

### **Legal, ethical and assets based approaches to care**

The UK is committed to the European Convention of Human Rights, ECHR European Court of Human Rights & Council of Europe (1953) which was incorporated into UK law by the Human Rights Act 1998. There are several articles in the ECHR which are relevant to the care of people with advanced dementia, and these include Articles 2 (Right to life), 3 (Freedom from torture and inhumane or degrading treatment) and 5 (Right to liberty and security). There are legal processes in place throughout the UK to ensure that these rights are upheld when the person is no longer able to make informed choices (figure 1). Nurses should be aware of relevant legislation and the mechanisms for ensuring that the delivery of care and treatment are lawful.

[Figure 1]

Regardless of the individual countries' legislation, these laws are all underpinned by important principles. In England, Wales and Northern Ireland the term used in the Mental Capacity Act is 'Best interests' (Department of Health, 2005). While the Scottish legislation within the Adults with Incapacity Act refers to the principle of 'Benefit' (Scottish Government, 2000). Both of these Acts have processes for providing safeguards to ensure that the least restrictive practice is used during any intervention and is in the interests of the individual. Also, the Nursing & Midwifery Council Code of practice provides clear guidance concerning the Best Interests of the patient (NMC 2018). Despite these principles, the challenge to provide personal care needs when a person lacks capacity, care is unwelcome and requires legal processes, is a challenge with limited practical guidance for staff (Lyons, 2013).

A person-centred asset-based approach to personal care seeks to recognise, retain and emphasise abilities; working directly with remaining cognitive and functional skills. Evidence from neuro and cognitive psychology suggests that the type of memory that uses past experiences, called implicit memory, may still be intact in advanced dementia (Sabat, 2006). There are some strategies to maximise the use of implicit memory, and these will help a practitioner to create an experience for

the person to help them feel involved and able to contribute. For example, beginning to sing a song can help connect with the person before care is given and has shown to reduce distress in morning care (Hammar et al., 2011). Personal care can be enhanced by using bridging and mirroring techniques. Bridging uses objects to connect action with implicit memory; for example, the person holds a hairbrush while the nurse brushes the hair. Mirroring the action expected from the person by the nurse can stimulate memory for the body movements required, such as in cleaning teeth.

Other asset-based approaches include; carrying out care activities from the dominant side of the body where the memory is strongest, breaking the task into steps and using multisensory prompts. Nonverbal approaches include strong facial and visual cues and language should be limited to short sentences or single words. While sensory loss can reduce the impact of some nonverbal communication, every effort should be made to establish what the person is experiencing and how communication strategies could be enhanced. Eye conditions prevalent in older people, for example, macular degeneration, intensify specific changes in sight related to the deteriorating visual pathways in the brain caused by dementia (Salobar-García et al., 2016). Therefore communication strategies should go beyond glasses being clean and well fitted and hearing aids being in place and working. Active engagement should involve the positioning of the nurse where the person can see them within their visual field and slowing movement and action to give the person time to respond. This approach is known as Visual, Verbal, Touch by Teepa Snow.

[Box 2] VVT by Teepa Snow

The principles of asset-based personal care and working with those assets the person retains, should apply to all care. A selection of strategies to consider for specific personal care interventions are:

### **Washing and dressing**

Washing, bathing and shaving are intimate experiences and the person with advanced dementia may misinterpret what is happening and feel their privacy and dignity is threatened. Taking a person-centred approach is essential (Holmerova et al., 2016). Knowing something about the person's preferences, such as the best time of the day for washing may help. Environmental considerations including temperature, ambience and comfort of the bathroom all need careful attention. The experience of water may be painful to sensitive skin, and bathing aids may influence how enjoyable the experience can be. A sensitive approach to the gender of staff or the relationship the member of staff has with the person is also essential (Barrick and Rader, 2008). Where the person shows an

aversion to water, there are products requiring no wetting of the hair or body. These can provide a substitute to bathing, carried out in the form of warm massage with minimum intervention, as there is no need to rinse the product off. Haircare can also be carried out with no-rinse products in the form of solutions, wipes and shower caps.

Shaving can be less distressing using previously preferred shaving routines and equipment. When shaving, it is helpful to carry out alternate strokes on each side of the face in case the person wishes to stop; this ensures the result is not uneven. Shaving and washing can be carried out throughout the day with rest periods in between. Alternatives to wet shaving (such as an electric razor) may be considered through discussion with the family carers and a trial with the person with dementia the outcomes of which can then inform future care planning and delivery.

