A Carewatch Dementia Guide

Learning to Live with Dementia

By Robin Dynes

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Learning to Live with Dementia

In many ways caring for someone with dementia is like taking a leap into the dark. Most people are unprepared and fearful about how they will cope. It is a journey during which you will experience turbulence, confusion and go through many emotions. These include joy, worry, stress, anger, laughter and tears.

You will need all your strength and problem-solving skills to overcome the difficulties. Here are ten suggestions to help you.

1 Identify and acknowledge your own emotional needs

Caring for someone with dementia is very demanding in time and effort and is emotionally draining. The person you are caring for may get angry with you and hurt your feelings. The fact that one day they do not recognise you or mistake you for someone else will hit hard. You too may feel sad, discouraged, lonely, confused, frustrated, need to grieve and wonder how you will cope. This is normal. Acknowledge that you are doing your best. You can’t do and control everything. Find someone – a friend or a relative - to talk to about your feelings. Join a support group so you can share with others going through a similar experience. Don’t allow yourself to become desperate; if necessary, get help from a counsellor. Learn to forgive both yourself and your loved one.
2 Focus on strengths

Concentrate on taking full advantage of what the person with dementia can still do. If they always loved gardening, find gardening projects to do together. If they enjoyed going to football matches go with them or arrange for someone interested to go. It can be difficult to judge ability to do things as it may vary from day to day. Pushing too hard to do things can result in the person becoming irritable. Be adaptable and adjust activities to suit. In the early stages using memory aids such as lists, notes, etc., will help. Later you will need to use other tactics such as always beginning a conversation, laying out their clothes in the right order, and so on.

3 Be prepared to adapt to changes in your relationship

Whether you are a son, daughter, partner or friend there will be changes. It can be difficult accepting and changing a mind-set such as taking a parental role to someone who has looked after you all your life or mentoring someone who has always guided you. The person may always have been very private and particular about personal hygiene. Now they may start to lose sense of what is appropriate in different situations.
Keep in mind that the problems are probably due to the condition, not the person

Losing memory means the person is unable to make decisions and judgements. To do that they need to be able to hold information in their mind and analyse it and they can no longer do this. Consequently, they may not be able to judge whether or not their behaviour is appropriate. They may blame you for losing something because they can’t yet face the fact it is due to them. Often their feelings may be mixed up and they become sad, confused, anxious or suspicious because they do not understand what is going on.

Don’t predict the future, focus on the present

Make plans for the future but live day-to-day. Take each day as it comes and enjoy it to the best of your ability. What course dementia will take is hard to predict and may not follow an expected path. Live in the present, make the most of each day, be ready to adapt and make changes to deal with anything that might occur but don’t focus on these changes. Encourage the person you are caring for to do the same.
Listen and communicate

It becomes more and more difficult for someone with dementia to communicate what he/she feels or wants. It also takes much more effort for them to understand what other people are trying to communicate to them. There are traffic blocks both ways. This means you will need to invest more time and effort both into listening and communicating with them. The more advanced the condition the more effort is required.

Listening is demanding. Be sensitive to hidden messages in repeated words, phrases and non-verbal behaviour. Ask yourself ‘What might this mean?’ Does repetition of some words indicate a theme to be picked up, such as the person being anxious about something? It is thought over 90% of what we communicate is non-verbal; voice tone, facial expression, eye contact, hand movement, touch and body posture. Respond to non-verbal signs.

Keep your communication simple and straightforward. Speak slightly slower and clearly. Keep sentences short and to the point. Check that the person has understood. Allow extra time for the person to formulate an answer. Make sure your non-verbal communication matches what you are saying. The person will pick up meaning from your body language.
7 Look after yourself

If you don’t look after your own health you won’t be able to care for your loved one. Search out and accept help. Incorporate breaks and time for yourself into your routine. That is not being selfish, it is ensuring that you are fit and have the energy needed to provide good care. Keep a list of things that could be done by others. You are then prepared when someone asks if there is anything they can do to help. It might be a simple thing such as picking up a prescription or staying with your loved one for two hours so you can go to a pottery class. Be specific about the help you need. You will get a more positive response that way.

