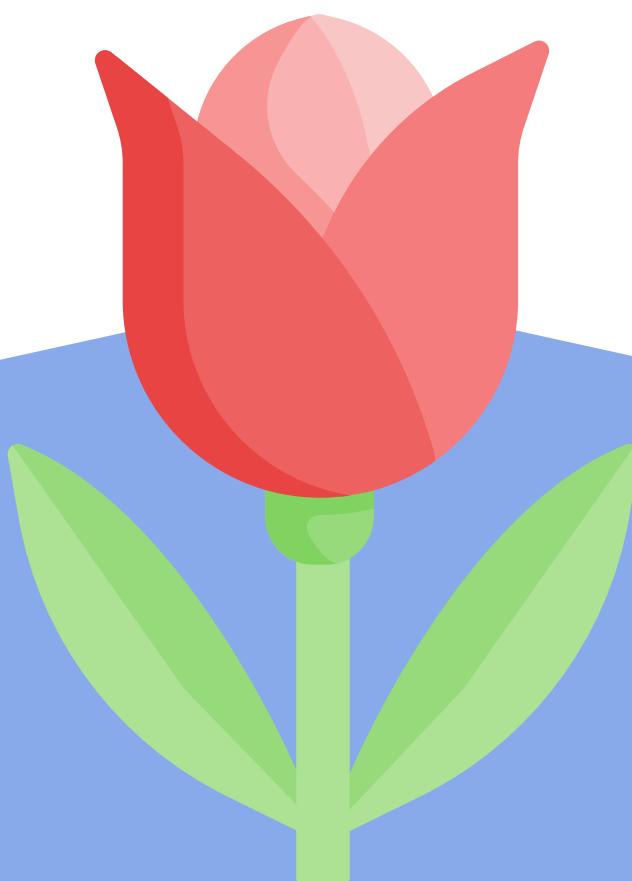


# AFTER OUR LOVED ONE WITH DEMENTIA HAS PASSED AWAY

○ What Former Carers Want You To Know... ○

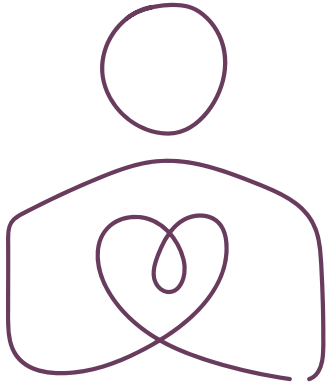


**THIS LEAFLET HAS BEEN WRITTEN BY FORMER CARERS OF  
PEOPLE WITH DEMENTIA**

**It can be difficult for people who have not experienced a life involving caring for a loved one with dementia to understand the complexity of emotions that we may be experiencing following bereavement. Many people struggle to know what to say, so they say something entirely inappropriate (even if they mean well). As a society, we are quite poor in dealing with grief. We need to be able to speak openly about it, which makes it even harder for people to know what to say and how to deal sensitively and empathetically with us following our loss and the end of our caring role.**

**That caring role may have continued for many years. Who we are has been defined by that role, we have lost the identity of husband/wife/sister/brother/son/daughter and become a carer. It is a difficult transition to make from being needed and on call often 24/7, 7 days a week to suddenly have huge expanses of time stretching ahead of us, with seemingly no purpose now. We need you to be mindful that it is not just our loved one that we have lost but often our identity too.**





## How can you help?

**Don't just say 'I am here if you need anything' – generally people won't respond to that**

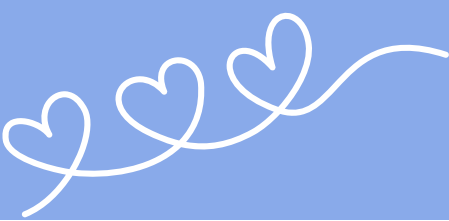
**Far better to phone up and just say 'I wondered if you fancied a cuppa and a chat' or send a text saying 'Just thinking about you and wondered if you fancy meeting for a coffee?'**



**Too often, people shy away from those of us who are bereaved for fear of upsetting us or saying the wrong thing or not knowing what to say.**

**We don't expect you to have all the answers or wave a magic wand and make all the grief and pain go away. What you can do is to be a friend. Listen and let us talk and cry if that is what we want or laugh and tell stories about our loved one. Take your cues from us.**

**Even if we refuse your invitation at first, don't stop asking us or inviting us, we really do appreciate it and one day we will be ready to accept it.**



**Grief is as individual as the person who has died. No two people handle it in exactly the same way. Just let people grieve in the way they need and resist (however tempting) offering advice - unless specifically asked for...**

**Let us talk about the bad times too though and let us vent if we need to. It can be a long, hard, lonely road as a carer of a loved one with dementia and giving us the permission and the safe space to acknowledge that and speak the words out loud if we need to is invaluable. Just listening, can be the most powerful and useful thing you can do for us.**

## **Try not to say:**

**You'll get over it**

**You'll come back stronger**

**It's for the best**

**They'd want you to move on and live your life now**

**They were in a care home/very poorly**

**You've been/ you are so strong**

**Whilst saying the following may be a comfort to some, please understand everyone is different:**

**They are in a better place**

**They are watching you/looking down on you/by your side**

**They are waiting for you**

**What you could do...**

**Say their name**

**Give us as much time (and space) as we need**

**Talk about them**

**Take your cue from us**

**Allow us to talk**

**Allow us  
to grieve**

**Invite us  
for a  
coffee  
(again)**

**Don't say I  
know just the  
person for you  
now you're  
available**

**Listen**

## **How it feels...**

**'It's such a lonely place, with no instruction booklet available to explain how you are likely to feel and cope in the aftermath of losing a loved one, whether that is from going into a care home where your caring role is reduced or losing them entirely'**

**'Without realising it, as a carer, we give so much of ourselves, our identity, our time and our love that we lose a parts of ourselves for a while. It is a new and difficult world we enter to be the other half of that person. That's all fine, but after they have died, when you are on your knees outside that caring bubble, having left your career on hold, in financial difficulties perhaps, and a lot of your friends have drifted away over the years and who now don't know what to say to you, and you have lots of time to go over events'**

**'I just remember how I felt afterwards and I was lucky enough to have a good network of friends, my husband and the hospice that provided mums end of life care at home put me into one to one counselling and group bereavement counselling within a week of the funeral. Not everyone has that available to them.'**

**'So many people trot out well-meaning platitudes. We don't like talking about death which does not help but we can change that just by getting the knowledge out there as well as some words we can say.'**

**After my husband died , someone said " you have wasted 5 years of your life looking after your husband." My response was a very polite that my life has been enriched by being a carer, and I have many happy memories.**

**'Life is hard at the moment but with help I can see light at the end of the tunnel and I have no regrets, just a sense of pride with what I was able to do for him.'**

**'I just wanted to express my emotions without fear of judgement after she died. I loved her desperately, but years of caring had left me physically and emotionally spent. I needed to be able to say that I was glad that my caring role had come to an end , for my own sanity's sake but felt that I would be judged if I did'**

# Thank you for listening to us



**Please share this leaflet. It is important we acknowledge people's grief and are able to approach this with compassion, care and understanding.**

**If you are a carer, former carer or dementia professional, tide (Together in Dementia Everyday) is here to help. Check out our events page to see what we have on [www.tidecarers.org.uk/events](http://www.tidecarers.org.uk/events)**

**For more information about tide, please get in touch:**



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**[www.tidecarers.org.uk](http://www.tidecarers.org.uk)**

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