

Life for Caregivers after Placing a Relative with Dementia in a Nursing Home



A Guide for Family Caregivers and Nursing Home Staff

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Introduction

This booklet is written for family caregivers who have recently placed their relatives with dementia in long-term care and for nursing home staff involved in their day-to-day care. For most family caregivers, the decision to place a relative with dementia in a nursing home is not easy and much time will be needed to come to terms with the changes that caring for a relative at a distance creates. Likewise, for nursing home staff, adjusting to providing care to a new resident may be challenging, particularly if that person appears “disruptive” and needs time adjusting to his or her totally changed environment: a new bed, a different dining table, an unusual bathroom and being surrounded by unfamiliar faces.



As a first step for the family caregiver, getting to know nursing home staff by name, learning more about their roles and responsibilities and

developing good relationships, especially with key front line staff members, will be very beneficial to all. Good nursing home care is very much about family members building trust and developing partnerships in care relationships. By telling staff members all that is known about the new residents' likes, dislikes, interests, desires, preferences, hobbies, fears and concerns, very valuable information is being provided that will help professionals provide the best care possible.

The new resident may have been a Mum or Dad - a teacher, a housewife, a carpenter or a secretary, who had enjoyed a full life complete with challenges, pleasures, jobs and hobbies. Such life-time experiences can be built upon and used positively by both staff and by family caregivers after placement occurs. By knowing the resident's personality, interests and preferences, nursing home staff can provide more individualised care and can develop tailor-made interventions likely to enhance well-being and improve quality of life.

An important aspect of life in a nursing home is the role played by activities. Everything we do in life essentially constitutes an activity so nursing home activities do not always have to be “therapeutic” but rather normal life; even domestic tasks can constitute meaningful activities for a person with dementia. At the outset family caregivers need to provide staff with vital information about their relative’s hobbies and interests to enable staff know their residents well.

The range of activities enjoyable to someone with dementia is endless. The basic requirements, however, are that these activities are varied, offer choice, and are pleasurable. Remember too that it is the quality and appropriateness of the activity rather than its duration that is most important for a person with dementia. The belief that it is pointless introducing an activity to a person with an advanced dementia is a myth since even passive activities can address different levels of concentration and facilitate various levels of involvement. Likewise, the belief that family caregivers need to know nothing about the activity programmes run in the nursing home is erroneous since often these same activities can act as catalysts for conversation during nursing home visits or, indeed, can be pursued during these visits to make them more meaningful.





After Nursing Home Placement: Caregiving at a Distance

After a person with dementia's move into the nursing home, it is generally advisable to allow time for him/her to settle into the new environment. To facilitate this and during this initial phase, family members are usually advised to keep nursing home visits to a minimum, although each individual case differs and nursing home staff should be able to advise here. As mentioned, relinquishing home care, particularly if a family member has lived at home with the carer for many years, will require considerable adjustment.

Studies have shown that caregivers who have access to a variety of personal resources and supports are better able to cope with the transition. Therefore, on-going support from other relatives and friends is very important during this period. Some nursing homes have excellent support groups where relatives can regularly meet and speak with other family caregivers going through similar experiences. Remember too that to be an effective caregiver at a distance, family members need to look after their own individual needs.

After a relative's move into long term care, due consideration should be given to the fact that a family caregiver may experience a myriad of different emotions - including feelings of loss, guilt and sometimes concern over relinquishing their home care role. Mixed feelings including guilt on the one hand and relief on the other are not uncommon. Indeed, if caring has become all encompassing to the point where the carer's social world has shrunk, feelings of emptiness may prevail. Such feelings are to be expected since placing a loved one constitutes a major life change event.

Emotional struggles can continue for some time after placement as most family caregivers believe (whether rightly or wrongly) that nobody besides them can provide the same quality of care to their relative. Tensions can arise over what family carers feel they should be able to continue to do versus what they actually can do, given that day-to-day personal care is no longer their responsibility.

After placement, many family caregivers choose to stay integrally involved in the care of their loved ones and continue to have specific caring responsibilities whether that means taking laundry home, managing a relative's financial affairs, or bringing in toiletries or food. Although no longer physically responsible for the day to day care of a loved one, the family caregiver is still probably the person who knows best what makes the person with dementia "tick".

Most nursing homes welcome input from family caregivers and encourage their involvement in residents' care. It is important, however, for family caregivers to negotiate with nursing home staff what they hope to continue to do for a relative; for example whether the caregiver intends to visit during meal times (some Nursing Homes welcome this while others have strict policies discouraging this), plans to take their family member out at weekends or for family events. Family members should not be afraid of sharing their skills and expertise with the professional staff, rather they should bear in mind that everyone is likely to benefit from this.



