



# Advice for relatives





## **Good advice for relatives of people with dementia**





## Here are four pieces of advice for anyone who is a close relative of a person with a dementia disorder.

***Dementia changes the way in which you are used to being together. This can feel painful and very frustrating, both for the person who is ill and the relatives. Some people describe it as saying goodbye to a person who you still get up with in the morning and who sits in their regular place in the kitchen.***

### 1. Take care of yourself

It is hard to remember to take care of oneself when another person needs you. Many relatives have difficulty finding the time and energy to do the things they like doing. This impacts their quality of life. Close relatives of people with dementia are therefore more often stressed and are more prone to depression than other people, because supporting and caring for a person with a dementia disorder demands a lot of time and energy.

Practical tasks are one thing – the thoughts and concerns that are always present are something else. You should therefore do what you can to take a break where you can do something you enjoy. Maybe you just need a few hours to read or go for a walk. Regardless of what you need, prioritise finding the time, so you can also find fresh energy to be there for your loved one.

If friends and families offer their help, accept it – even though it may be difficult to do so. You can help your relatives by telling them where and how they can help. Be open about what you and your loved one need. You can also apply for professional help in the home, for example home help. You can also get relief care for the person with dementia, ranging from a few hours a week to several weeks at once.

### 2. Search for knowledge

Search for knowledge about the disease, the support available, and how you can get home help if the need arises one day.

It is hard to watch as your partner changes or disappears into his- or herself. If you search for knowledge about the disease, you will be in a better position to care for your loved one. You will have fewer conflicts because you know what the disease entails and how it can affect your partner and your daily lives. Your time together will be better if you are prepared and try to accept the changes.

You can also seek out knowledge about support options and the possibility of professional help. For example, in Denmark it is possible for you as a caregiver to be hired as a personal helper or to receive special care leave if you work. Ask your doctor or the health and social services in your municipality for advice. They can help you.

### 3. Talk to others

As relatives you may feel very lonely. Your friends and family may not fully understand the illness or the situation you find yourself in. It might be challenging to have to help a parent or spouse with personal hygiene, but at the same time it may be too difficult to refuse.

It is important not to isolate yourself. Everyone needs social contact and to feel understood. You can use your friends, family, networks for relatives of people with dementia or seek sparring with a psychologist. A psychologist is particularly good in helping if you have difficulty with your own boundaries. Sessions with a psychologist can be subsidised if you get a referral from your own doctor.

As a relative of a person with a dementia disorder, you will at some point experience emotions that you are reluctant to talk about. As relatives, you may become angry, upset and frustrated, and this affects your mood and patience. These are natural emotions, and it can be good to know that others in your situation feel the same way. It is difficult to push your own needs to one side and always have to take the needs of your partner into account. Still, the majority of relatives find it difficult to talk about these kinds of feelings. Many are ashamed of the anger and frustration they feel. It is therefore good to have a network where you can also talk about difficult emotions and taboos.