

Preparing for in-home help and support

Ways to make in-home help and support a positive experience

How to prepare your relative

Meeting the needs of the person you are caring for can be difficult. At times, as a family caregiver, it may be necessary to bring in others to help “share the care.” It is common for people with dementia to find new environments and new people unsettling. Because of this, it is important to plan ahead for a positive experience. Many families and caregivers have found it useful to:

- Start using regular in-home help and support as early as possible so that everyone can get used to sharing dementia care.
- Start with small breaks and build up to longer ones.
- Base your timeline for telling the person with dementia about in-home help and support on their mood and behaviour. Choose a time when things are calm.
- Reassure them if they are anxious and make sure they know that you are positive about the break even if you’re feeling a little anxious yourself.
- Talk with other families and caregivers about ways they’ve managed to make this a positive experience. It may give you some practical ideas for managing. Consider joining an Alzheimer Society support group.

When you meet resistance

Trying to understand why your relative might be resisting help can be an important first step. This could be because persons with dementia often “fear” new situations and will become upset and respond that “they do not need help”. Also, it is often difficult for

people to accept help because it means having to acknowledge an illness and the physical and cognitive changes that accompany it, particularly if personal care is needed. These problems are not unusual and should not stop you from obtaining in-home help.

What to try:

- **Advance introduction.** Introduce the care provider to the person with dementia before care begins so the care provider is not a stranger.
- **Begin with small breaks.** Consider having the care provider come the first few times while a family member (or someone the person trusts) will be at home. Leave for a short time and return. The next time, leave for a bit longer. Repeat this until the person with dementia begins to feel comfortable alone with the care provider.
- **Put the focus on you.** Sometimes people are more willing to accept in-home help if it is presented as being for the family member. For instance, someone to help clean the house.
- **Use “I” language.** Frame the situation so it’s about you rather than the person with dementia. An example would be saying, “I know you are very independent and don’t feel you need extra care at home, but I worry a lot about you and this would help me not to worry so much when I’m not able to be here.”
- **Regular contact and reassurance.** Sympathize and understand the fear and vulnerability associated with the transition. Take time to listen and realize the first time may not work. It could take a few months before the person with dementia feels more comfortable with the situation.

Working with the care provider and the agency

When planning to use in-home help and support, find out what type of help is available and what will work best for you and the person with dementia. It can be helpful to think about in-home help and support as a partnership between yourself and the care provider, working together to make a positive experience. To make this a positive experience:

- **Communicate** your needs and the needs of the person with dementia clearly and openly. A strategy might be to fill in a Personal Care Book which is a communication tool used between caregiver and case worker.
- **Give important information** to the respite worker or facility. Knowing the individual likes and dislikes of the person will help staff care more easily, and will help minimize any changes. Share historical information about their life. Some people find that sending a life story photo album or board works well as an aid to conversation.
- **Explain** what is important to you and the person with dementia about the care they receive. For example, perhaps there is a special soap that is preferred for bathing.

What to do when a person with dementia is living alone

- **Use your visits wisely.** Meet with the care provider agency staff to discuss help and support needs. Make any appointments you need with professionals including doctors. Try to be in the room for the first doctor's visit to establish rapport and connections. Spend time talking and listening to your relative before and after visits.
- **Turn to others for help.** Establish a support system for your relative and yourself that could include friends, neighbours, church group,

community group, and use of available community resources.

Some final considerations

- You may get some practical ideas by talking with other people in a similar situation about ways they've managed to make in-home help and support a positive experience. Contact your local Alzheimer Society for information about community services and support groups.
- Keep trying! In-home help and support is an adjustment for all families and caregivers as well as the person with dementia and it can take time to build a sense of trust. If you're not happy with the experience – try again.

Further information on this topic

Visit the following websites:

- Alzheimer Society of Canada:
<http://www.alzheimer.ca/en>
- Canadian Caregiving Coalition:
<http://www.ccc-ccan.ca/>
- Alzheimer Society of PEI:
<http://www.alzheimer.ca/en/pei>

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