

UNDERSTANDING YOUR FEELINGS – NOTES FOR CARERS

Caring for someone with dementia requires time and energy and can be a demanding and stressful task. It is important to recognise and acknowledge your feelings and to be aware of the signs of stress in yourself.

Stress can not only limit the rewards that caregiving can offer, but it can seriously threaten your health and therefore needs to be dealt with. Carer's stress is not the result of personal failure – stress is the result of the demands of the caring role.

Some stress is normal, but too much stress can be damaging to carers and the person being cared for. Recognising the signs of stress and learning how to reduce it can help to sustain your caregiving role.

Accept your feelings

You may experience a range of different and often extreme feelings. This can be particularly difficult because dementia causes gradual changes in a person's abilities and personality and the nature of your relationship will also change. Feelings like anger, resentment, guilt, embarrassment, loneliness and grief are very common among carers. **It is important to be aware that these feelings are all normal.** Keep in touch with family and friends and discuss what is going on.

Anger & aggression

It is natural to feel frustrated and angry – angry at being the carer, angry with others who do not seem to be helping out, angry with the person in your care for various reasons and angry at inadequate support services. Caring for a person with dementia can be stressful and frustrating and sometimes you may feel like shaking, pushing or hitting a person with dementia. These feelings could well be a signal for you to start caring for yourself. Abuse of a person with dementia is never acceptable. You need to make sure that you are getting enough help and support.

Guilt

It is quite common to feel guilty for the way one treated the person in the past, guilty at being embarrassed by the person's odd behaviour, guilty for losing one's temper, guilty for not wanting this responsibility, guilty

for taking time off, or guilty for considering sharing care with professional caregivers. You may have made tacit or overt promises like "I'll never put you in a rest home" and it can be very difficult if this proves necessary.

It is important to recognise the guilt feelings so that you can reduce them. Underlying feelings of guilt can limit your energy and well-being.

- Talk to somebody you trust, either a friend, a counsellor or family member.
- Set realistic standards of behaviour for yourself.
- Tell yourself that all humans are fallible and limited, and that you are no different from others.
- Try to accept that you have to be able to look after yourself first, before you can care for another person.
- Make realistic and positive statements such as "I am doing this job to the best of my ability" instead of saying "I should do" say "I could do".

Remember that you are not alone in your role as a carer, and there are supports available to help you.

Grief

Dementia is a disease with many losses and grief is a normal reaction to loss. Many carers say that grief is an ongoing process, with different losses becoming apparent as the disease progresses, such as loss of companionship, intimacy and mutual support.



Depression can occur due to the high levels of stress associated with the caring role. It is important to advise your doctor if you are feeling consistently “blue”, you are not sleeping, or generally feeling sad.

Attitude

Accept that there are stress factors you can't change like the responsibility and demands of caring for a person with dementia. Other stress factors you can change are:

- Unrealistic expectations placed on yourself
- Unrealistic standards to be maintained
- Inflexible thinking
- Withdrawing from support offered
- Maintaining a false public face

To minimise your stress you may need to lower your expectations and your standards. Try to be open to unusual solutions and to be flexible. Change your attitude.

Recognise your limits. Maybe you can provide care until a person with dementia dies. Then again, maybe you can't.

Isolation

As a carer you can be at risk of becoming socially isolated because it is likely that caregiving will become more and more time consuming.

You may find that family and friends don't visit as often, perhaps because they don't know how to react and what to do to help.

Write down all the things that are worrying you: the practical difficulties of managing the physical care; your feelings and emotions; lack of space or time out for yourself; and ideas about what would help – be specific even if they seem impossible. Identify who you could talk to in order to get support and help: family members, friends, doctor, district nurse, a community worker at your local Alzheimers organisation, minister of religion, social services.

The occupational hazard of caregiving can be burnout and depression. If you burn out or come close to it, you cannot provide good care. One of the symptoms of burnout is resistance to the mere suggestion that you can't do it all.

- If you feel that whatever you do is not enough
- If you have sudden mood changes
- If it becomes increasingly difficult to face each day
- If your health is deteriorating
- If you become forgetful yourself or have difficulty concentrating
- If you feel overwhelmed or regularly irritable – then chances are you need help urgently

Don't let caring become your whole life. Accept the need to care for yourself.

For details on how to look after yourself, see Alzheimers New Zealand Information Sheet Fifteen “Caring for the Carer”

Alzheimers New Zealand has a range of information sheets and booklets available for people with dementia, their carers, families and whānau. Alzheimers member organisations located throughout New Zealand provide a variety of services and support to all people affected by dementia. Contact your local organisation on freephone 0800 004 001.

This information sheet provides a general summary only of the subject matter covered and is not a substitute for informed professional advice. Any person with dementia or their carer or family/whānau should seek professional advice about any individual case. Alzheimers New Zealand is not liable for any error or omission in this publication, as a result of negligence or otherwise. This information sheet was produced in March 2010.

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