Caring for a relative with dementia can be challenging for families. A case study outlines simple interventions that can improve the quality of life of the whole family.

**Helping family carers to cope with dementia**

**In this article...**
- Challenges of caring for a relative with dementia
- Strategies to help families cope
- Importance of effective health and social care interventions

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Living with and caring for a family member who has dementia can have a significant impact on family life and relationships. Families can support their relative at home in a safe and secure environment, but they need to be vigilant for signs of deterioration in mental and physical abilities and behaviour, and act quickly with appropriate changes. The inclusion of all generations in providing care at home can strengthen the family unit and increase their coping skills. This case study outlines the experience of one family from their mother’s early symptoms of Alzheimer’s disease until she was transferred to permanent residential care.

**Diagnosis**

Diagnosis can be the key to good communication between the person with dementia, family and health professionals. However, dementia is often undiagnosed in its early stages, leaving people with dementia and caregivers to cope at home with unmet needs (Black et al, 2013). Ideally, families should be involved in the diagnosis process (Siemens and Hazelton, 2011). My mother’s diagnosis was challenging as she managed to mask her signs and symptoms from health professionals.

In the home environment my mother had all the classic signs of dementia, including forgetfulness, frequent episodes of weepiness, and inability to recognise familiar faces and items (Alzheimer’s Society, 2013a). These were reported on numerous occasions to the GP, who attributed them to grief following the loss of her husband. No further discussion was permitted due to patient-doctor confidentiality and our attempts to pursue our mother’s symptoms were blocked. My mother then began to show the characteristic signs of deterioration, including increased agitation, confusion, fear and anxiety, disrupted sleep, weight loss and lack of interest in her appearance (Alzheimer’s Society, 2016a). She was struggling to recognise familiar objects, people and places. As her condition deteriorated her personality changed dramatically from a happy woman to one who was angry and frustrated. On one occasion she was making tea and did not know what to do with the carton of milk; she started screaming and shook it all over the kitchen covering everything and everyone. These episodes were followed by uncontrollable weeping and bouts of aggression, sometimes levelled at family members. Again, we found it difficult to engage her GP in considering a diagnosis of dementia.

Driving can be a safety issue for people living with dementia (Carter et al, 2014).
Our mother continued to drive although she regularly stopped the car to ask pedestrians how to switch the lights on and what the handbrake was for. Concerned about her and others’ safety, we wrote to her GP who asked us to remove the car keys; she was given a diagnosis of probable Alzheimer’s but no diagnostic tests were performed.

The rapid and profound deterioration in our mother’s condition was dramatic on all levels: physical, mental, emotional and behavioural. We sought guidance from the literature and identified several issues, which are outlined in Table 1.

### Table 1: Priorities for Safe Home Living

<table>
<thead>
<tr>
<th>Category</th>
<th>Priorities</th>
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</thead>
<tbody>
<tr>
<td><strong>Safety</strong></td>
<td>Keep a safe environment, Keep the person with dementia safe, Keep others safe</td>
</tr>
<tr>
<td><strong>Enhancing memory</strong></td>
<td>Provide prompts and cues to jog memory, Label everyday objects</td>
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<tr>
<td></td>
<td>Use photographs relevant to stage of memory deterioration, Put memorabilia on display</td>
</tr>
<tr>
<td></td>
<td>Encourage story-telling of pleasant memories</td>
</tr>
<tr>
<td><strong>Supporting activities</strong></td>
<td>Meaningful activities e.g. dressing, eating, bathing</td>
</tr>
<tr>
<td></td>
<td>Personal appearance: clothes, hair, nails</td>
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<tr>
<td></td>
<td>Sleep, diet, mobility, companionship</td>
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<tr>
<td></td>
<td>Family life: support through laughter, humour, tears</td>
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<tr>
<td><strong>Ensuring financial security</strong></td>
<td>‘Assisted autonomy’ for money decisions, Third-party mandates</td>
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<td></td>
<td>Power of attorney</td>
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<tr>
<td><strong>Negotiating social services</strong></td>
<td>Persevere, Prepare to discuss situation on multiple occasions</td>
</tr>
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<td></td>
<td>Keep a record of all communications</td>
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<td></td>
<td>Consider a risk assessment for the main carer</td>
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</tbody>
</table>

### Safe environment

Enabling someone with dementia to remain at home as long as possible requires modifications to improve the safety of the home, maintain functional ability and reduce the risk of falls and injury. Many people with mild-to-moderate dementia have good mobility and may only require modifications to allow them to move safely around their home, such as reducing furniture and clutter (Marquardt et al, 2011).

We switched off the gas to the cooker, removed lighters and de-cluttered the house. Potentially hazardous household items such as the kettle and vacuum cleaner were replaced with smaller and easier-to-handle alternatives; we also attached timer switches to electrical items such as lamps to come on and off at specific times, and installed movement-sensitive lighting so areas lit up as our mother moved from room to room. Neighbours and friends were given contact numbers to use if they found our mother wandering outside. Protecting house keys was difficult, and despite luminous bands and key rings that ‘beeped’, many sets were lost.

### Supporting memory

Our mother’s memory was deteriorating; she would go into the fridge to answer the phone and use a teabag in the washing machine. At times she knew it was “not quite right” and this caused her distress and frustration; we explored ways to help her.

