

Activities of Daily Living & Other Problems

Living alone

If someone close to you has dementia and is living on their own, you are bound to feel anxious about their ability to cope. Wherever possible, talk things over with the person concerned, with members of the family and with experienced professionals. A number of measures may enable the person to retain their independence and live at home for longer if they wish. Here are some suggestions.

It is important to remember that familiar surroundings and routines are reassuring for people who are confused and that they may be happier if they can continue to live in their own home for as long as possible. Indeed, some people with dementia deteriorate quite quickly when they move in with a member of their family or into residential care.

However, anyone with dementia who is living on their own will probably need a good deal of support, particularly as the dementia develops. Get in touch with the local health centre or public health nurse at an early stage.

Handling risks

Although many safety hazards can be minimised with thought and planning, a certain amount of risk may be unavoidable if the person with dementia is to retain their dignity and independence.

It will help if you can discuss how the question of risk can be handled in the most caring way with other family members and with any professionals involved. You need to agree on what you consider to be an acceptable level of risk after all reasonable precautions have been taken. Then, if something does go wrong, no one person can be blamed.

Of course, other arrangements for care will have to be made if the person's quality of life becomes too poor or the risks to themselves or to others become too great.

Family responsibility

All too often, one member of the family assumes responsibility or is given for the person with dementia and others fail to recognise the stress involved. It is easier for everyone in the family to contribute if they participate in the care from the start.

Try to have a family meeting at an early stage and work out what each family member can realistically offer now and in the future. This may help to avoid later feelings of resentment or guilt.

- Regular visits or an agreement to take the person shopping once a week or to do their washing, for example, are ways of providing support.
- Relatives who live at a distance may be able to contribute towards the cost of some private care or agree to stay in your house and cover for you while you take a holiday.
- Keep in touch through regular visits, letters or phone calls so that everyone remains aware of the changing situation and can participate in decisions that have to be made.
- If there are likely to be family tensions or difficulties in communicating, ask an objective outsider such as a social worker or public health nurse to attend the meeting.

Other commitments

You may feel torn between offering support to the person with dementia and your other commitments.

- If you have a partner or children, try to make sure that they fully understand the needs of the person with dementia. If you can involve them in some aspect of caring, they may be more inclined to give you the backing you need.
- If you are working, explain the situation to your employer or colleagues whom you trust.

Saving your energy

Dementia involves a deteriorating condition which can go on for many years. It will not help you to care if you wear yourself out. Look carefully at what you are doing and decide how best to direct your energy.

- Some efforts, such as trying to keep the person's house immaculate, may not be necessary.
- Some activities, such as doing the shopping, might be carried out equally well by someone else. Accept help from others.
- Even if you are prepared to be the main carer, you must stress to both family and professionals that you need support and a life of your own.

Attitudes to help

People with dementia are often reluctant to admit that they really need help. However, it may be easier for someone to accept help if it is introduced at an early stage.

- Try to persuade them that they need help in order to remain independent when they seem able to understand. Then, if they object at a later stage, you can gently but firmly remind them of your discussion. This is often effective and may help you to remain calm.

- Sometimes you may have to resort to strategies to avoid upsetting the person. For example, you might arrange to take them out while someone else cleans the house or ask someone to distract their attention while you clear out the fridge.
- If the person with dementia sometimes objects to paying for care or forgets to do so, you may be able to make payments on their behalf
- Anyone providing help for someone with dementia must be prepared to have their efforts criticised or ignored or to have the person claim that no one gives them any help. Although this is hurtful, try not to take it personally. It is simply part of the disease.

Tips

Telling other people

Explain the person's dementia to people they know including their friends and neighbours, local shopkeepers and post office staff, the milkman, postman and perhaps the local Gardai. These people may make time to chat, offer help in various ways or keep a tactful eye on the person. Explain that because of their difficulty in concentrating and remembering, it helps to keep sentences clear and short and to use a reassuring but not patronising tone. Gesture and touch can also aid communication.

Health

Any illness may increase the person's confusion. If possible, accompany them to the GP or to a hospital appointment, talk to the doctor yourself and check on any medication. Hearing aids, glasses and dentures should be regularly checked as should the person's feet, particularly if they are having problems with walking. You may be able to arrange for an optician, dentist or chiropodist to call if the person with dementia is housebound.

