

Finding a Suitable Nursing Home for a Relative with Dementia



A Guide for Family Caregivers to Placing a Relative with Dementia in a Nursing Home

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Introduction

In the last decade the issue of choice and consumer involvement has become increasingly important in the area of planning older peoples' services. In Ireland, the advent of Home Care Packages for example has introduced some opportunity for older people to exercise choice in terms of home care services, although cut-backs mean that real choices are often limited. Achieving choice regarding long term care is often difficult when an older person develops a dementia¹ and when for a variety of reasons, a decision needs to be made to move into nursing home care. Because of the dementia, often the person cannot exercise choice about something as fundamental as where he/she will live in the future.

Undoubtedly admission to a nursing home is a major life event for both people with dementia and for family members. The difficulties that family members experience



are often exacerbated by the largely negative image of nursing homes held by the public at large and by older people themselves including those with a dementia. Most older people, including those with a dementia, want to stay in their own homes irrespective of their level of dependency.

Accordingly for family members, the decision to place someone in long-term care is not made easily. It is also not unusual for caregivers to vacillate in their decision making, as a decision like this takes a long time to process; one minute the carer thinks he/she is able to cope, the next he/she finds the whole situation is way beyond him/her.

Questions often asked include—“how will I know when is the right time to find a nursing home”; “which facility is most appropriate for my relative because of the dementia”; “will I be able to afford the cost of care”; “how will I maintain our valued relationship if my relative no longer lives with me or recognises me” and “what if my relative refuses to move or refuses to stay in the nursing home?”

¹ Dementia is an umbrella term used to describe a group of diseases that have common symptoms but different causes. Symptoms may include impaired memory, language, ability to communicate, mood and personality. Alzheimer's Disease is the most common type of dementia.

Moving a relative with dementia into a nursing home is a complex process and unfortunately, all too often the information provided to caregivers is limited to a simple list of homes, without due attention being paid to the emotional and psychological consequences of the move for the individual and for family caregivers. Being well prepared and knowing what questions to ask when choosing a nursing home can make the decision a lot easier.

This booklet has been written to highlight some of the areas we think may be important to you as a family caregiver when confronted with the decision to relinquish home care. It covers issues such as (i) early indicators of the need for long term care, (ii) factors to consider when assessing the suitability of potential nursing homes, (iii) how to communicate news of the move to a relative and (iv) how to make a relative's transition into long term care easier. It contains information on the Nursing Homes Support Scheme, including what aspects of your relatives' care are included and excluded in the scheme.



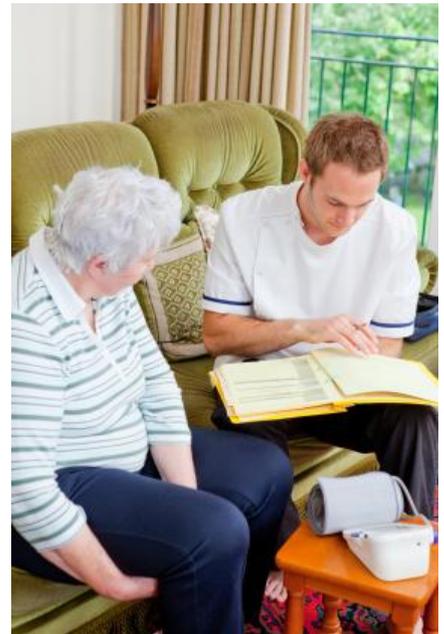
Making Decisions about Long Term Care and Dementia

As dementia progresses and as the caring role becomes more intensive, many family members struggle with the decision to discontinue home care, realising that for them long-term care may now be a more preferable and viable care option. Broadly speaking, the decision to place a relative with dementia in long-term care is not made easily; indeed for adult children, the placement of a parent is one of the great nadirs of life and is often associated with considerable sadness and distress. Likewise for spouse caregivers and particularly those in life-long marriages, the placement of a loved one may result in feelings of immense sadness, loneliness, guilt and sometimes betrayal, for example "I really feel I have let her down". The decision may be the start of caregiver's feeling bereaved.

