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How to support family carers in providing personal care for people with dementia

Rationale and Key Points

An estimated 700,000 people living with dementia are supported at home by family carers, who have a significant responsibility for supporting personal care. The physical, emotional and financial impact on family carers is considerable and challenges associated with providing personal care often precipitate care home or hospital admission.

Many family carers take on this role without prior experience, often relying on trial and error. Registered nurses are in a unique position to provide practical guidance, emotional support, and advocacy to help carers navigate both health and social care challenges effectively. By adopting a proactive and collaborative approach, nurses can help family carers to deliver person-centred care while maintaining their own well-being. This article outlines how nurses can utilise a series of resources that have been developed to support family carers in providing personal care for people living with dementia.

- Registered nurses play a vital role in providing, leading and coordinating care that is compassionate, evidence-based, and person-centred. Almost every nurse will meet someone living with dementia during their career and should therefore have the knowledge and skills to provide support for family carers.

- Personal care can involve physically demanding tasks and emotionally sensitive situations, particularly when it includes intimate care. Understanding these challenges from a family carer's perspective allows nurses to offer practical advice and tailored interventions.
- Nurses should explore the experiences of family carers as part of their holistic person-centred assessment, to help identify actual and potential challenges.
- Involving family carers in decision-making, acknowledging their expertise, and ensuring they have access to resources and training can benefit both the family carer and the person living with dementia.
- Many family carers struggle to access appropriate services and feel unheard by professionals. Nurses play a crucial role in ensuring that information, services and multidisciplinary support are both accessible and responsive to family carers' needs. Additionally, they contribute to raising awareness through participation in wider community initiatives.

Reflective activity

'How to' articles can help to update your practice and ensure it remains evidence based. Apply this article to your practice. Reflect on and write a short account of:

- How this article might improve your practice when supporting family carers of people living with dementia, and how you could adapt your current approach to better meet their needs.

- How you could use this information to educate nursing students or your colleagues about the needs of family carers.

Dementia is an umbrella term used to describe a range of symptoms caused by a progressive neurological disease (Harrison Denning, 2023). It is characterised by impairment of cognitive functions such as the processing of information, thinking, memory and reasoning (World Health Organization, 2023) which often leads to impaired social functioning and impacts on activities of daily living. It is estimated that there are currently over 900,000 people living with dementia in the UK (Wittenberg et al., 2019). Of these, 61% live in the community and receive care at home from unpaid family carers (Dementia Carers Count, 2023). The Kings Fund (2024) define unpaid carers as 'anyone who provides unpaid care for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support'. For this article, the term 'family carer' is used to encompass any unpaid carer that may be supporting someone living with dementia. This may be a direct family member, friend or acquaintance.

The adverse impact of undertaking the role of a family carer for someone living with dementia has been widely discussed and documented. Providing ongoing support and care can have a negative effect on a family carer's mental health, increasing the risk of depression and anxiety (Queluz et al., 2020), and of physical conditions such as cardiovascular disease, diabetes and musculoskeletal disorders, as the responsibilities of caring can impact on their own access to healthcare services (Carers UK, 2023). In addition, the responsibility placed on the family carer can lead to social withdrawal and isolation (Alzheimer's Research UK, 2015), and in turn

contribute to an increased risk of developing dementia themselves (Livingston et al., 2024). However, whilst many family carers experience these challenges, there are also many that find the role rewarding and an integral part of the relationship they have with the family member (Alzheimer's Research UK, 2015).

Contreras et al. (2022) identified that family carers were often left with a feeling of helplessness after diagnosis and have significant concerns about how they will cope as dementia symptoms progress in the person they support. The impact of changed behaviours and a decline in the performance of activities of daily living related to personal care is often the tipping point for the person living with dementia to move into a care home. Moreover, it has been suggested that a family carer's reduced ability to support a person with dementia may influence health professionals' decisions to recommend a move to a care home (Cole et al., 2022).

Recognising the role of the family carer for people with dementia is fundamental and nurses have a responsibility to provide optimal support through holistic assessment, care planning and signposting or referral to external services (Robinson, 2018; Williams et al., 2019). This includes recognising and supporting carers' statutory rights, such as access to a Carer's Assessment, as set out in national legislation (such as the [Care Act 2014](#), the [Social Services and Well-being \(Wales\) Act 2014](#), and the [Carers \(Scotland\) Act 2016](#)). Andrews (2024) argues that focusing solely on delivering direct nursing care is no longer enough and all nurses should have the education, knowledge and skills to support family carers in navigating both the health and social care system. By gaining a deeper understanding of the impact of caring, nurses can deliver more person-centred and emotional support whilst also playing a

crucial role in raising awareness through collaboration with local carers' groups and participation in wider community initiatives.

Preparation

- Andrews (2024) argues that nurses are not expected to 'know it all', however with the right level of knowledge and understanding it is possible to help signpost family carers to existing support and help them anticipate and gently adapt to what changes may lie ahead.
- [This website](#) has been co-produced by an Expert Advisory Group, comprising of individuals and organisations with experience in providing advice and support to people living with dementia. Whilst it provides information and advice for family carers, it can also enhance your own understanding. Each section includes leaflets, films and booklets that can be downloaded and shared with family carers. These can also be useful in starting conversations about topics that people may find difficult to talk about.