Medication

Drugs can add to confusion. Make sure the person is only taking medication which the doctor feels is absolutely necessary.

Ensuring that someone with dementia takes the right amount of medication at the right time can be a problem. Compliance packs are available with clearly labelled separate compartments for tablets to be taken at different times. At an early stage, a phone call may be enough to remind them. Get rid of any old unwanted medicines, as they may take these by mistake. Check with the doctor or pharmacist before giving an over-the-counter remedy such as an aspirin.

Money

The person will need help in managing their finances. You can handle their money and pay their bills directly if you are an appointee or if you have Enduring Power of Attorney (see information sheet on Financial and Legal Arrangements). Anyone handling cash for the person should keep careful account of what is spent to avoid any possible problems. People with dementia may forget what has been agreed and accuse carers of taking their money. If you are not paying their bills you should ensure that the electricity, gas and water companies know about the situation so that they will not suddenly be cut off.

Memory aids

A prominently displayed noticeboard with useful telephone numbers, details of who is calling and when, and information such as the location of the stopcock and fuse boxes may be helpful in the early stages. It may also be helpful for the carer, particularly if there is a crisis.

Clock

A clearly-visible clock with hands that does not need frequent winding may help the person to keep some track of the time, at least at first. Similarly, if someone visits each day, they could cross off days on a calendar with the person. Labels or notes on cupboards, drawers and doors can serve as useful reminders.

Food

It is important to ensure that the person has a balanced diet. At later stages shopping and even cooking for them may not be enough. Someone may need to be with them to make sure that they eat at least one proper meal a day. You may also need to check regularly that food has not been left to decay. This is particularly important as the person might eat the decayed food by mistake.

Household safety

Make sure the home is well lit and that there are no obvious hazards such as trailing flexes, loose stair rails or unsteady furniture. Items in daily use in the kitchen should be within easy reach. Remove dangerous substances such as cleaning fluids and paint stripper or lock them away. Electric and gas appliances should be checked for safety. If the electric wiring is very old, it may be dangerous. Ask advice from a qualified electrician. Make sure the person does not take an electric fire or other electrical equipment into the bathroom. Remove locks from the bathroom and toilet if the person is likely to lock themselves in. (See Safety in the Home).

Aids and equipment

The person will probably not be able to learn how to use new equipment so installing a shower, when they have been used to a bath, may not be of much help. However, handrails on the stairs and by the bath and toilet may be helpful. An occupational therapist can advise on rails and on other ways of making the home safer.

Warmth

It is important that the person's home or at least the room where they are living is adequately heated. Draught proofing and insulation can help keep down heating costs. Wearing several layers of clothing can also help to keep them warm. If they forget to put the heating on, you may need to consider some form of heating that switches itself on and off automatically. Fires can be a hazard so make sure that any fire or heater has a fixed guard. Avoid electric blankets if the person is or is likely to be incontinent.

Gas

If you are worried about the person's use of gas appliances - for example, if they are inclined to turn a gas on or gas fire on without lighting it - contact your Bord Gais. They will visit and advise on helpful adaptations and a range of safety measures or cut off the gas supply if necessary.

Water

You may worry that the person will forget to turn off the tap and flood the home. Contact your local corporation or county council for advice on how best to manage this situation. Devices which can help may not be cheap but they may be less expensive than the cost of clearing up after a flood.

Wandering

If the person is inclined to wander, it may be sensible for them to wear or carry some form of identity with your telephone number or the telephone number of a helpful neighbour, for example. It may also help to alert the neighbours, local shops and Gardai of the situation in the event of the person becoming lost or wandering.

Security

Security can be a problem. The person may go out leaving doors and windows wide open. They may welcome strangers into their home or they may lock themselves in and not answer the door. It is helpful if a neighbour can keep an eye on the home and have a spare set of keys. A crime prevention officer from the local Garda station can advise on suitable window and door locks, including doors that you can open from the outside. It is preferable to avoid chains or bolts that would prevent getting in in an emergency. Ask neighbours to inform you if they see strangers going into the person's home.