Developing a Trusting Relationship with the Nursing Home Staff

The relationship the family caregiver develops with nursing home staff is critically important to ensuring that a new resident gets optimal care. Whilst the new resident's psycho-social profile and life story was no doubt first discussed with staff at the time of admission, it may be helpful at this stage for both staff and family members to renew the opportunity to revisit this relevant information. This can be issues such as what time the new resident generally likes to get up at in the morning, go to bed at night, what makes her laugh or cry, what her favourite time is to bathe or shower, what she likes most to eat when out for a treat, what her favourite drink is.

Family members should also discuss with staff what approaches or activities have proven to be useful in helping a loved one settle down when they become cross, upset or distressed. The correct identification of a known intervention may mean the difference between a contented person and one who becomes agitated for "no apparent reason". If feasible, family members need to work with the nursing home staff to develop a care plan and review it together on a regular basis.



The Importance of Activities

As stated earlier, keeping mind and body active is important for all of us, both young and old. Leisurely interests and activities including exercise, games and hobbies keep us stimulated, healthy and engaged. These same activities are no less important when a person develops a dementia, when self worth and morale may be diminished or when the day becomes so totally boring or predictable that it is almost depressing to wake up.

Imagine for a moment living inside the same shared environment and day after day experiencing the same monotonous routine, Exercise on Monday, Bingo on Tuesday, the Hairdresser on Wednesday, Sing-along's, Crafts on Thursday and Mass on Friday. Imagine also living in a home and being subjected to the



annoyance of having to play bingo twice a week or being asked to participate in singsongs, or craft work when all your life you had a distinct distaste for such activities and instead enjoyed hiking and tennis. It is little wonder, therefore, that people with dementia may become very bored or exhibit disruptive behaviour when placed in long stay care settings where no activities are available, or worse still where those activities on offer are not customised and offer no choice.

In the context of dementia care there has been a tendency for each of us to associate nursing home activities with only “therapeutic interventions” such as Reality Orientation¹, Reminiscence Therapy² or the Sonas programme³. However, normal life therapy which seeks to replicate parts of the person's life before getting a dementia is equally important.

¹An intervention strategy based around orientating the person with dementia to the 'time', 'place' and 'person' of their immediate environment. This is done for example through large face clocks, large print calendars in different rooms, and maps and signs to orientate their living environment.

² An intervention based on discussing past events, life experiences and activities, either in a group or one-to-one. Aids are often used to help the person with dementia reminisce, such as old photographs, a favourite song/music from when the person was young, life story books, and so on.

³A therapeutic communication activity focusing on sensory stimulation; structure and repetition are important factors. The group sessions involve sensory and social stimulation and the focus is on ability, not disability.

Normal life therapy can include activities such as sitting with a person as he/she watches a favourite TV show, listening to a favourite piece of recorded music, or taking a resident with dementia out to the Post Office or to a local shop or children's park.

Even people with an advanced dementia may still derive much satisfaction from having someone sit alongside them flicking through a chatty magazine (Hello/OK), reading a newspaper article, or just sitting alongside the resident holding a hand. Similarly, domestic activities such as helping staff set or clear the table, fold laundry, or sweep the floor may also be very enjoyable to a person with dementia keen to be involved in nursing home life, although obviously getting involved in these type of activities need to be carefully discussed and negotiated between all three parties, the resident, the staff and family members.



People with dementia in long stay care have more than physical needs; many are extremely vulnerable and have unique and specialist psychosocial needs. Some may feel overstimulated by virtue of their being exposed to a noisy, busy, sometimes cluttered environment whilst others may feel bored and idle. Accordingly, having nothing to do may mean their

having to fill their own time with “aimless” activities. It is imperative therefore that individualised activities are designed that are failure free and promote dignity, reinforce personal identity and enhance self esteem.

Examples of Individual Activities

The fundamental principle of any individualised activity is that it is personally meaningful and that it sets the person up to succeed rather than highlight their disability. Every nursing home offering dementia care can potentially offer activities designed to preserve people's skills and reduce “problem” behaviours. Therefore, in planning individualised activities, due consideration needs to be given to the physical and cognitive demands of the activity versus the skills, competencies and strengths of the person with dementia. Other fundamental principles of any activity include simplicity, appropriateness and choice.

