



Carers' Stories loss along the journey

**Supporting people living with dementia -
A guide for carers written by carers**

Introduction

"This booklet will give other carers information about what it's really like being a carer from a carer's point of view, wherever they are on the dementia journey."

Susan

"...all carers have similar problems to cope with and feelings to deal with. To be able to read advice from 'real' people who have experienced all of this can help the carer/reader to realise they are important too..."

Ann

The carers who have written this guide wanted to give an honest account of their experience and the reality of life as an unpaid carer.

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There are over 670,000 people (such as family and friends) in the UK acting as primary, unpaid carers for people with dementia. (Alzheimer's Society, 2014).

This guide has been produced by the Bereavement Supporter project, a partnership between Cruse Bereavement Care, and The ExtraCare Charitable Trust, funded by the National Lottery Community Fund.

The project is improving bereavement support for older people, including those living with dementia and their carers, in ExtraCare retirement villages and housing schemes.

However difficult the carer role can be, there is support out there and you are not on your own. There is a list of organisations and resources that can help you in your role as a carer on page 34.

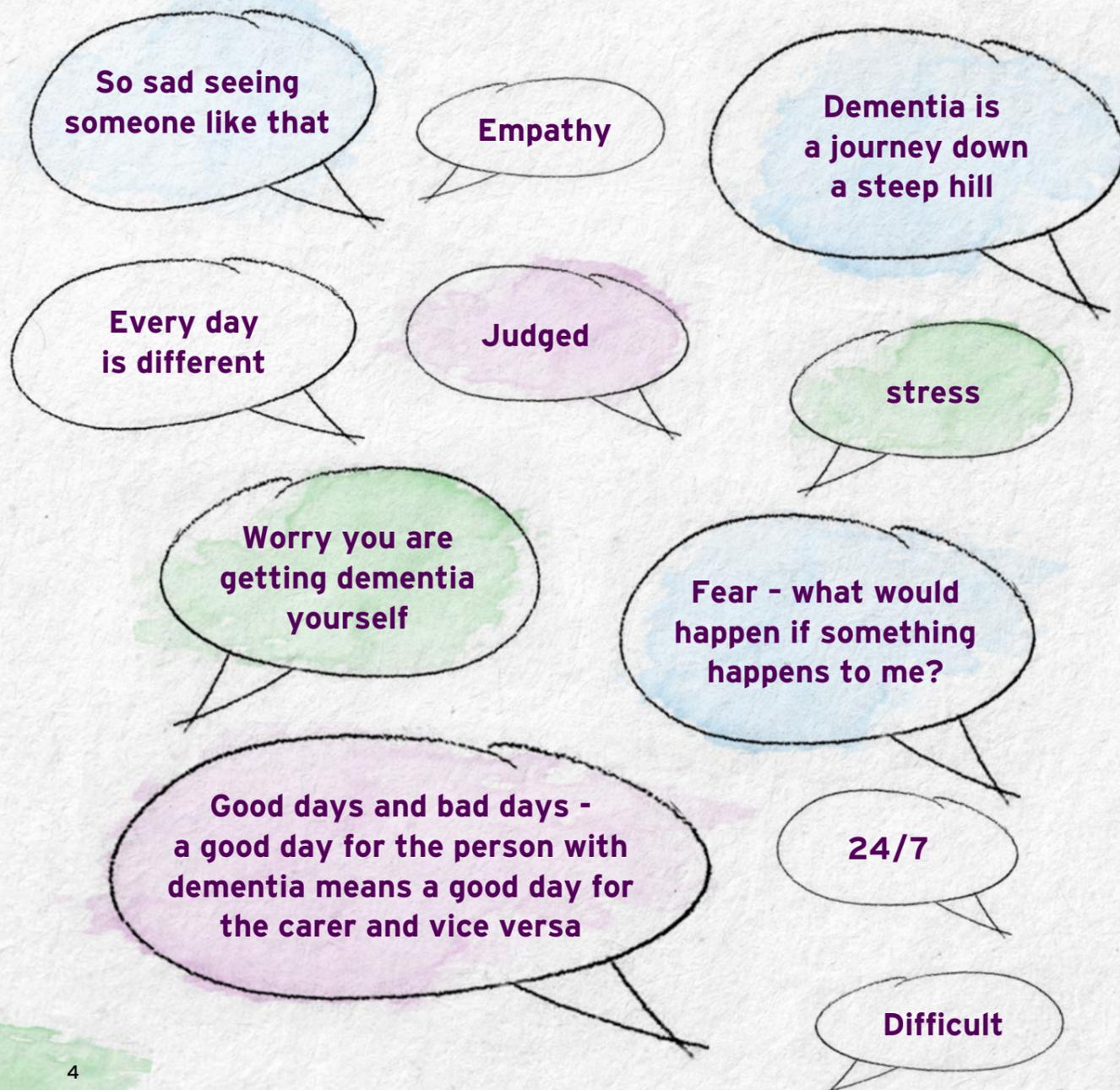


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Section 1

What is it like being a carer for someone living with dementia?



It can help to talk to others who understand the situation (see pages 30-33 for further advice)



Section 2

Diagnosis and dealing with the 'system'

People think of Alzheimer's disease when you mention dementia and don't see there are many other types of dementia with diverse symptoms, which are all different.

The word dementia doesn't represent how each person is affected differently, there isn't one size fits all.

Dementia is 'democratic', it affects every level of community, race, career, religion, and position in society.

"Dementia can happen to him up the road or me"



Diagnosis

It's really important to receive a diagnosis for dementia, without diagnosis there is limited help available.

It was a relief to get a diagnosis.

I felt alone during diagnosis, the focus is on the patient so it was an isolating experience.

I was "treading on eggshells" leading up to the diagnosis.

"Diagnosis opens doors for help"



What prompted seeking a diagnosis?

- I pursued this
- I wanted my partner to make that decision
- It works best if you do it as a couple
- My husband was forgetting things and had another condition so that helped us seek diagnosis as I could use his diabetes as a 'cover story' to encourage him to see the GP
- It was gradual, there wasn't one turning point
- Unusual behaviour was noticed by the family prior to diagnosis, but we didn't know what to do. There was a moment when I realised something wasn't right. It was a huge/steep learning curve
