



 *Living Well*  
With Dementia

**Adjusting to My New  
Reality**

## **What is Dementia?**

A chronic or persistent disorder of the mental processes caused by brain disease or injury and marked by memory disorders, personality changes, and impaired reasoning

## **But what does this mean for me and my loved one?**

This means that someone you love has a currently incurable condition that affects the structure and/or processes of their brain that might change the way they think or behave in the future.

This can be very scary and frightening news to hear for everybody involved. It might often feel like the very worst diagnosis possible. Suddenly the future is uncertain and daunting and you can find yourself worrying about a million different things.

Sometimes understanding what might happen and what resources could be available to you and your loved one can help you to feel more prepared and in control.

The fear and sadness you might be feeling is completely normal and it can be important to acknowledge how news like this can affect not only your life, but your mind and heart as well.

## **My emotions are real and I am allowed to feel them**

It is normal to feel overwhelmed by your own emotions and thoughts. Some of the things that are often experienced when a loved one is diagnosed with dementia are:

- Shock and numbness – this can't be real
- Fear and worry – what is going to happen?
- Anger – this is so unfair!
- Guilt – did I miss something?
- Disbelief – maybe they made a mistake?
- Hope – we could find a treatment/cure
- Sadness – this is the worst thing that could happen
- Loneliness – no one understands what this is like
- Shame – I should not be thinking about myself right now

**But isn't it wrong to focus on my own feelings when my loved one is the one going through this?**

No, it's not. How can we be strong for others if we are ignoring our own emotional needs? We need to adjust to our own new reality before we can support our loved one with theirs.

## How do I make peace with this?

Surely that is an impossible task? One cannot make peace with something as life changing as a diagnosis of dementia.

While for some that might be true, acceptance and kindness to oneself can go a long way in helping you adjust to your new reality in a way that may allow a meaningful and ongoing relationship with your loved one despite the challenges of living with dementia.

You can't stop the waves, but you can learn to surf.

- Joseph Goldstein

## What does acceptance look like?

Acceptance can be different for every person, but at its core it is finding a place where one can acknowledge one's new reality and find ways to maintain meaningful relationships with our loved one.

Acceptance can be discovering and nurturing new values and possibilities within one's changed reality. Life may be different, but life can still be beautiful.

Acceptance can be letting go of the exhausting fight against what is unchangeable and embracing the fact that the value of love and connection can remain unchanged.

Acceptance doesn't mean resignation; it means understanding that something is what it is and there's got to be a way through it.

– Michael J Fox

## **Practical Steps to Acceptance**

- **Understand the diagnosis**

It can be helpful to understand the clinical facts and progress of dementia. Being taken unawares by changes in a loved one can be very upsetting, even when we know what to expect. It can be tempting to want to avoid bad news or frightening information, but that can also mean that we often feel out of control or unprepared.

The following organisations are may be useful for information and have online websites:

Alzheimer's Research UK – 0300 111 5555

Dementia UK – 0800 888 6678

Alzheimer's Society – 0300 222 11 22

Alzheimer's Association

Age UK

National Institute of Neurological Disorders and Stroke

- **Acknowledge your feelings**

The strong feelings that might accompany news of a dementia diagnosis can make one feel very uncomfortable and it might seem easier to just ignore how we feel entirely by focusing on the practical aspects of our loved one's needs. Unfortunately, while that might help our immediate distress, in the long run these emotions can find other ways of escaping and can leave us feeling out of control. Some ways to explore difficult emotions can be:

Start a journal

Do something creative to express your feelings

Talk to someone – a friend, counsellor or support groups can be valuable places to find support

Practice mindfulness and/or meditation

Find quiet time or your own space to explore your thoughts and emotions

**We all know that being able to express deep emotion can literally save a person's life, and suppressing emotion can kill you both spiritually and physically.**

**- Lisa Kleypas**

- **Find support**

It is easy to feel that we should be able to cope on our own and that there is nowhere to turn to. We might want to keep our difficulties to ourselves and put on a 'brave face'. But the progress of dementia is going to be a long journey with ups and downs along the way. If we are able to build our foundations of support early in this journey we will have a strong and stable base from which to weather the confusing times.