Given the enormity of the decision it is recommended that it is not made alone but in association with other family members and health service professionals such as GPs, Social Workers and Public Health Nurses. Remember too, that whilst some family members and relatives may resist the decision to place, arguing that it is premature and unnecessary, the one who knows best is the person in closest contact with the person with dementia, usually the primary caregiver.

Indicators of the Need for Long Term Care and Dementia

In the context of Alzheimer's disease or the related dementias, placement decisions are made for many different reasons. Some family members are advised by their GPs or the Geriatrician (Medical Specialist for older people) or Old Age Psychiatrist (Specialist in older people with mental health problems) to wait-list their relative for a nursing home because of a general deterioration in that person's health, or because of behaviours that a caregiver can find challenging such as aggression, sleep disturbance, delusions, hallucinations, or paranoia. Thereafter the family may engage in a potentially very lengthy process of investigating, visiting and wait-listing their relative for different nursing homes. Other caregivers struggle to provide a level of care way beyond their capacity until another family member intervenes, or until a crisis or emergency situation arises.



The following are some warning signs for you as a family caregiver about the need to consider long term care placement:

- You feel physically and emotionally exhausted and are struggling to provide the level of care required
- You feel all other care options have been exhausted, and you have not had a break or a holiday from caring for a significant amount of time
- You have witnessed a major decline in your relative's cognitive or physical health

- Your relative's health and welfare or that of others is at risk at home due to dangerous or challenging behaviours such as delusions, sleep disturbance, or aggression
- The caring role has advanced to a point where you feel your own health is being adversely affected

Once the decision about nursing home placement has been made, questions often asked by family caregivers include:

- Where will I find a suitable nursing home?
- How do I communicate news about the move to my relative?
- How much will the nursing home care cost?

The next section of this booklet attempts to answer these questions. It commences with a brief overview of the Nursing Home Support Scheme and the cost of long-term care.



The Nursing Homes Support Scheme

The Nursing Home Support Scheme (previously known as the Fair Deal) enables an older person or a person with dementia to be fully assessed by a health service professional in the context of his/her medical and social care needs. Based on individual circumstances, the scheme offers financial support for the cost of long term care. A request for Nursing Home Support can be made at your local Nursing Home Support Office; this can be found on www.hse.ie or by ringing the HSE (1850 241850). The request can be made by the person with dementia (provided the person has capacity) or by another person on his/her behalf.

Whilst under the current legislation, an application to the Nursing Homes Support Scheme can be made without the person's knowledge, we would strongly recommend that irrespective of the level of memory and cognitive loss, efforts are made to discuss the matter with your relative in advance of making the application.

The Nursing Home Support Scheme application procedure consists of three parts:

1. Care Needs Assessment
2. Financial Assessment
3. Nursing Home Loan (optional)

1. Care Needs Assessment

The Care Needs Assessment can be carried out in a hospital, a community setting or in the person's home and is undertaken to identify whether the person needs long term nursing care. It is done by a health care professional appointed by the HSE and it may include a physical examination. Assessment consists of reviewing a person's abilities to carry out activities of daily living (ADL's) such as dressing, food preparation, bathing and shopping. The person's individual wishes and preferences are noted during assessment, and consideration is given to the type of community support (formal and informal) being received.

2. Financial Assessment

The Financial Assessment evaluates the person's overall income and assets, and uses this information to determine the contribution that the person will make, and the corresponding level of financial assistance likely to be given by the State. Income includes all earnings, pensions, social welfare benefits/allowances and dividends or interests. The general rule of thumb is that irrespective of means, the expected contribution from the person is 80% of his/her assessable income annually. This means that if the cost of nursing home care is €1000 per week, and the person's weekly contribution is €300, the HSE pays the balance of €700. In addition, a person is required to contribute 5% of any assets each year towards the nursing home care.

An asset is any material property or wealth including that held outside Ireland. Cash assets include savings, stocks and shares. Non-cash assets include all forms of property, for example a person's principal residence or land. Details of income and assets are provided on the assessment form.

If the person is married or part of a couple, half of the combined incomes and assets will be assessed. In relation to assets, the first €36,000 (or €72,000 for a couple) will not be considered in the asset assessment. Also, the person's principal residence will only be included in the financial assessment for the first three years. This means that irrespective



of how long the person remains in the nursing home, a maximum contribution of 15% (5% per year for three years) will be paid on the principal residence. Of course, if the person is in the nursing home for a shorter period than three years, contribution will only be required for the time spent.