- Recognising the person was confused, little behaviours/symptoms not always apparent to others but when pieced together we realised something was wrong
- A close friend had some similar symptoms that were visible, which worried me about our situation

It was gradual,
there wasn't one
turning point



Unusual behaviour, forgetfulness, diagnosis, support, professionals, care

What does diagnosis involve?

Diagnosis starts with a visit to your GP. Book an appointment if you have a concern or suspect the person you care for has dementia. There is no single test for dementia.

Diagnosis may involve:

- Blood tests
- Referral to a memory clinic
- Assessment of thinking abilities
- Brain scans
- Diagnosis

The assessment process takes time and happens slightly differently depending on where you live. Diagnosis by a GP is becoming more common.

More information about diagnosis can be found at www.alzheimers.org.uk

Our experience of diagnosis

- The diagnosis process was personalised to both me and my partner, and took the carer story into account
- It took almost three years for diagnosis and felt like a fight. The tests were too general, they didn't take into account my wife as an individual and her intelligence
- Memory problems were picked up
- It was a battle for assessment/diagnosis
- My husband got angry and frustrated at not being able to do things. He saw a consultant regarding another condition, who asked me what had changed and then the consultant helped to influence my husband to seek diagnosis

After diagnosis:

- I didn't accept what was happening or the diagnosis. I can see now that a lot can be done after diagnosis and more education is needed
- It's often down to the carer to be proactive and access information
- I got information from the hospital, consultant, internet, Alzheimer's Society booklet, and books. Talking to others helped to piece together information and create a picture
- Going to a support group was helpful and made it feel less lonely

Key points: Diagnosis

- It is important to receive a diagnosis for dementia as it opens doors for help and support
- There are different reasons that might prompt diagnosis, although unusual behaviour and forgetfulness are common prompts
- Some carers have a positive experience of diagnosis, whilst others have a more tricky and difficult experience
- Accessing information can help you understand what is happening



Going to a support group was helpful and made it feel less lonely

Dealing with the system and professionals

- Confusing
- Professionals came all at once
- Some professionals listen, some don't
- New role taken on, dealing with a range of professionals
- Some look at the bigger picture
- Can be at sea if you don't get the right support from professionals
- Professionals often speak to me, and treat me as an advocate answering questions, instead of talking to my wife. I feel this is wrong so I walk out the room so the professional has to spend time talking to my wife

"At sea"



What would have helped?

