

Transition into permanent care: the effect on the family

Family caregivers undergo what can be a traumatic transition when placing their loved one into nursing and residential care. Care staff can positively influence this transition by developing supportive relationships with the family caregivers

According to the Alzheimer's Society (2013) there are over 300 000 people with a diagnosis of dementia living in care homes. The transition when a person with dementia moves into a care home permanently is a challenging time, not only for the person with dementia, but also the family caregiver and the staff. Staff may feel caregivers visit the care home too often, ask too many questions, exaggerate the importance of something that appears to be trivial, are demanding of staff and challenge the way staff work. In turn, staff can begin to resent the caregiver, label them as 'mitheresome' and actively try to avoid engaging with them. This article aims to highlight the plight of the family caregiver and suggest that it is important for care staff to remember caring doesn't cease just because someone has moved into permanent care (Keady and Swarbrick, 2011).

Impact on caregiver after relinquishing care

There are an estimated 670 000 family caregivers who are caring for a family member or friend with dementia in the UK (Newbronner et al, 2013). Should the time come when the person with dementia moves into permanent care, the caregiver is often left feeling bewildered, they lose their sense of purpose and there is a great sense of guilt that they failed the person somehow even if they understand it was the right thing to do, and as a result of the person with dementia needing additional support (National Institute for Health and Care Excellence (NICE), 2006; Bramble et al, 2009). Being a full-time caregiver for someone with dementia can consume who the caregiver is as an individual. Over the time of their caring role, they begin to identify solely as a caregiver for someone with dementia and become an expert at that (Palmer, 2012). Once that is gone, caregivers often struggle to remember who they were before and can become lonely (Bramble et al, 2009). They forget how to be an individual again when they've spent so many hours fused together with the person they care for as one unit, making all the decisions for themselves and the person.

Admiral Nurses (Dementia UK, 2014) can be instrumental in helping the caregiver come to terms with the change in the relationship and how to begin focusing on themselves again. Staff can try to reassure the caregiver, seek the caregiver's advice about the person (as the caregiver knows the person best), give accurate information about care in a timely manner and involve the caregiver in decisions wherever possible. One way to include the caregiver would be to begin Life Story work or to use existing Life Story work (Keady and Swarbrick, 2011). Life story work is an activity based on creating an individual biography for a person; it involves recording past and present life events and can be presented in the form of a scrapbook. It aims to improve understanding of the individual, promotes relationships and facilitates delivery of person-centred care (Thompson, 2011). Consider *Box 1*.

Grief, guilt and loss

Many family members feel an overwhelming sense of guilt when they have to agree to someone moving into full-time care. Guilt is a powerful emotion and can change people's behaviour. Guilt is caused by multiple factors. It can be brought on by a feeling that the family caregiver didn't do enough and feel like they have failed their relative and should have been able to cope better (Bramble et al, 2009). Even though people try to reassure them that they did their best, it is hard for them to see a different perspective when they are emotional. Sometimes guilt is magnified when the person with dementia asks to go home; this is extremely difficult for family members to cope with and it magnifies their feeling that they should

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Table 1. What is everyone thinking?		
Staff	Caregiver	Positive staff responses
'They're a nuisance, they visit constantly'	'I'm lonely, there's no one at home and I miss my partner'	<ul style="list-style-type: none"> • Acknowledge concerns • Listen • Remain polite • Don't be defensive • Put yourself in their shoes • Explain • Inform in advance • Reassure • Communicate • Don't guess or assume if asked something you don't know the answer to • Catch problems early • Acknowledge the caregivers feelings • Don't use jargon
'They're mitheresome, every time they're here they ask a million questions and I don't have time'	'I use to make all the care decisions for my partner and now I don't know what is going on, I'm worried'	
'They criticise the care we give. Nothing we do seems good enough to them'	'I feel guilty my partner has come into care and wish I could still do these things for them'	

have coped better. The family member may be missing the person they cared for, they may not have as much contact with them and they may feel that this is detrimental to the person being cared for. If the person is unsettled when the family visit, this can add to feelings that they should have coped better, the level of depression in the caregiver is very closely linked to how well the person with dementia settles into the care home (Whitlatch et al, 2001). Family caregivers will often compare themselves to other similar situations and may see other families caring for someone at home who is perceived to be worse than their relative, but in these cases, the person doesn't know the whole story, and it is a mistake to compare themselves. Another cause of guilt can be where a family caregiver has struggled with the care for their relative and then they see that when in the care home environment, the person with dementia is much more settled. It is hard for them to see this as they again may start to feel like they have failed and not cared for the person in the right way. Similarly, when the staff tell the caregiver that person is no problem, it can have similar effects, reinforcing their guilt because it was such a struggle at home, and so actively seeking the caregivers unique knowledge helps them to deal positively with their feelings of guilt (Palmer, 2012). Consider *Table 1*.

