

For next of kin

Roles and expectations

As dementia progresses, major adjustments are often necessary and result in changes to the relationships between the person with dementia and their next of kin, family members, friends and social networks. As a next of kin, you will find that the person with dementia will become increasingly dependent on assistance and support. In the early stages of dementia, there is often a significant amount of uncertainty and anxiety for all concerned.

Your experiences as next of kin will vary to a large degree depending on whether you are a partner, a child, a sibling, or have some other relationship with the person with dementia. A great deal will also depend on the nature of your relationship and how close you have been to the person with dementia. A reversal of roles and expectations within a family is never easy, and some may find that having a loved one with dementia undermines their own sense of security in life. Perhaps the person with dementia was once a source of security and support for others in the family.

Coping with daily life

Coping with daily life as a next of kin will involve dealing with transitions on both an emotional and practical level. It will require problem solving in everyday life, as well as long-term planning. At the same time, you will want to maintain the best possible relationship with the person with dementia. Many next of kin find it best to take one day at a time and try not to dwell on all their worries and concerns for the future. This can be a useful coping mechanism for managing challenges that arise.

Cultures and traditions

Family members may all have different reactions, and there may be disagreements about how serious the situation is and what should be done. There will be different practices and traditions, both within and outside the family, for how to discuss problems. There may be negative attitudes and taboos surrounding dementia. In families where care tasks are primarily perceived as a personal responsibility, next of kin may be especially reluctant to ask for help from the public sector.

Care and responsibility

It is common for next of kin to feel as though they are struggling to sufficiently manage tasks and meet expectations. It is important to be kind to yourself in a situation that often makes demands you were neither prepared for, nor accustomed to dealing with.

One transition that may be particularly difficult is when the person with dementia must move from their home into a nursing home. Next of kin will often experience both grief and a certain relief, which may result in a sense of guilt. It may be helpful to remind yourself that good care also involves handing some of the responsibility over to professionals. This doesn't mean you have stopped caring about them.

Loss and grief

Many next of kin describe losing the person with dementia "bit by bit". This is known as 'anticipatory grief'. It is characterised by feelings of depression, anger, and increased vulnerability and fatigue. This type of grief has much in common with reactions following the death of a loved one.

In addition to their own grief, close relatives will often observe grief reactions in the person with dementia. This can be painful to witness. Dealing with change and loss without becoming overwhelmed or incapacitated is emotionally challenging. Many find it helpful to express their feelings of grief. Talk to family and friends or seek professional help.

Self-care

Next of kin are often told: "*You have to take care of yourself.*" Such encouragement may be well-intentioned, but advice on what you *should* do can sometimes be an added burden. It may be perceived as yet another unmanageable task. Although it can be difficult to prioritise, it is important to make time for yourself. What do you enjoy and what helps you relax? Is it meeting friends, physical activity, or just spending time alone? Making time for yourself and maintaining good habits is important for your personal health. It can also give you more energy to manage your situation and role as next of kin.

Openness

We all cope with challenges in different ways. There is no "right" way to react, or single "recipe" for everyone to follow. Many have found it helpful to talk to someone about their situation. This can also help you sort out tasks and expectations.

As dementia progresses, it poses many challenges for the person with the disease, their next of kin and their community. Being open about the diagnosis can make it easier to get the necessary assistance and receive support from others.

Help from family and friends

As next of kin, you may need a helping hand and a break from the situation. It is a good idea to consider who in your family and social network would be able to help. They may have wondered about changes they have noticed in the person with dementia. Being open and willing to include others at an early stage of the disease will make it easier for them to offer help and support. They could provide essential support and help ensure that the person with dementia, and you as next of kin, can continue activities and retain a sense of community.

Be specific when asking for help from family, friends and acquaintances. They may find it difficult to know what they can do to help. Creating a list of specific tasks can lower the threshold, making it easier for them to contribute.

Services

Although public services and programmes may not be needed at first, they will become essential as the disease progresses. Your municipality can provide an overview of available services and programmes. Relevant services include day activity programmes, home-based services, respite care, short-term stays, personal support contact persons, and information and support services.

Many find it beneficial to meet others in a similar situation to share experiences and grief, and to support each other in their daily lives. Both health and care services and voluntary organisations provide services such as "caregiver schools" and discussion groups.

Collaboration between next of kin and health and care professionals

Collaboration between next of kin and health and care staff is essential in both home-based services and institutional care. It is helpful to share information, clarify what you expect from one another and how you can work together to ensure that the person with dementia has the best possible quality of life.

As next of kin, you can help staff in the care system by familiarising them with the habits, traditions and values of the person with dementia. Studies show that when people with dementia receive support from healthcare professionals who are understanding, facilitate individual care, are familiar with the individual's cultural and language background, and who use interpreter services when necessary, this helps next of kin feel more secure. An open dialogue and a regular contact person in the support system are also valuable for next of kin.

Relevant websites

<https://www.aldringoghelse.no/demens/>
www.hvemsermeg.no
www.tidtillavareung.no
www.nasjonalforeningen.no/demens/parorende-og-demens/

Dementia line, Norwegian Health Association
– tel. 23 12 00 40.

References and literature tips: Ageing and health: www.aldringoghelse.no/demens/parorende/hverdagen-som-parorende/, *Jeg trodde jeg var den eneste som hadde det sånn ...* (2016). Norwegian Health Association: *Håndbok for pårørende til personer med demens* (2018), *Demens i familien* (2018).

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