

Using Respite Care

A background sheet for family members and others 'caring' for a person with dementia

Respite care is a DHB allocated and funded support for short-term care used as a temporary alternative to a person's usual care arrangements. It can provide a break from the responsibilities and demands of caring for someone with dementia. It enables family and other carers to have a rest, go out, attend to business or go on a holiday. Many carers/care partners find that a regular break helps them relax, and avoid burn out. Respite care may also be needed in other situations. For example, the primary carer might have to go into hospital, or might have other important commitments. Respite care also gives a person with dementia an opportunity to socialise and meet other people.

Managing feelings such as guilt or anxiety:

Many people who care for someone with dementia feel worried or guilty about taking a break and leaving the person they are supporting, even for a short period. It is important to remember the following points:

- If a carer stretches themselves too far and becomes ill or depressed, life may become more difficult both for them and for the person with dementia
- carers are entitled to time to themselves, to do what they want to do.

Many carers find it helpful to discuss such concerns with a social worker from Dementia Canterbury or another professional with knowledge of dementia, and/or with other carers/care partners.

If possible, also discuss the situation with the person with dementia. This person may prefer one sort of arrangement to another.

It is natural to prefer to stay in familiar surroundings, especially for someone with a diagnosis of dementia. The person may not fully understand if they have to go away and may feel confused, and may say they don't want to go. This can make the person who normally cares for them feel guilty about wanting or needing some time alone. However, it is important to remember that taking an occasional break is good both for the carer and the person with dementia, as time apart will enable the carer to 'recharge' their batteries and both may feel refreshed.

Care at home:

Arranging care in the home of the person with dementia has some advantages - for example, the person may find it reassuring to remain in familiar surroundings. However, the people who normally care for them might have to spend considerable time and effort making arrangements to ensure that the person is well cared for and that the home runs smoothly while they are away.

The easiest solution might be to arrange for a friend or relative to stay. If this isn't possible there are a number of other options. It is important to think carefully about the type of care required.

It is essential to leave very clear explanations and instructions for whoever is caring for the person with dementia, preferably in writing. This means that there is less possibility of them forgetting, or of there being a misunderstanding. Instructions should include:

- details of the usual routine and activities of the person with dementia, their likes and dislikes and any dietary, religious or cultural practices that should be respected
- clear instructions about the running of the home - for example, which keys lock which doors, and how the washing machine operates
- important phone numbers - for the GP surgery, neighbours
- your contact details, other family members, or of someone else to contact in an emergency.

Care away from home:

If short-term care is arranged away from home, the person with dementia may take some time to settle into their new environment. It may also take them some time to readjust when they get home. The person with dementia may not understand why they need to go somewhere else, so those around them need to give calm reassurance that this is only for a short time and carers need to be firm about the fact that they need a break.

Visit the place beforehand, preferably with the person with dementia, to ensure that the place is suitable and that it can cater for individual needs. Ensure staff have enough information to enable them to relate to the person with dementia as an individual, to reassure the person when necessary and to avoid any unnecessary distress.

Dealing with any difficulties:

Difficulties can arise, especially when using respite for the first time. Some families and carers find that the person with dementia does not wish to leave them or leave home for a break, or that they want to come home whilst using respite. Other families and carers are concerned about uncharacteristic behaviours that occur when using respite or the effects on a person with dementia after respite. These problems are not unusual and should not stop you taking a break. There are many ways to manage these difficulties so that you and the person you are caring for can make the most of respite care.

What to try:**Plan ahead -**

Many people with dementia find new environments and new people unsettling. It is important to plan for a positive respite experience.

Many people have found it useful to use regular respite early in the care situation, so that everyone can get used to sharing the care.

You will know best how far in advance to tell the person about respite. Reassure the person if they are anxious and make sure that they know that you are feeling positive about the break, even if you're feeling a little anxious yourself.

Prepare background information for respite carers -

A Life History book, photos or personal profiles can help to give vital information about the person with dementia to others caring for them at home or elsewhere. These will aid respite carers to understand their needs and interests.

Start with short breaks -

Many families and carers find it best to start with short breaks and build up to longer ones. This enables both of you to gain some confidence about the experience. It may be useful to have an initial meeting with the person with dementia and the respite carer prior to the break.

Keep trying -

Respite is an adjustment for families and carers and the person with dementia, and it can take time to build a sense of trust. If you're not happy with the respite experience – try again. The person you are caring for may well get used to different things over time. Perhaps planning to do something differently next time will improve the experience.

Remember that regular breaks are important for all families, carers and people with dementia. You will almost certainly enhance your ability to carry out the demanding role of caring for someone with dementia – so keep trying.

Adapted from:

'Looking after Families and Carers' - Dementia Australia help sheet 'Taking A Break'

'Respite care' fact sheet 462 Alzheimer's Society UK

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