- Consistency so the professional gets to know the person with dementia and can see any deterioration
- Accessible and helpful key contacts that you can call and speak to when you need to
- Respite that is easily accessible and doesn't require several processes and a long wait
- Professionals with a better understanding, more experience and training about dementia
- Professionals speaking to the person with dementia, not the carer

Key points: Dealing with professionals

- Things can go wrong but the things to make it better are obvious and clear
- To access care and support you need to contact the Adult Social Care team in your local council

You can find your local council by visiting:
www.gov.uk/find-local-council

Section 3

Losses along the journey

Relationship and emotional losses

- Everyone's experience is different
- You lose the support of your partner because they can't support you anymore
- Your spouse can't always give you the empathy or support that they did before, I miss that in the relationship, it makes it hard
- Your partner reacts to you differently and may not understand if you explain that something is wrong or you are upset
- My husband still does pick up on my emotions as a carer
- You can feel lonely and isolated both when they are there with you and when they are not
- There are still moments of humour amongst the hard times
- The dynamics of the relationship have changed, we're no longer equal partners
- Like living a double life:
 - o One life when visiting my partner in a care home, learning to adapt to the change
 - o One life at home - a different life where I don't have to give care, can have 'me' time, and feel less exhausted

It can help to talk to others who understand the situation (see pages 30-33 for further advice)

- "My life is on hold" and how long for depends on the person with dementia
- "Loss of our relationship" - the loving relationship and intimacy changes, such as finishing each other's sentences
- It broke my heart not being able to share a bed anymore because of my husband's health and care needs
- I regret us having to sleep in separate beds and wish we could have done things differently
- No carer's experience is the same:
 - o my husband still recognises me
 - o my wife doesn't recognise me anymore
- "I lost my wife a long time ago" even though she is alive. I feel guilty having a life. I have started to grieve while she is alive because she's not there anymore, there has been a shift and I've already lost that person
- I feel bitter about how dementia has affected our life together

"Dementia is a recipe for isolation"



Changes to the person living with dementia

- Worry about your partner getting lost, it's a scary feeling if you lose them in the supermarket or if they walk off. They may not be safe crossing the road
- My wife is still able to sing hymns at church and remember words, but can't have a coherent conversation any more
- Repetition is common - my partner asks the same thing over and over, and repeats the same action e.g. folding paper
- Frustrating and draining for the carer and can lead to you losing your temper and then feeling guilty afterwards
- Can be "stressful" for carers, I've said horrible things in frustration when trying to go shopping

Communication has changed:

- I can't always understand what my partner is saying
- Words get mixed up so it's "like learning a new language"
- We're developing our own skills for communication as a couple
- My husband thinks he knows what he has written but then reads it back and realises his communications skills are affected. I can empathise and I try to explain, one instruction at a time
- My partner can get frustrated and aggressive because they can't communicate

Key points: Relationship and emotional losses

- Being a carer can mean your relationship changes and you experience some losses emotionally
- Everyone's experience is unique, and dementia can affect every relationship differently

Physical impact and losses

- Less opportunity to get outside, exercise or experience nature
- Worry that you are 'getting dementia' yourself - the stress of caring can contribute to forgetfulness, which is common amongst carers
- Tiring because of reduced sleep and getting up in the night
- You can hurt your back because of lifting and delivering care
- Poor diet due to eating out, not cooking or eating 'on the go'
- Stress



...the stress of caring can contribute to forgetfulness, which is common amongst carers

Move into residential care

- You can leave the care home behind after a visit, but you can't leave the guilt behind
- It can feel like the person you care for is living in a "dementia prison", despite you knowing they are receiving the care they need. I visit 2 or 3 times a week and I know he is being cared for while I'm not there
- It was a really difficult time getting a care home place, and the care home is some distance away
- Care home has a peaceful environment, we can go for walks as a couple and enjoy time together
- We make a plan for each visit

"Quality time together"



- There is either consistency with carers in the care home, or many different carers who don't know my wife as a person
- I feel "wracked with guilt" if I have a day off from visiting
- You either lose your life or rebuild your life after your partner moves into care. It's not easy to rebuild your life and not everyone can
- Some carers spend their life in the care home visiting the person with dementia
- Bereavement can start once the person moves into care