8 Learn as much as you can about dementia

With knowledge comes understanding. If you understand more about how dementia affects people then you will be better equipped to come up with solutions to problems. You will be more able to separate the condition from the person you have always known and keep things in perspective. You will feel less frustrated, feel more in control of your emotions and be more able to make decisions that you feel are right, both for you and the person with dementia.
9 Keep things as normal as possible

Establish normal daily routines. If the person likes going to Bingo or to cricket or football matches continue in the same way as you have in the past. When they are no longer able to go, organise a Bingo session with friends and family at home. Watch and discuss cricket on TV. Keep things as normal and seeing family and friends. Also, involve the person in all decisions both large and small. This will help maintain their self-esteem.

10 Maintain a sense of humour

If you haven’t got a sense of humour develop one. It can be a lifesaver. Instead of being embarrassed by unusual behaviour see the funny side of it. If you did something silly or stupid at work you would have a good laugh with a friend about it. Do the same when the person with dementia does something silly or unusual. Most things, unless they present danger to life, are not that important. Does it really matter that the person thinks it is Sunday when it is Tuesday, they tried to take off their blouse on the bus because they were too hot, or put the dishes in the washing machine? Help the person you are caring for see the funny side of it too. Laugh with them and help them feel at ease with their mistakes. Humour will also enable you keep things in proportion.

More help

If you need some support and help in engaging your loved one with activities, Carewatch is more than happy to help you whenever you need it.

We can help with looking after your loved one while you take a break. We understand that caring for someone with dementia is a hard thing to do for a family, so we help by providing you with rest breaks so that you feel more energised to be able to do more meaningful activities with them. It also means that you can take a step back and view the situation more clearly and with fresh eyes. This can help a lot when you’re trying to plan more activities in the life of your loved one.
Organisations and sources of useful information

The following organisations provide a range of information, advice and support

**Alzheimer’s Society.**
Provides information and advice both for people with dementia and their carers.
- info@alzheimers.org.uk
- www.alzheimers.org.uk
- 020 7423 3500
- Helpline: 0845 300 0336

**AT Dementia**
Provides information on Assistive Technology that can help people with dementia live more independently.
- info@trentdsdc.org.uk
- www.atdementia.org.uk
- 01162575017

**Carers UK**
Provides information and advice to carers about their rights and how to access support.
- info@ukcarers.org
- www.carersuk.org
- 0808 808 7777

**Carers Direct (Part of NHS Choices)**
Provides free confidential information and carers. Calls are free from UK landlines.
- carersDirect@nhschoices.nhs.uk
- www.nhs.uk/CarersDirect
- 0808 802 0202

**Dementia UK**
Provides training for those who work with people with dementia as well as employing Admiral Nurses who specialise in dementia care and provide both practical and emotional support.
- info@dementiauk.org
- www.fordementia.org.uk
- 020 7697 4160
- Helpline: 0845 257 9406
- or e-mail direct@dementiauk.org

**Princess Royal Trust for Carers**
This one of the largest providers of carer support services. They provide information, advice and support.
- info@carers.org
- www.carers.org
- 0844 800 4361

**Royal College of Psychiatrists**
This website contains some excellent information on Alzheimer’s and treatments
- rcpsych@rcpsych.ac.uk
- www.rcpsych.ac.uk
- 020 72352351

**Solicitors for the Elderly**
This is an independent, national organisation of lawyers such as solicitors, barristers, and legal executives who provide specialist legal advice for older and vulnerable people, their families and carers. To locate a solicitor near you:
- admin@solicitorsfortheelderly.com
- www.solicitorsfortheelderly.com
- 0844 567 6173

**Benefits Enquiry Line**
Provides advice and information on the benefits you can claim if you are disabled or a carer.
- www.gov.uk/benefit-enquiry-line
- 0800 882 200

**UK Homecare Association Ltd**
This is the national association for organisations who provide social care to people in their homes.
- enquiries@ukhca.co.uk
- www.ukhca.co.uk
- 020 8661 8188