

Chapter 3 part 2

1.1 Chapter 3

1.2 introduction

Hello, and welcome again to coping skills for families and carers. This is chapter 3: Maintaining relationships Part 2: Living with losses.

1.3 Losses and changes

It is not uncommon for families to notice changes in their loved ones living with dementia. These changes are part of the dementia journey and may start immediately after a diagnosis or they may emerge as the journey of care continues. Click on the video to hear carers talk about losses and changes.

1.4 Carers' feelings

You may have feelings of loss and grief as these changes set in. You may experience many emotions at different times throughout the care-giving journey.

Here are some of the common feelings experienced by carers in responses to changes brought upon by dementia .

Denial

- hoping that the person doesn't have dementia
- expecting the person to get better
- convincing yourself that the person hasn't changed

Anger

- being frustrated with the person

- resenting the demands of caregiving
- resenting family members who can't or won't help provide care
- feeling abandoned and resenting it

Guilt

- wondering if you did something to cause the illness
- regretting your actions after the diagnosis
- feeling bad when you take a break
- feeling that you've failed when you can't care for your loved one at home
- having negative thoughts about the person with dementia, or wishing that he or she would go away or die
- regretting things about your relationship before the diagnosis
- having unrealistic expectations of yourself

Sadness

- feeling despair or depression
- withdrawing from social activities
- withholding your emotions

Acceptance:

- coming to terms with the diagnosis and with the reality that your day to day life will eventually change
- finding personal meaning in caring for someone who is terminally ill
- finding pleasure in being with the person in the moment
- seeing how the grieving process affects your life

- appreciating the personal growth that comes from surviving loss

1.5 Coping with feelings

How do we cope with those feelings?

- Face your feelings: think about all of your feelings - positive as well as negative. Let yourself be as sad as you want. Work through your anger and frustration. Know that it is common to feel conflicting emotions. It's okay to feel love and anger at the same time.

- Prepare to experience feelings of loss more than once: as dementia progresses, it is common to go through feelings of grief and loss again. Accept and acknowledge your feelings. They are a normal part of the grieving process.

- Claim the grieving process as your own: no two people experience grief the same way. Grief hits different people at different times. Some people need more time to grieve than others. Your experience will depend on the severity and duration of the person's illness, on your own history of loss, and on the nature of your relationship with the person with dementia.

- Talk with someone you trust either formally or informally: talk formally to a therapist who is experienced in bereavement counselling or talk informally as part of a support group or in an Alzheimer cafe. Talk about your grief, guilt and anger

- Combat feelings of isolation and loneliness: carers often give up enjoyable activities and friendships. Make a lunch date or go to the movies with some friends. Taking a break could help relieve stress and grief, and would strengthen your support network.

- Join a support group: when you talk to other carers, share your emotions, don't limit your conversations to caregiving tips. Cry and laugh together.

- Know and accept that some people might not understand your grief> most people think grief happens when someone dies. They may not know that it's possible to grieve deeply for someone who has a cognitive illness.

- accept yourself: think about what you expect from yourself. Is it realistic? Learn to accept the things that are beyond your control. Make responsible decisions about the things you can control.

- take care of yourself: the best thing you can do for the person in your care is to stay healthy. This includes taking care of your physical, mental and emotional well-being. See our chapter 2: looking after yourself.

1.6 As dementia progresses

As dementia progresses, you might be faced with more and more challenges.

- try to remain calm: it can be painful when you are called by a different name, or not recognized, but try not to show that you are hurt. This is a symptom of the dementia, and not a reflection of a change in the person's feelings about you.

- Respond with a brief explanation: try not to overwhelm the person with contradictions or reason with them. Instead, clarify with a simple explanation.

- Show photos and other reminders to remind the person of important relationships and places.

- Be with the person where he or she is in time, engage in conversation about past memories with an understanding that this is their current reality.

- Most importantly, do try not to take anything personally. Dementia causes your loved one to forget, but your support and understanding will continue to be appreciated.

- Share your experience with other who understand what you are going through. Keep going to support groups, Alzheimer cafes, etc.

1.7 Later stages

Later in the dementia, memory loss becomes more severe.

A person may no longer recognize family members, they may forget relationships, they may call family members by other names, they may become confused about the layout of home and by

the passage of time. They may forget the names and purpose of common items, such as a pen or a fork. These changes are some of the most painful for carers and families. Be aware that throughout dementia, you will need to re-evaluate and re-position yourself in relation to the person with dementia. There may come a time when you will need to consider transition to long term care.

1.8 Long-term care

At the time of transition into long term care, it can take some time for carer, family and friends to adjust, and it is not unusual to experience grief.

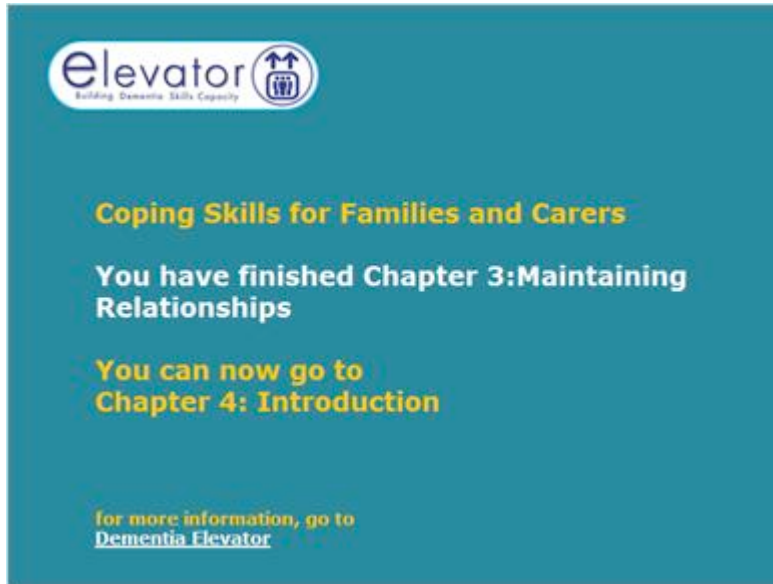
How can you deal with the transition to long-term care?


- If you are actively involved in the decision-making process regarding the nursing home, it makes it easier to accept the change. Think of Filling in a "think ahead form" which will help you to plan for the future.
- your input into the care of the person with dementia is still important, it is in fact vital to staff members in the nursing home.
- Involve staff in the person's life story; by working with them, you can help them provide the best possible care for the person. Make sure that family members and friends visit regularly.
- speak with other carers who have been through the same experience. Share tips and information.
- Talk about your feelings about the transition to long term care with someone you trust, a family member, a friend, or a professional Counsellor.

1.9 Long term care: the carers' experience

Click on the video to hear about the experience of carers with the transition to long-term care.

1.10 For more information




Building Dementia Skills Capacity

Coping Skills for Families and Carers

You have finished Chapter 3: Maintaining Relationships

You can now go to Chapter 4: Introduction

for more information, go to [Dementia Elevator](#)