Social impact and losses

There are a number of tips (see page 26) and organisations (see page 34) that can help with the carers journey

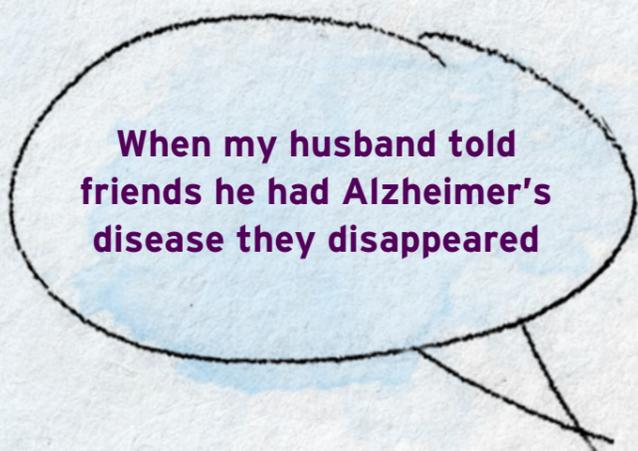
- I can't leave my spouse on their own to attend things socially
- Loss of independence
- Lifestyle change - less social life and holidays
- Loss of identity:
 - o I feel lost with the routine change, now I'm not caring anymore
 - o I became more 'me' after the care home move or during respite care
- I have to be rude sometimes during social occasions to put my husband and his wellbeing first

"Dreams and plans"



Reactions from others

- When my husband told friends he had Alzheimer's disease they disappeared
- People avoid us because they don't know how to handle the situation
- Dementia is the "leprosy of today"
- Fear - people are afraid so don't want to know
- Stigma
- I have to ask for help, which doesn't feel great, instead of people offering to help
- People don't volunteer to visit the person with dementia in a care home
- People can ask stupid questions "will she get any better?"; "can tablets help?"
- I have more understanding now for other carers
- Other people make assumptions about what the person with dementia can and cannot do



When my husband told friends he had Alzheimer's disease they disappeared

Practical impact and losses

- Professional carers are not always reliable so it can be difficult to plan around care
- Professional carers coming into my home were an intrusion initially
- I have a new role in the relationship reminding my partner to drink and take medication
- Financial loss paying for care
- There is a lot of admin for the carer to undertake which can be stressful
- Loss of driving license:
 - o My husband is still driving but a diagnosis means additional testing. It would be a big loss/blow if he lost his license.
 - o My husband wouldn't stop driving, he didn't want to accept it and blamed me as the carer - it was my "fault" he could no longer drive

Key points: Losses and changes

- Being a carer can impact on all areas of life - health, mood, relationships, and lifestyle - in different ways for different people
- Although carers share similar losses and emotions it can feel like a unique and isolating experience

Family

- My extended family do listen and understand what I tell them
- They have no understanding of dementia sometimes
- Family don't always see the full picture if they are not there all the time
- There can be an assumption that each person with dementia will deteriorate and then go into a care home
- Some family members couldn't accept or understand the changes because my wife didn't look ill and you couldn't tell from her appearance
- I regret not asking family for more help
- The carer has the worst part, your partner reacts differently in front of a visitor and their behaviour is not representative of everyday life. If the person is acting differently in front of the GP for example you may need to provide some context as a carer
- It felt like a bereavement telling my husband's brother that his sibling had dementia

What advice would you give to family members?

- When talking to the person with dementia, don't start a sentence with "do you remember?"
- Get more involved
- Stay with me day and night so you can see the true picture of life for the carer
- Let me ask you for help with specific tasks, asking for help can be the hardest thing but really helps
- Ask me more than once if I'm ok, as the first time I'll probably say I'm fine even if I don't mean it

"Ask and listen"



Post bereavement

- I have regrets, I could have spent longer with the person
- Your identity changes once the caring role ends
- What will you do with your day once the person dies?
- Life was on hold, but I can now move forward with life
- Everyday life felt "worse than a bereavement" because there wasn't the finality or ending
- I feel relief for the person as they are no longer 'suffering'
- I feel guilty

Key points: Family and bereavement

- Asking family for support can be difficult but can really help
- Carers can experience grief in different ways at different times
- A range of losses can be felt prior to a bereavement
- Although not every carer has the same journey there is a lot that can be shared and understood from other carers' experiences
- There is more information about supporting yourself after a bereavement on page 29



Your identity
changes once the
caring role ends

About bereavement

For most of us, bereavement will be the most distressing experience we will ever face. Grief is what we feel when somebody we are close to dies. Everyone experiences grief differently and there is no 'normal' or 'right' way to grieve. You may feel a number of things immediately after a death.