Clothes and the process of dressing can support a sense of personhood and selecting, managing and wearing clothes support and maintain the active construction of a person's identity (Buse & Twigg, 2015). Assisting the person with dressing can be an opportunity for therapeutic interventions, rather than a task or time-driven care experience. There is a risk when helping with dressing, of infringing upon the person's dignity and privacy or causing pain or discomfort. When undertaking activities such as washing and dressing, providing an uncluttered space and presenting one garment at a time can help. It is important not to assume the person knows what you are doing, so gentle touch, such as a light touch to the hand, brief information and an approach that breaks the activity down into steps can help. Rest breaks when the person appears tired or overwhelmed can be used to distract the person, perhaps offer a drink or gentle touch. Make sure the care space is well lit and warm and ensure the person is covered at all times.

There are clothing solutions available, which are dignified, fashionable and comfortable to wear. A size larger in clothing may prevent moving stiff or sore limbs too much. There are also examples of assistive clothing available such as smart trousers with side, front or rear fasteners. Maintaining dignity and wellbeing when a person disrobes requires a problem-solving approach, considering alternative fabrics and contemporary adapted clothing, underpinned by a legal and ethical approach; then evaluating and recording what works and repeating this.

### **Continence care**

Urinary and faecal incontinence is not only a result of advanced dementia, urinary tract infections, urgency, urge incontinence, and nighttime incontinence (nocturia) can be part of disease processes or

getting older. Common bowel pathologies such as inflammatory bowel disease, bowel cancer and bladder cancer may leave a person with faecal and urinary challenges before developing dementia. Despite this, a recent European review of the evidence on continence care in dementia shows a lack of recognition and support especially where the person is living in the community (Gove et al., 2017)

Price (2011) argues that urinary or faecal incontinence may not only be attributable to changes in bowel and bladder function; instead, the symptoms and experience of dementia can result in functional incontinence. In the advanced stage of dementia physical problems can impact on the person's ability to recognise physical signals to empty the bladder or bowel, they may have reduced movement and may not be able to identify where the toilet is or how to use it.

As with all nursing care, carrying out a biopsychosocial assessment in partnership with people living with dementia and their families is the starting point for person-centred care planning. The Care Inspectorate (2015) emphasises that everyone has a role in supporting the continence needs of people with chronic conditions including dementia, based on five key messages;

- Know me and what's important in my life and do what's best for me.
- Know me and how I communicate.
- What I need to stay continent and how you can help.
- Create an environment that supports me to be independent and promotes continence.
- Look for every opportunity to promote my continence – be creative.

The protection of dignity and privacy is reported as an influencing factor in a reluctance to seek help from professionals for bladder, bowel and continence issues (Drennan et al., 2011). This reluctance places the onus on nursing staff to ask questions to establish what is normal for the person and what support is required. A precise assessment can guide care delivery which promotes the person's normal bladder and bowel habits and management of food, fluid and nutrition which may influence bladder and bowel patterns. Family members may already have established continence management strategies, which nursing staff can adapt where possible and maintain practices which focus on personal strengths. Recognising and responding to a change in bladder and bowel habits in line with guidelines from the National Institute for Health and Care Excellence (NICE) (2007) and NICE (2012) is essential. Healthcare professionals can also explore and develop professional knowledge using the Minimum Standards for Continence Care (Continence Care Steering Group, 2015).



## **Nutrition and Hydration**

Weight loss is not inevitable in advanced dementia yet feelings of hunger and thirst may progressively diminish; the ability to recognise food (agnosia) or know how to use utensils (apraxia) is lost, and the sensory experiences of smell and taste deteriorate. Despite this, it is possible to maintain weight, quality of life and pleasure in eating (Queen's Nursing Institute for Scotland, 2015)

Nursing staff, play a fundamental role in the assessment, care and support of nutritional needs (NMC, 2015). Nutritional screening tools such as the Malnutrition Universal Screening Tool (MUST) (British Association for Parenteral and Enteral Nutrition, 2006) should be used to support assessment. Person-centred care planning supported by family/carer involvement and/or the use of documents such as "Getting to Know Me" (Alzheimer Scotland Dementia Nurse Consultants and Scottish Government, 2013) support the implementation of nutritional strategies in keeping with individual preferences and cultural beliefs.

Good mouth care promotes nutritional intake; however, a systematic review by Foley et al., (2017) found people with moderate or severe dementia were 5.4 times more likely to have dental caries than the general population. Although some staff may find mouth care distasteful and may give this a lower priority than other aspects of care, nurses are accountable for ensuring the effective delivery of fundamental care activities and have a professional duty of care to ensure that no patient is subject to neglect (NMC, 2015).