3. Nursing Home Loan

This is an optional part of the Nursing Home Support Scheme, which aims to ensure that people are not required to sell assets such as land during their lifetime. The 5% contribution that comes from assets such as property or land can be deferred and taken from the person's estate after death instead, when the accumulated amount of money owed will be collected.

Processing Applications and HSE Support

The HSE cannot guarantee immediate payment of the Nursing Home Support Scheme – this means that if unable to support an application due to funding restrictions, the HSE will place the person on a waiting list. It should also be remembered that the Nursing Home Support Scheme only covers the cost of bed, board, and nursing care. Any additional costs associated with services such as occupational therapy, physiotherapy, chiropody, ophthalmic/dental services, hairdressing, incontinence wear, activities, or medication, are not included. For older people who do not have a Medical Card or a Long Term Illness Book, these additional costs must be paid for by the individual or his/her family.

Families seeking nursing home care for a relative with dementia can choose between approved public, voluntary, or private nursing homes from a list available from the HSE. The individual contribution made by a person in no way affects access to any particular nursing home. The right to choose a particular nursing home is enshrined in the legislation, and the HSE are obliged to provide a complete list of all approved nursing homes. For more information you can contact the HSE or Nursing Homes Ireland—contact information is provided at the end of this booklet.

Choosing an Appropriate Nursing Home

You may need to visit several different nursing homes before you select the one most appropriate for your family member's needs. Like many things in life, forward planning is important and the following suggestions may be useful.

A person with dementia tends to respond well to small, familiar domestic-style environments with separate rooms for separate functions. A basic prerequisite is that the nursing home subscribes to a person-centred philosophy of care and has staff experienced in dementia care. When you visit nursing homes, bring with you a list of relevant questions and do not be afraid to be overly inquisitive. Questions for you or for staff may include:

- Does the nursing home feel friendly and welcoming?
- Is it located close enough for friends/family to visit?
- Do the staff listen and ask for relevant information about your relative, including his or her life story/biography?
- What training do staff members have?
- What is staff resident ratio, during the day and at night?
- Are family members invited to become involved in care-planning and reviews?
- Are visiting times flexible for family members?
- Can outings/overnight stays/holidays with the family be easily arranged?
- Are residents allowed to make choices about their daily routine?

- Does the nursing home have an outdoor area?
- Do staff offer individual as well as group activities?
- Will your relatives increased care needs be catered for over time?
- What is the nursing home policy regarding end-of-life care?
- Has the fee structure been fully explained; what are the additional costs for services for example chiropody or hairdressing?
- Does the nursing home have specialist support, such as access to services including Old Age Psychiatry, Geriatric Medicine, Physiotherapy, Speech and Language therapy and other allied health services?
- Remember, today all nursing homes are inspected by the Health Information and Quality Authority (HIQA), and inspection reports are available on www.hiqa.ie. Based on such reports, what, if any, conclusions can you make about the nursing home having reviewed the inspection reports?

Specialist Care Units and Dementia-Specific Criteria

A minority of nursing homes have Specialist Care Units attached to their facilities and a small number of stand-alone Alzheimer's Units and Specialist Care Units exist around the country. These purpose-built units are especially equipped to cater for the complex needs of people with dementia. They have trained staff, a multi-sensory garden, use appropriate cueing and signage and have activity programmes designed to ensure that residents are kept occupied and enjoy a good quality of life. Remember however that in Ireland, most people with dementia are placed in general nursing homes rather than in Specialist Care Units, as these are the main type of long-term care services available. Listed below are a series of questions worth considering if you have secured a bed in a Specialist Care Unit for your relative.

- Has the facility a home-like domestic atmosphere?
- Are there quiet places available for conversations?
- Is there an open door policy allowing unrestricted visits?

- Are staff trained in dementia?
- During visiting time can you assist your relative with activities such as eating or showering?
- Is there a safe, protected outdoor space or other safe area for your relative to walk around?
- Is it obvious how to get to the toilet from most parts of the unit?
- If lost in the facility, is it easy to find one's way back?
- Is there a broad range of activities for residents which stimulate their senses?
- Is there sufficient choice?
- Are staff skilled in knowing how to cope with challenging behaviours?
- How is the facility regarded in the community?