Shock: It may take you a long time to grasp what has happened. The shock can make you numb, and some people at first carry on as if nothing has happened. It is hard to believe that someone important is not coming back. Many people feel disorientated - as if they have lost their place and purpose in life or are living in a different world.

Pain: Feelings of pain and distress following bereavement can be overwhelming and very frightening.

Anger: Sometimes bereaved people can feel angry. This anger is a completely natural emotion, typical of the grieving process. Death can seem cruel and unfair, especially when you feel someone has died before their time or when you had plans for the future together. We may also feel angry towards the person who has died, or angry at ourselves for things we did or didn't do or say to the person before their death.

Guilt: Guilt is another common reaction. People who have been bereaved of someone close often say they feel directly or indirectly to blame for the person's death. You may also feel guilt if you had a difficult or confusing relationship with the person who has died, or if you feel you didn't do enough to help them when they were alive.

Depression: Many bereaved people experience feelings of depression following the death of someone close. Life can feel like it no longer holds any meaning and some people say they too want to die.

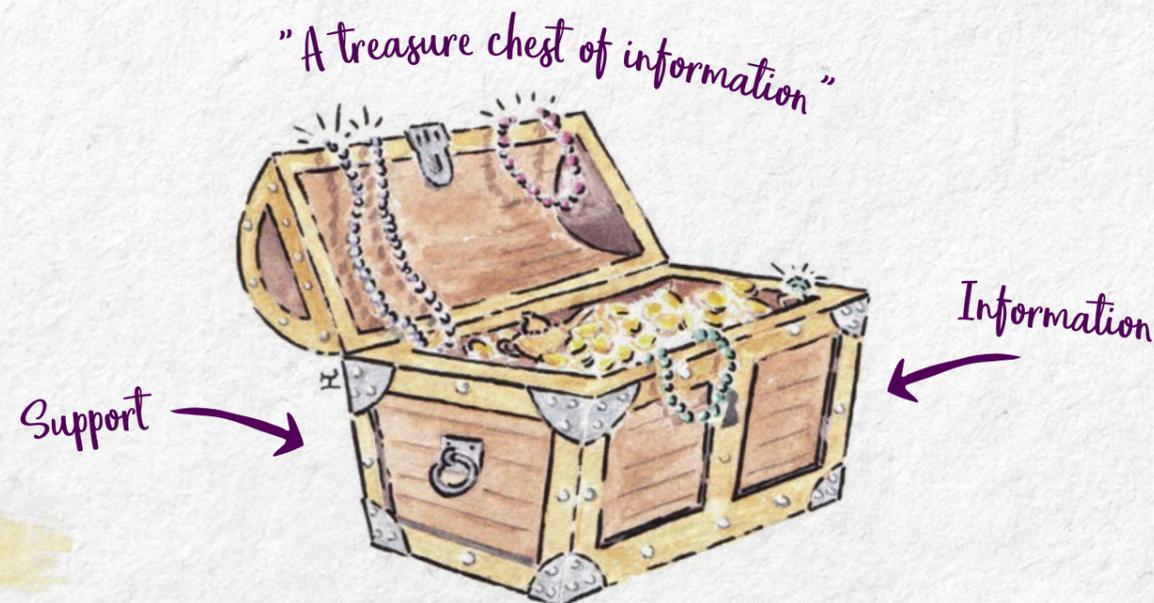
Longing: Thinking you are hearing or seeing someone who has died is a common experience and can happen when you least expect it. You may find that you can't stop thinking about the events leading up to the death. "Seeing" the person who has died and hearing their voice can happen because the brain is trying to process the death and acknowledge the finality of it.

