

# Dementia: Information for caregivers

## **Q. How do I reach out to others for help when caring for someone with dementia?**

- A. Caring for someone with dementia can be overwhelming and does not need to be a lonely experience. Remember that you are not alone – ask for help. Describe your problem and what kind of help you need. It might be help with cleaning or preparing meals, support for activities with the person with dementia, or emotional support or information. Be flexible - you may not get exactly what you asked for, but it is a start and will be helpful.

Organizations that provide these types of support may be available in your local community, or online. Your local Alzheimer's association or your local doctor can be a good place to start.

## **Q. How can I care for myself?**

- A. Social support is important – stay connected as much as possible. Talk regularly to someone you trust and who understands your situation and feelings. This might be family, friends, a community, religious or spiritual leader, a neighbour, or a volunteer.

You may think that events make you feel angry, sad or guilty. However, it is how you think about them that makes you feel that way. It can be helpful to identify the specific situations that make you feel bad and what your thoughts are in that situation. You might also want to identify what would be a more helpful way of thinking and how more helpful thoughts can make you feel better.

## **Q. How do I ensure that the person with dementia continues to receive care if I am no longer able to provide it?**

- A. Plan in advance – ask the person with dementia about their care preferences, including by whom and where they would like care to be provided. Identify people who would be willing to provide support if you can no longer provide care. Plan for costs of future care and discuss preferences in case of more advanced care needs and end-of-life decisions.

Gather information to make informed choices. Make decisions together and talk with your family, friends, doctor, any others close to you and the person with dementia. Prepare instructions that reflect the wishes of the person with dementia in accordance with the legal framework in your country.

**Q. How can I respond to changes in the person with dementia?**

- A. As dementia progresses, the person with dementia may change. Changes may include agitation, depression, anxiety or apathy, becoming withdrawn or overly suspicious, having difficulty sleeping or changes in judgement. The person may also show signs of confusion, deterioration of existing cognitive problems (e.g. memory), delusions and hallucinations, and repetitive behaviours or wandering.

Identify the changes and what appears to be triggering them. Think about the best ways to respond that will be the least distressing to you and the person with dementia. Try different responses and approaches – your first response may not always work.

If the person has serious and constant mood changes or if you think that they are in danger of harming themselves, seek immediate medical advice.

**Q. How can I provide everyday care to the person with dementia?**

- A. As dementia progresses, you may need to provide more care than you are currently doing. Make sure that the person is eating and drinking. You may need to regularly remind them to do so. Adjust their diet according to their

preferences and health. Remember to keep inedible items, sharp objects, household chemicals and flammable materials in a safe place.

Modifying the environment can help reduce incontinence accidents. For example, put a picture of a toilet on the bathroom door. Remind the person to go to the bathroom regularly. Consider using incontinence aids and equipment if necessary. Do not blame the person for accidents.

Engage the person in personal care by helping them do as much as they can themselves. Try modifying the environment, for example by switching from a shower to a sponge bath, and provide guidance. Be mindful of falls – use a non-slip shower or bath mat. The person with dementia may resist when you try to assist with personal care. Be compassionate and try to understand why.

It is important to maintain routines similar to the ones that the person had before developing dementia. Be prepared to adapt routines as necessary as the abilities of the person change over time.

**Q. How can I communicate effectively with the person with dementia?**

- A. Dementia can often make communication difficult. This can have an impact on your relationship with the person you care for and can be frustrating, upsetting or irritating for both of you.

Get attention in a respectful way. Speak clearly, slowly and at a volume that is comfortable for them. Speak face-to-face and at eye level. You might also try lightly tapping a hand, arm or front of the shoulder, or calling the person by their name or a nickname that they recognize.

Ask or tell the person with dementia one thing at a time. Use short sentences and simple words that the person with dementia can understand. Repeat information calmly, as often as necessary. When needed, change from open-ended to close-ended questions that can be answered by yes or no. Make sure that there are no distracting background noises such as a television or radio.

Try to stay in control of your feelings. Sometimes, you might not understand what the person you care for is trying to say. It is important that you take the person seriously – they are trying to tell you something. Be patient and give the person time to find their words. Pay attention to their reactions, including facial expressions and body language. Show compassion about the feelings that the person expresses. Remember that saying something positive or complimenting the person can make them feel good.