A person in the advanced stages of dementia may not always welcome support with eating and drinking. Strategies to promote acceptance, processing and swallowing of food begin by establishing and maintaining rapport, good eye contact and a comfortable dining position. A quiet non-stimulating environment and the use of adapted utensils and drinking cups can aid difficulties with coordination or concentration. Flexible mealtimes and the availability of regular snacks or finger foods may also help encourage dietary intake.

Chewing and swallowing difficulties (dysphagia) can lead to increased risk of malnutrition, which increases the likelihood of additional complications such as infection and poor wound healing. Problems with choking and pulmonary aspiration are also commonly associated with the development of aspirational pneumonia and increased risk of mortality (Sato et al., 2013). Referral to dietetic and speech and language services for advice on interventions such as food supplements, food modification or careful hand feeding can be provided. Interventions such as these may reduce, but cannot eliminate the risk of aspiration. The loss of the ability to eat, drink and swallow is to be expected during the end of life, and if unable to accept oral nutrition, the person should never be coerced to eat and drink.

Enteral feeding should not be routinely considered (NICE, 2018) as the focus at the end of life, should be around retaining quality of remaining life and not prolonging of life.

## Conclusion

Supporting personal care delivery for people with advanced dementia in a human-rights based, person-centred, biopsychosocial, legal and ethical manner requires a multi-professional approach led by nurses. This article has provided only a snapshot into the complexity of working with people with advanced dementia; each knowledge and skill area outlined here could and should be the subject of contemporary research and application of evidence-based care underpinned by learning from the experienced of people living with dementia and their families. Further information on all the aspects of personal care can be found in the links to resources in box 3 below. Research is urgently needed to advance nursing knowledge and practice in all aspects of personal care with people with advanced dementia supported by valuing the knowledge and skills of nursing for people living with dementia now and in the future.

[Box 3] Additional resources

## References

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Box 1; Biopsychosocial approaches to personal care delivery

Make use of personal profile information to inform approach, assessment, planning, implementation and evaluation.

Learn from and work in partnership with people who know the person well.

Ensure pain is assessed and managed before any personal care interventions

Gain visual attention and verbal engagement before touching the person

Engage the person in something interesting; including singing or talking about a favourite person/subject.

Consider alternative times, people and environments around the needs and wishes of the person.

Break all tasks down into short actions.

Provide verbal and visual prompts such as simulating the actions required

Reduce the number of staff involved or involve someone else who may relate more closely to the person.

Box 2 VVT from the Positive Approach to Care™ Teepa Snow( 2017)

**First**

Gain **visual** attention- make sure the person has seen you and given consent for you to approach.

**Second**

Make a **verbal** connection-introduce yourself and wait for a response.

**Then you can**

**Touch** and make a physical connection to start working in partnership.

## Box 3: Additional resources

## Getting to Know Me

[http://www.alscot.org/information\\_and\\_resources/information\\_sheet/3472\\_getting\\_to\\_know\\_me](http://www.alscot.org/information_and_resources/information_sheet/3472_getting_to_know_me)

## This is Me

<https://www.alzheimers.org.uk/get-support/publications-factsheets/this-is-me>

Urinary incontinence in neurological disease: assessment and management. Clinical guideline (CG148)

Published date: August 2012

<https://www.nice.org.uk/guidance/cg148>

Bladder and bowel problems: Common problems and how to manage them.

[https://www.ageuk.org.uk/globalassets/age-uk/documents/information-guides/ageukig15\\_managing\\_incontinence.inf.pdf](https://www.ageuk.org.uk/globalassets/age-uk/documents/information-guides/ageukig15_managing_incontinence.inf.pdf)

Toilet Problems and continence: Alzheimer Society

<https://www.alzheimers.org.uk/get-support/daily-living/toilet-problems-continence>

Marshall, M (2018) *Toilet Talk: accessible design for people with dementia*. Australia: Hammond Care Media

RNIB Dementia and sight loss

<https://www.rnib.org.uk/services-we-offer-advice-professionals-nb-magazine-health-professionals-nb-features/supporting>

Anticipatory Care Planning <https://ihub.scot/project-toolkits/anticipatory-care-planning-toolkit/anticipatory-care-planning-toolkit/>

Social Care Institute for Excellence When people with dementia refuse help

<https://www.scie.org.uk/dementia/living-with-dementia/difficult-situations/refusing-help.asp>

**Figure 1** Capacity/incapacity legislation in the UK