Other people's reactions: One of the hardest things to face when we are bereaved is the way other people react to us. They often do not know what to say or how to respond to our loss. Because they don't know what to say or are worried about saying the wrong thing, people can avoid those who have lost someone. This is hard for us because we may well want to talk about the person who has died. It can become especially hard as time goes on and other people's memories of the person who has died fade.

Section 4

What can help with the carer journey?

- Having a break from caring is so important, whilst knowing my partner is being looked after
- Overcoming challenges as a couple
- The more information for the carer the better. Information and talking has been "golden". Read as much information as you can
- Make the best of what you've got, while you've got it
- Dementia cafés can be a helpful support network - they can be beneficial, and offer a source of support, companionship, and understanding of dementia
- Step into the person with dementia's reality to have a meaningful conversation e.g. talk about things from a long time ago if that's what they remember
- Support from others who understand the situation



What has helped living in an ExtraCare village?

- Support and stimulation in the village
- Making the effort to take part in village activities and entertainment for company, instead of being on my own
- Other people in the village can't see the changes to my husband because they don't know what he was like before, therefore they are more understanding
- It's reassuring for me to know that if I am ill, my partner can receive care and meals within the village if needed
- Good experience of information through the village
- The carer group in the village is wonderful - to hear others in similar circumstances, to help each other, I feel less alone and I have someone to call on
- My neighbours are a support
- Easy access to activities in the village is a benefit, as I haven't got to travel. Attending activities and having a break helps me be a better carer.
- I volunteer at a puzzle group. It helps me to engage with other people living with dementia to see how they can be affected
- Helps raise awareness and understanding regarding dementia. I've learnt a lot since living here. Once people are aware of dementia or a disability, it's important to treat the person the same

Public awareness and understanding

- More public awareness and understanding of dementia is needed
- Unless someone is affected by dementia they are not interested in knowing about it
- Carers are not acknowledged
- More representation is needed in TV and film, both good and bad representation can help raise awareness
- Public figures with dementia are a start e.g. Barbara Windsor, Terry Pratchett
- Ignorance makes the carer role harder

Key points: What can help?

- Having a break from caring is very important for your own wellbeing
- Talking to others in similar circumstance can be a source of support
- Taking part in social activities can provide support and a break from caring

Supporting yourself after bereavement

One of the most helpful things is to talk about the person who has died and your relationship with them. Who you talk to will depend on you. It may be your family, friends, a faith/spiritual adviser, your GP or a support organisation.

Do.....

- Talk to other people about the person who has died, about your memories and your feelings.
- Look after yourself. Eat properly and try to get enough rest (even if you can't sleep).
- Give yourself time and permission to grieve.
- Seek help and support if you feel you need it.
- Tell people what you need.

Don't....

- Isolate yourself.
- Keep your emotions bottled up.
- Think you are weak for needing help.
- Feel guilty if you are struggling to cope.
- Turn to drugs or alcohol - the relief will only be temporary

How to help a bereaved person

People who have been bereaved may want to talk about the person who has died. One of the most helpful things you can do is simply listen, and give them time and space to grieve. Offering specific practical help, not vague general offers, can also be very helpful.

Do.....

- Be there for the person who is grieving - pick up the phone, write a letter or an email, call by or arrange to visit.
- Accept that everyone grieves in their own way, there is no 'normal' way.
- Encourage the person to talk.
- Listen to the person.
- Create an environment in which the bereaved person can be themselves and show their feelings, rather than having to put on a front.
- Be aware that grief can take a long time.
- Contact the person at difficult times such as special anniversaries and birthdays.
- Mention useful support agencies such as Cruse Bereavement Care.
- Offer useful practical help.

Don't....

- Avoid someone who has been bereaved.
- Use clichés such as 'I understand how you feel'; 'You'll get over it'; 'Time heals'.
- Tell them it's time to move on, they should be over it - how long a person needs to grieve is entirely individual.
- Be alarmed if the bereaved person doesn't want to talk or demonstrates anger.
- Underestimate how emotionally draining it can be when supporting a grieving person. Make sure you take care of yourself too.