Many family caregivers can be overwhelmed by a sense of grief and loss. In dementia care, we talk about an idea called 'living grief' or 'ambiguous loss' (Alzheimer Society of Canada, 2013). This refers to feelings that family caregivers may experience, which are similar to those experienced when a loved one has died. This type of grief has strong links to depression in this caregiver group (Paun and Farran, 2011). Even before going into full-time care, the family member may experience a living grief, because they have seen the person with dementia change a lot and they often feel like they have lost them and they are not the same person they once were. This feels like the person had died, yet it is mixed up with the fact that the person is alive in front of them. There are many other losses that family caregivers may face as a

Box 1. Considerations

Put yourself in the family caregivers shoes:

If everything you identified with was taken away, how would you feel? How would you begin to put yourself back together?

result of dementia that can also be made worse by going into full time care. Often the caregiver may feel they have lost their close companion, they may feel they have lost the intimacy that they once shared and the whole changing relationship between them can be a huge loss. Indeed Paun and Farran (2011) have identified that the loss felt in a spouse relationship is greatly different from that in an adult-child relationship. There may come a time when the person with dementia is unable to recognise the family member, which can make the family member feel more and more like they have lost them. This in turn can be made worse by seeing good relationships between the person with dementia and the home staff. It can promote feelings of jealousy and hurt if the person with dementia is having a good relationship, such as a laugh or a cuddle with a staff member when the person doesn't recognise their own family. Staff should remember not to strive to take over completely (Keady and Swarbrick, 2011). Family members might now face a great sense of loss in their lifestyle, they may be lonely and isolated, with nobody coming into the house. There may be a financial loss leading to the caregiver struggling to pay bills, buy food or even visit the home.

Loss of role and adjustment

The caregiver may feel like they are losing their role, predominantly as a decision maker, while also trying to preserve the role and identity of the person with dementia (Keady and Swarbrick, 2011). Many caregivers will want to maintain a role by continued involvement in the



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care of the person with dementia (Alzheimer's Society, 2007). The role a family caregiver adopts within the care home will differ from those they adopted while caring for the person in their own home. Helgesen et al (2012) identify that, while these altered roles can potentially be just as stressful, they are deemed necessary (on the part of the family caregiver) to maintain the wellbeing of their loved one. An important aspect where caregivers are keen to remain involved is with their loved one's health care, as highlighted by Dijkstra (2007). If caregivers want to continue their role, care staff should have flexible systems in place to facilitate this, and provide information around home routines and practices (Keady and Swarbrick, 2011).

Communication

One of the best ways to maintain any healthy relationship is with good communication—this is true of the relationship between family caregiver and care staff. Many potential complaints can be eliminated with good communication as this promotes optimum care (Palmer, 2012), and often the caregiver is overlooked as needing to be included in many of the care processes (Bramble et al, 2009). Common problems are the caregiver not being invited to meetings, not being told of changes, not having a process explained to them, poor continuity of staff and

the caregiver receiving mixed messages, staff guessing an answer or being very vague because they don't know. Caregivers need to be communicated with to promote understanding and trust.

Current research on interactions that promote communication between care staff and caregiver is limited to date (Palmer, 2012). Staff should try to keep the caregiver at the forefront of their mind when making decisions about the patient. It may help to sit down with a family when someone first arrives to discuss expectations and discuss what is feasible. For example, some caregivers may want to attend any appointments when a doctor, nurse or other professional comes to assess their loved one, whereas others caregivers may be happy to be told the outcome. Similarly a caregiver may ask to be contacted anytime a change to care is made; however, that may not be realistic due to time restraints and instead a compromise can be reached, such as a weekly update meeting or call with the family. Carers are a huge source of information for staff, providing continuity about the past, helping the person with dementia maintain their identity and contributing to future decisions by being an advocate for the person's wishes (Hennings et al, 2013). Palmer (2012) identifies preferred patterns of communication which offers the chance for optimal care, these six patterns are represented by the acronym TALKKK (*Box 2*).

Box 2. Preferred patterns of communication

- **Tell:** caregivers desire to be told information about their relative, particularly as their relative is often unable to do this themselves due to their cognitive impairment
- **Ask:** caregivers desire to be asked about their loved one as they are experts in the persons needs, habits, routines and behaviours
- **Listen:** frustration ensues if caregivers feel their 'warnings' are not heeded. Caregivers fear they have communicated their concerns to the wrong staff
- **Know:** it is expected that staff will get to know the person with dementia and respect their personhood
- **Knowledgeable:** care staff should know how to care for someone with dementia and be knowledgeable about dementia
- **Knowledge:** care staff are expected to offer expert advice when they see a caregiver struggling

Conclusion

Research into the impact a move into a care home has on a family caregiver of a person with dementia is limited, further research into this area would be beneficial. Steps to promote meaningful relationships and wellbeing could include carer support groups within the care establishment and care staff working on life stories with the resident and their family, this will be with a view to facilitating effective communication and building trust. Staff should be trained in dementia and respective care issues in order to allay fears of family caregivers. For care staff, facilitating family involvement can bring about feelings of enjoyment and the positive relationships that develop can improve quality of life for all, not just the cared for. **NRC**

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Key points

- Family caregivers are experts—they know their loved one better than anyone else
- Family caregivers can be consumed by guilt for moving their loved one into a care environment, even if no other option was available
- Care staff play a pivotal role in the success of a care placement
- A move into a care home does not mean the family caregiver no longer has a role
- Communication is key to developing trust and promoting understanding

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