Guidance suggested that cognitive activities and interventions can support people with dementia with their declining memory. These include ‘face-name’ training and memory-provoking activities (Scottish Intercollegiate Guidelines Network, 2006). We decided to label everything and everyone in an easy-to-read way, including the contents of the fridge and kitchen cupboards, photographs with names and white boards with key contact numbers. This was a controversial issue for our mother, who would remove adhesive notes from the fridge and tear them up; her young grandchildren were involved in noting when labels had been removed and replaced them. Reluctance to accept this level of intervention is common in the early stages of dementia (Marquardt et al, 2011), but gradually our mother accepted our efforts and they helped her to cope.

Our mother’s short-term memory deteriorated to the point where she could not remember her children as adults. Her long-term memory was still intact, so we replaced adult photographs with those from our childhood; when she began to ask when her late mother, father and siblings would visit we added their photographs. My mother used to talk to these photographs and took comfort from telling us about her childhood. It is known that speaking about memories, particularly those that are most meaningful, helps to preserve the identity of people living with dementia. They also feel safe and content when they are able to maintain their sense of self (Karlsen et al, 2014).

### Involving family

Like many families, the adults felt confused and did not know how to deal with my mother’s behaviour (Purves, 2011), while the grandchildren were wary of their grandmother, who now did not know them by name. We appreciated guidance from the literature on how to interact with her childlike behaviour, and followed the recommendation that grandchildren be given age-appropriate methods of communicating with her (Philipp-Metzen, 2011).

Our mother loved babies in prams and toys so we shopped for soft toys with her; this was a time of fun and laughter with the grandchildren. Some of the younger ones were initially confused by her behaviour but quickly came to accept it. They also spent hours with her singing nursery rhymes; this involved physical activity, which helped to keep her mobile. The children used to send postcards, which delighted our mother; they also played in warm soapy water with her to wash plastic toys, which also kept her fingernails clean.

### Activities of daily living

Reduced participation in everyday activities is an isolating experience for people living with dementia. Meaningful activities are important in maintaining their sense of self and relationships with relatives (Phinney, 2006). Although we found guidance on what ‘meaningful’ activities were, such as dressing and preparing meals, there was little information on how to help her to participate (Truscott, 2004; Redfern et al, 2002); the changes outlined in Box 1 (page 13) worked well for us.

### Financial security

People with dementia gradually lose their financial capacity, affecting their ability to count money and make judgements about purchases (Marson, 2001). However, they often overestimate their abilities, while carers sometimes underestimate their needs. We switched off the gas to the cooker, removed lighters and de-cluttered the house. Potentially hazardous household items such as the kettle and vacuum cleaner were replaced with smaller and easier-to-handle alternatives; we also attached timer switches to electrical items such as lamps to come on and off at specific times, and installed movement-sensitive lighting so areas lit up as our mother moved from room to room. Neighbours and friends were given contact numbers to use if they found our mother wandering outside. Protecting house keys was difficult, and despite luminous bands and key rings that ‘beeped’, many sets were lost.
Nursing Practice

**Case study**

**BOX 1. MEANINGFUL ACTIVITIES**

- Simple and basic changes gave our mother some form of control and achievement
- Clothing was reduced down essentials so they could be clearly seen and identified
- Clothing was arranged in layers of ‘one-day supply’ so she could easily find all items each morning
- Nightwear and outdoor wear were kept separately
- For a period of time, it was still important for our mother to have her handkerchief, scarf and gloves in her bag although it needed to be cleaned out daily to remove debris and biscuits
- Important personal items such as her purse, hairbrush and makeup were labelled
- Drinks and snacks were left readily accessible when our mother was at home alone

Our mother’s behaviour eventually went out of control. Someone had to remain awake overnight as she roamed the house incessantly. The situation was relentless and we were at the end of our tether. Emergency social services were called after she attacked one of her adult grandchildren with a knife. The social worker who attended was excellent and could not believe the circumstances we were living in. The carer risk assessment findings played a role in the quick decisions made at this time; the social worker arranged emergency respite care for two weeks, which was extended to four weeks and then to permanent care. Although difficult, the family welcomed this decision. It was apparent that our mother had deteriorated to such a poor state that she could no longer be supported at home.

**Specialist nurses**

Dementia specialist nurses have a key role in helping people with dementia to remain at home, and supporting family and carers (Hibberd, 2014). This requires specialist knowledge and skills to manage the complex nature of the dementia process and provide practical advice, and emotional and psychological support. As the single point of contact, these nurses support families and carers and are often the essential link with health and social services. Dementia specialist nurses need the necessary interpersonal and communication skills to liaise with other professions and disciplines in community services and to provide a caring and compassionate culture through education and leadership, and can deliver substantial benefit for family, carers and people with dementia.

Caring for a relative with dementia can compromise family life, and families may experience delays in diagnosis and assessment. However, given appropriate guidance it is possible for families to work together. They need to be prepared to make ongoing changes, taking account of the individual’s needs, stage of dementia and subsequent behaviour. Safety issues, enhancing memory, supporting the meaningful activities of daily living, ensuring financial security and obtaining appropriate support are key factors that families need to tailor to suit their own circumstances. Adults should consider involving children in safe activities suited to their age. This can strengthen the family unit as they move into often unchartered territory, helping them to care for their relative at home for as long as possible.

**References**