You can read more information about grief at www.cruse.org.uk

Section 5 -

Advice for other carers

Living in the present

- Take videos and photos of your partner, and of you both together, while they are still well or having a good day, to build those memories to look back on
- Take one day at a time
- Accept how the person with dementia is behaving now - e.g. it doesn't matter if they can't use cutlery any more
- Live for now, don't look back

"Live for now,
don't look back"

Accept help and support

- Forget logic
- Don't be a martyr
- Ask for help and support
- Take people up on the offer of help
e.g. 'sitting' with your partner while you go shopping
- Talk to others in similar circumstances
- Don't keep it to yourself - tell someone something is happening, it can feel like a burden is being lifted

"Don't keep it to yourself"



Practical advice

- Take a break/have some "me time" instead of doing jobs - it can be a small break such as having a coffee while your partner is in the shower
- Get out of the house while a carer is there and care is being delivered
- Have a special place of your own (e.g. a chair) to read when your partner is watching TV or is occupied
- Allow yourself extra time to get anywhere - it can take the stress away from the situation
- Mention appointments to your partner only on the day they are happening, or just before they need to leave
- For any special occasions, plan ahead the hotel, travel etc
- When you need to make phone calls with professionals, and may need to talk about your partner, plan to have support there so your partner can be distracted or can be in a separate room

If you feel you are losing your temper...

- Pick your battles
- Know when to walk away
- Have a cry
- Have a break from the situation
- Use distraction
- Find a way to release your emotions away from the situation

Future planning

- Be aware that things will deteriorate
- Plan for the future and a change of situation:
 - o Practical arrangements can take time so start planning now
 - o Make Lasting Power of Attorney arrangements
 - o Think about where you are living and your situation now, sell your property or move house if it's needed, as it can be too late when it becomes a necessity
- Accept that a care home might be a necessity
- Look at the CQC rating when selecting residential care

Key points: Advice for other carers

- Take one day at a time
- Build memories to look back on
- Ask for help and support
- Talking to someone about your situation can be a huge relief
- Plan for the future

Section 6

Useful sources of information

Organisations

Alzheimer's Society

National Dementia Helpline
0300 222 11 22
www.alzheimers.org.uk

Alex says "the Alzheimer's Society magazine has useful articles and relates to real people"

Cruse Bereavement Care

National Helpline 0808 808 1677
www.cruse.org.uk

'Bereavement, Loss and Dementia' booklet - www.cruse.org.uk/bereavement-and-dementia

Carers UK

www.carersuk.org/help-and-advice

Carers Trust

www.carers.org

Age UK

www.ageuk.org.uk

Care Quality Commission

www.cqc.org.uk

For information about finding, choosing and comparing care services

Books

Sue found these books useful:

- 10 helpful hints for carers: practical solutions for carers living with people with dementia - *June Andrews and Allan House*
- Understanding Alzheimer's disease & other dementias - *Dr Nori Graham and Dr James Warner*
- Dementia: support for family and friends - *Dave Pulsford and Rachel Thompson*
- ABC of dementia - *Bernard Coope and Felicity A. Richards*
- Communicating across dementia - *Stephen Miller*
- How to Handle Later Life - *Marion Shoard*

This tree was created by ExtraCare residents, using their fingerprints and words.

The Reference Group members (residents and staff) felt a tree symbolised the many different 'branches' of emotions and challenges that can be faced following a loss or bereavement.



Developed by the Bereavement Supporter Project Reference Group



Somewhere to turn when someone dies

Cruse Bereavement Care is the leading national charity for bereaved people in England, Wales and Northern Ireland.

Our mission is to offer support, advice and information to children, young people and adults when someone dies to enhance society's care of bereaved people.

Cruse offers face-to-face, group, telephone, email and website support. We have a Freephone National Helpline and local services throughout England, Wales and Northern Ireland, and a website specifically for children and young people.

Our services are provided by trained volunteers and are confidential and free. Cruse provides training and consultancy for external organisations and for those who may come into contact with bereaved people in the course of their work.

For more information, please email: training@cruse.org.uk

f Find us on Facebook:
Cruse Bereavement Care

t Follow us on Twitter:
[@crusecare](https://twitter.com/crusecare)

For more information:

www.cruse.org.uk

Freephone National Helpline number: **0808 808 1677**

www.crusescotland.org.uk

National Helpline number: **0845 600 2227**

(calls cost 5p per minute plus you phone company's access charge)

www.hopeagain.org.uk

Cruse Bereavement Care, Registered charity: 208078.

Cruse Bereavement Care Scotland, Registered charity: SC031600