Good support systems can be:

Admiral Nurses – 020 8036 5400

Turn 2 Me (online support group) – [turn2me.org](http://turn2me.org)

National Dementia Helpline – 0300 222 11 22

Talking Point (online community)

Dementia Action Alliance

Time to Talk

**The healthy and strong individual is the one  
who asks for help when he needs it.**

**Whether he's got an abscess on his knee or  
in his soul.**

**- Rona Barrett**

- **Find new value and meaning**

While many things might remain the same, it is unquestionable that some things will change. The nature of our relationships will always be there. A beloved spouse, parent or sibling will always remain that to us. The ability to love and be loved is a corner stone of these relationships and is of immeasurable value. But some things will also be different. Some memories will fade, behaviours might change and things we might have done together might no longer be possible one day.

But different does not have to mean less. If we are able to find new ways to experience the same value and connection we will be able to retain much of the beauty and joy of our relationships. Some practical steps towards this goal can be:

- to identify our current values (*e.g. experiencing love from a parent through a shared hobby*)
- to understand how they are being met (*e.g. we go fishing together on weekends*)
- to think of how this might change (*e.g. they might no longer be able to manipulate a fishing rod safely*)
- to find alternative ways to achieve the same value (*e.g. we start watching musicals together that make us happy and help to stimulate memories*)

If one does not wish bonds broken, one should make them elastic and thereby strengthen them.

- Ardant Du Picq

## **I feel as if I'm going to lose the person I love**

Unfortunately, loss is a realistic aspect of life. We will lose many things as we experience both the joys and sorrows of living. We lose our childhood, we lose youthful infatuations, interests, friends and one day loved ones. To live is to change.

Dementia however can feel like a slow, creeping loss as memories and skills might incrementally be affected over time. It feels beyond our control and against our will. We are powerless and it might feel like an inevitability. Change is a reality of living with dementia. How we make sense of that change can play a valuable part in how we experience it.

While a loved one might forget some precious moments, those memories remain fresh and present in our own mind. The meaning of those memories and the value they bring us cannot be taken from us. And as our loved one might lose some pieces of their past we become the caretakers of those connections. In this way our bonds continue indefinitely.

## **It sounds too simple**

Indeed it does. Unfortunately life is not that simple or that straightforward. It is absolutely normal to feel as if you have the hang of this one day and then feel completely overwhelmed the next, or vice versa. We might feel prepared and then become completely overwhelmed, or we might have a period where everything feels possible.

And that is completely normal. It would be so much easier if there were distinct steps we could follow to get through difficult changes easily, a colour-by-number path through to acceptance. These ups and downs can shake our confidence and might even make us doubt our own abilities to adapt to the new circumstances we find ourselves in.

We need to be kind to ourselves, to show some understanding of how hard this process can be and to accept that it is quite normal to have ups and downs. You are allowed to look after yourself, to make space for your own needs and to grieve for the things that might be lost.

You are allowed to express your emotions and needs, to have very strong feelings and to take the time for self-care. And you are allowed to hope, to trust in the unbreakable bonds of love and in your ability to grow into a new relationship of equal value with a loved one that can live very well with dementia.

## **Suggested Reading**

**The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer's Disease, Related Dementias and Memory Loss – Nancy L Mace and Peter V Rabbins (Johns Hopkins University Press)**

**Ahead of Dementia: A Real-World, Upfront, Straightforward, Step-by-Step Guide for Family Caregivers – Luciana Mitzkun and Karen DAldenderfer**

**Caring for a Loved One with Dementia: A Mindfulness-Based Guide for Reducing Stress and Making the Best of your Journey Together – Marguerite Manteau-Rao (New Harbinger Publications)**

**The Dementia Caregiver: A Guide to Caring for Someone with Alzheimer's Disease and Other Neurocognitive Disorders (Guides to Caregivers) – Marc E Agronin (Rowman & Littlefield Publishers)**

**Keeping Mum: Caring for Someone with Dementia – Marianne Talbot (Hay House UK)**

**Dementia: The One-Stop Guide: Practical Advice for families, professionals, and people living with dementia and Alzheimer's Disease – June Andrews (Profile Books)**

**The Essential Carer's Guide – Mary Jordan (Hammersmith Press Limited)**

**The Selfish Pig's Guide to Caring: How to cope with the emotional and practical aspects of caring for someone – Hugh Marriott (Piatkus)**

Self-care is never a selfish act – it is simply good stewardship of the only gift I have, the gift I was put on earth to offer others. Anytime we listen to true self and give the care it requires, we do it not only for ourselves, but for the many others whose lives we touch.

- Parker Palmer

**Next in series: Making Lasting Connections**

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