Activities for Outgoing People with Moderate Dementia

Some examples of activities an outgoing person with a moderate dementia may still continue to enjoy whilst living in long-term care are detailed below:



- Playing adapted sports games such as bowling, putting, or simple ball games in the nursing home grounds
- Exercising or fitness classes can be introduced to prevent stiffness and muscle wasting, to maintain a healthy heart, and to address disturbed sleep patterns
- Dancing or exercising to music with others. It is important to ensure the person is taught new moves and steps to keep the activity interesting and fun
- Going out (accompanied) for leisurely walks, which may offer some focus of attention such as a visit to the seafront to watch boats at sea or children swimming or a visit to a park to pick berries in autumn. Such activities can be done in small groups or just the person with dementia accompanied by the staff member
- Going for a drive to the local village can be satisfying for someone who does not often get out from the nursing home
- Helping out with special nursing home events/activities such as birthday parties, themed nights, karaoke nights and with annual seasonal events such as Christmas, St Patrick's Day, Easter and Halloween
- Listening and singing along to music or group singsongs
- Helping with personal grooming, such as washing/brushing hair, or painting nails

Activities for Creative People with Moderate Dementia

For creative people, particularly those residents who were used to doing art and engaging in creative activities prior to their developing a dementia, several different types of activities exists. When led by an enthusiastic and well motivated staff member these activities can be used to empower older people and promote their independence and improve well-being. Examples include:

- Pottery work using clay or even plastercine
- Crochet/knitting or simply stringing beads
- Poetry reading or short stories
- Painting using watercolours
- Flower arrangements, perhaps using dry flowers
- Validation therapy—the person rolls a ‘feeling dice’ and talks about the emotion that comes up
- Group photo session—bring photos and talk about them within a group
- Videos – of recent or past events that may be meaningful to the older person such as the recent visit of the Queen to Dublin or President Obama’s visit to Ireland
- Reminiscing either individually or in group setting—using peoples’ life experiences to highlight remaining skills and abilities or using computer programmes like YouTube to capture age-related songs or images



Activities for People with more Severe Dementia

As the cognitive impairment advances, usually a decline in the desire and ability to participate in active pastimes (games, cross-words and quizzes) will arise. For people with advanced dementia, momentary pleasures such as enjoying the taste of a favourite ice-cream or drink, looking at a photograph of a loved one or simply having a bag of favourite sweets on the bedside locker, are what they most prefer. Even if the person can no longer remember exactly what it was that was so gratifying, some awareness of feelings of self worth or satisfaction may continue. Detailed below are other examples of these type of passive activities appropriate for people with more advanced/severe dementia:

- Pet therapy – having a dog come into the nursing home may be comforting to those with an advanced dementia and may offer a focus for affection. Pet therapy can also act as a catalyst for some even piecemeal conversation
- Music may arouse, subside and help to relax a person who is severely cognitively impaired and unable to communicate his/her needs. Music may rekindle feelings, resurrect old memories and may stimulate movement

- Visits from small children may also promote well-being. Young children are naturally spontaneous and are often very accepting of older people, particularly those who are confused or who may exhibit bizarre behaviour. Their visits can have a positive effect, even short-term, on older residents
- Passive ranges of motion, adapted to suit the person
- A stimulation box such as a rummage box, containing interesting objects to help to stimulate and occupy the person
- Reaching activities such as reaching for and grabbing things
- Air mat therapy— a gymnastics-type mat attached to an air compressor, where the air flow has a calming effect and is used for relaxation purposes
- Activities tailored to the level of impairment, for example throwing a ball or simple physical routines, may also be performed on the mat together with a therapist

Activities For People with End Stage Dementia

Even when someone is in the very advanced stages of dementia and may no longer recognise visitors including close family members by name, contrary to widespread belief, regular visits may still provide much comfort and stimulation. During such visits, it may be useful for family members to concentrate on activities that as best as possible reach out to the dying person's senses:

Touch — hand-holding may be reassuring, or a smile or a gaze

Hearing — music can provide comfort and familiarity

Hearing — read out loud from the person's favourite book

Sight/smell — a stroll around the garden might be enjoyable

Smell — hand massage with scented oils may provide relaxation

With end stage dementia, verbal communication may cease completely. However, the person may still retain limited awareness, and some studies have shown that it is the person's sensory and perceptual awareness that now becomes prominent. Even at this end stage, increasing the person's awareness through environmental influences and engagement in enjoyable activities are beneficial.

Visits

In the early stages and following placing a relative with dementia in long term care, many family caregivers find visiting the facility distressing and feel guilty about not visiting



more often or find that they are not really looking forward to the visit. It is important to remember that such feelings are very common, and that visits, and especially leaving after visits, can be difficult for both the caregiver and the person with dementia. Acknowledging the existence of such feelings can help caregivers find approaches that may make the process easier.