The Move

When you find a nursing home that you are happy with, it is important to take time to plan the move carefully. Many family members are unsure at this stage how to communicate news of “the move” to their relative. Some chose to say nothing, arguing that there is no point in holding discussions as due to the dementia, their relative will fail to understand or forget. Others lie and say that the move is only temporary, or pretend the person is going for “respite” or going for a “holiday”. Like every other aspect of dementia care, a case-by-case approach is recommended as no two people will be the same. Our advice, however, is as far as possible, be honest with your family member and try to communicate information about the move in a positive, supportive, non-threatening way. Honesty may ultimately militate against your relative becoming very distressed by the unfamiliar surroundings. Being honest may also mean that you yourself will feel less guilty about the decision.

Here are some further pointers:

- If possible, try to introduce your relative to the nursing home gradually so it has become a familiar place by the time the permanent move occurs. Ideally try to use the nursing homes' respite services in advance of the permanent move.
- Try to make the person's room in the nursing home and the area surrounding it as homely as possible. Familiar bedroom slippers, the person's favourite mug and other mementoes of sentimental value to the person will help to create a feeling of home.
- Other suggestions include taking in bed clothes such as a duvet, or small items of furniture such as a small arm chair, although the latter will have to be discussed in advance of the move with nursing home staff.
- Negotiate with staff about placing pictures of family members and loved ones in very visible places, or bring a favourite painting or other objects in from home.

After the Move into the Nursing Home



After the placement, it will take time both for you as primary caregiver, your relative, and the family to adjust to new roles and relationships. By being integrally involved in the decision-making process you yourself may be better able to accept the changed living/care-giving arrangements compared with other family members.

Remember too that whilst you will no longer be physically providing home care, this does not mean that you have stopped caring. Indeed your input into your relatives' care will be hugely important to staff members accordingly as they get to know their new resident. Involve staff in your relative's life story to help them get to know him/her. By working together with the staff you can help them provide optimum care for your relative. Support from other family members and friends is also important for the person with dementia. Try to ensure that friends and family visit regularly. The presence of family and friends may also be very important for you as well in this period of transition.

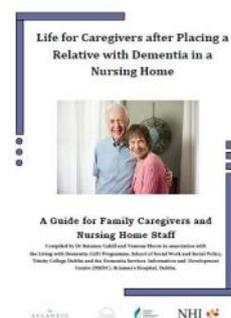
Summary

This booklet has been written for family caregivers of people with dementia. Its main aim is to provide guidance, information and advice to those considering discontinuing home care. It covers issues including (i) indicators for the need for nursing home placement (ii) questions to consider when choosing nursing homes, (iii) the cost of care including information on the Nursing Home Support Scheme (iv) communicating news of the nursing home placement to a relative and (v) how to personalise your loved one's bedroom and immediate environment.

Caregiving obligations are often deeply embedded in long-term marriages and in gendered kinship obligations and decisions to terminate home care tend not to be made until a whole range of other care options are first tried and exhausted. Despite adverse circumstances, including in some cases providing round the clock care, many family caregivers resist placing their relatives with dementia in long term care and continue to provide a level of care way beyond their capacity. Resistance to using nursing homes and struggling to provide home care arises for a whole range of reasons, not least the fear of the unknown (“you can't leave your Mum with a stranger”) and uncertainties about the future cost of nursing home care.

We hope that the facts and information provided in this booklet will make it easier for some of you to make informed choices on these complex matters associated with dementia that are often very stressful. Remember too that whilst most families would prefer to care for their relatives for as long as possible, there are clear instances where placement in nursing homes may be the best care option, for both you as the caregiver and for your relative coping with dementia.

For more information on life after placement of a relative in a nursing home, see our brochure *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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- www.hse.ie

Useful Websites

www.alzheimer.ie

www.hse.ie

www.carersireland.com

livingwithdementia.tcd.ie

www.dementia.ie

www.nhi.ie

www.hiqa.ie

www.myhomefromhome.ie

Useful Phone Numbers

HSE Infoline 1850 241850

Nursing Homes Ireland 01-429 2570

HIQA 021-240 9300

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