Procedure

Assessing needs and planning care

- As part of your holistic person-centred assessment identify the individual needs and preferences of the person living with dementia in relation to activities of daily living and personal care.
- The use of biographical tools, such as Life Story work (Dementia UK, 2023) and This is me (Alzheimer's UK, 2025) will help capture the personal preferences, values, and background of the person living with dementia.

- Explore the family carer's experiences, actual and potential challenges, and their confidence in performing personal care tasks. Consider:
 - What is their relationship to the person with dementia?
 - How much time do they have available for caring?
 - Do they have other commitments, such as work or childcare?
 - Are they balancing multiple caring responsibilities?
 - Are they living with any of their own physical or mental health conditions?
 - Have they received any prior training or support in providing personal care?
- Does the person with dementia or the family carer have cultural beliefs, values, and religious practices that may influence personal care activities and preferences?
- Have legal, ethical and financial considerations been explored, such as consent and capacity? Are there any advance care plans, decisions or directives, or lasting powers of attorney in place that may guide personal care decisions? Is the family carer aware of financial support they may be entitled to?
- Assess the physical environment: Is the space safe, accessible, and supportive of the person's needs? Consider lighting, flooring, equipment, and adaptations that may enhance safety and comfort during personal care.
- Have other assessments been undertaken by members of the Multidisciplinary Team (MDT) (eg. Specialist Dementia Nursing teams, Occupational Therapist, Physiotherapist, Bladder and Bowel Health service, Social Services)? Can these be integrated to support a comprehensive nursing assessment?

- Document the findings of your assessment and ensure records are clear, person-centred, and accessible to all involved in caring for the person with dementia and supporting the family carer.

Providing and evaluating care

- Using the information gathered during the holistic assessment and working in partnership with the person with dementia and their family carer, establish a plan of care. What is important? What matters most? What are the goals of care? What is needed to help meet these goals?
- Is there any specific equipment, guidance or training that could help the family carer in their role? Are there any tips on how to approach personal care shared within the [website](#) resources?
- Collaborate with the MDT to ensure a comprehensive approach. Signpost to appropriate services and resources if further support is needed. Are there any local or online resources that offer practical advice or emotional support?
- Continuously monitor, evaluate and reassess, readjusting agreed goals if necessary, whilst documenting progress and decisions made.

Evidence base

Between December 2022 and September 2024 a National Institute for Health and Care Research (NIHR) funded study, 'Crossing the Line', was carried out by the Association for Dementia Studies, University of Worcester. The aim of the study was to gain an understanding of the experiences of family carers in relation to supporting and providing personal care to people living with dementia. It followed a co-production approach to ensure the experience and expertise of people who are (or have been) family carers were at the core of the project. An Expert Advisory Group

(EAG), which included representation from NHS trusts and the voluntary, community, and social enterprise sector also contributed, ensuring input from those supporting people affected by dementia. A combination of survey and interview data helped to provide an overview of the commonly faced challenges, coping strategies adopted and support mechanisms necessary for family carers. Notably 67% of family carers provided daily personal care daily for someone living with dementia, while 82% felt unprepared due to a lack of knowledge, skills, time, and how to access practical support.

The study involved a series of collaborative co-production workshops, during which the emerging and final research findings were presented and discussed.

Consequently, it was identified that family carers would benefit from easy-to-find information about dementia in general, and practical advice on specific personal care activities (e.g. help with washing, teeth cleaning, continence). As a result, a range of resources has been co-designed by workshop participants to support family carers, accessible via a dedicated website (<https://caringhelp.on.worc.ac.uk/>). This includes a collection of 15 printable booklets, covering a wide range of topics associated with supporting someone with personal care (see Table 1). The leaflets are complimented by three educational films, which aim to give family carers the opportunity to share often-hidden voices and stories and thereby enable people in similar positions to relate to and learn from one another.

Table 1

1.	Why does having dementia make personal care difficult?
2.	Dealing with complex emotions

3.	Common physical issues that impact on personal care
4.	Legal and financial issues
5.	Changes to the home environment to make personal care easier
6.	Strategies that will help make giving personal care easier in the long term
7.	Staying strong in the long term
8.	Help with continence and using the toilet
9.	Help with washing, showering and bathing
10.	Help with teeth and dentures
11.	Help with dressing and undressing
12.	Help with eating and drinking
13.	Help with personal appearance
14.	Help with caring for hands and feet
15.	Supporting good hearing and vision

Since the resources were launched in August 2024, the online booklets have reached nearly 8000 downloads, with more than 3,500 paper copies distributed to professionals and family carers. All leaflets will be available in Welsh later in 2025. Feedback has been overwhelmingly positive, highlighting the value of these resources in supporting both family carers and health and social care professionals. One dementia support charity described the resources as *“one of the best publications we have come across so far that will really assist family carers when caring for their loved one.”* Health and social care professionals also recognised their significance, with one commenting that the resources are *“fantastic... really useful, with a massive implication for the world of practice. They’re helping informal carers and family members provide the best care while also looking after themselves.”*

Family carers echoed this sentiment, with one describing them simply as “*a terrific set of resources.*”

The findings of this study have informed the development of a comprehensive set of resources which, whilst designed to support family carers in providing person-centred personal care, also provide a valuable framework for nurses. They will help guide practice, promote collaborative care planning with families, and serve as an educational tool to enhance the knowledge and skills of nurses in delivering holistic, person-centred support.

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