Emotional memory is generally retained by those who have a cognitive impairment; the fact that the family member is visiting will most likely communicate to the resident that the person cares. Try to prepare as best as is possible for what mood the person with dementia may be in during the visit. It helps to be aware of the presence of emotional expressions, both those of the person with dementia and those which the caregiver may inadvertently communicate.

Conversation during a visit may be difficult at times depending on the cognitive status of the person with dementia. Try not to ask sharp, direct questions such as “do you remember who I am?” — instead, say “it’s me, Anne, your spouse/sibling/relative/friend”. Also, if the person begins to talk about someone who is not there or might even be dead for years, avoid correcting the person by saying “so-and-so is dead” but instead say something along the lines of “how nice that you are thinking of that particular person!” and use this as a cue for reminiscence.

Sometimes the person with dementia may struggle during conversation or take a long time to find words. Try to be patient and avoid rushing the person. Give the person time to absorb conversation and to think about what has been said, and give them space to respond in their own time. Also, remember that it is not important to fill every moment with conversation—just being together in silence may be a comfort for the person with dementia.

Saying Goodbye after a Visit

It is often commented that leaving the Nursing Home after the visit and saying goodbye to a relative with dementia can be difficult for family caregivers. It is generally advisable that the family member leave straight away without lingering, or apologising, as the latter can make it more difficult to leave the next time. Other suggestions to make leaving easier include letting the person with dementia know at the start of the visit how long it will last and why the visitor needs to leave at a certain time, and then reminding the resident throughout about this.

Another approach often used by family members is taking an activity into the nursing home to do during the visit, such as a magazine or photo album to browse through. The completion of the activity marks the end of the visit and the natural time for the family member to leave. Yet another



approach taken is that family caregivers ask nursing home staff to divert the resident's attention so there will be something else for that person to do (serving and eating a meal) at the time the family member is leaving.

Often at the critical moment, when the family caregiver is about to leave, the resident may decide that he/she wants to leave and go home, or worse still may plead to be taken home. The desire to go home as expressed by a resident with dementia is often triggered by a fear or insecurity, and of being left alone. Home may be perceived as a familiar, safe and comforting place resplendent with memories of childhood/home/friends that no longer exist. In situations like this, caregivers are generally advised to avoid reasoning with the person as this can cause further distress.

Instead the family member should be encouraged to acknowledge the residents' feelings and desire to go home while at the same time trying to provide reassurance about safety and security.

When the caregiver does leave, it is important to leave quietly and quickly, without long discussions, explanations and facial expressions that betray the often strong emotions that may be felt in this situation. It may also calm the situation if the caregiver puts the emphasis on "see you soon" rather than "I'm leaving". Being clear about the next visit, for example "I will be back tomorrow" or "I will see you on Saturday" helps reassure the person with dementia that the caregiver will return.

For the family caregiver, it may help to confront parts of visiting that may feel especially difficult. What aspects are particularly hard? Can anything be improved through increased interaction with the nursing home staff? Is the caregiver involved in the person's care plan and activities? Is there any other approach that can make visiting, and leaving, easier? It may be helpful to ask the nursing home staff for advice on any particular issue. Facing potential problems head-on and adjusting to what the caregiver expects from the person, or of how the person with dementia might be feeling on any particular day, may contribute to making visiting a more enjoyable and meaningful time for both caregiver and the person with dementia.



Summary

This booklet has been written to help family caregivers come to terms with life after having recently placed a relative with dementia in long term care. It has also been written for Nursing Home staff who are involved in front-line care work; admitting new residents with dementia into their long stay units, creating partnerships in care with family caregivers, and developing Activity Programmes designed to bring out the best in residents with a dementia and improve their quality of life. We hope it provides some practical tips for both professional and family caregivers.

Dementia is an extremely challenging condition which results in multiple losses. For this reason, a variety of skills are required by professional staff and family caregivers looking after people diagnosed, as complex problems arise that require considerable understanding and resourcefulness. The emphasis in this booklet has been on life after nursing home placement and on a positive approach to dementia care. It is our belief that many of the challenging behaviours associated with dementia can at least be minimised by “knowing the person” and by using creative approaches.

Whilst there are no interventions that guarantee success for everyone, we hope you will find some of the ideas put forward in the booklet and the examples given helpful. We hope that the booklet will be a valuable tool for all those committed to providing person-centred care and that at least some of the information and advice given may ultimately help to improve quality of life for all people with dementia living in long term care.

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- www.alzheimers.org.au

Useful websites

www.dementia.ie

www.socialwork-socialpolicy.tcd.ie/livingwithdementia

www.hse.ie

www.alzheimer.ie

www.carersireland.com

www.nhi.ie

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