Dementia Toolkit – Stay positive

Sharing is caring

Dementia Toolkit
Living your life with hope

Sharing is caring

Caring for a person with dementia comes with particular challenges. Talking to other people in the same situation can really help. For this page we collaborated with the blogger DementiaWho! to encourage more dementia carers to share their experiences in whatever way suits them.

In this booklet you will:

- hear from DementiaWho! about blogging the caring experience
- be directed to a video where a range of carers talk about the importance of speaking to other carers
- learn about online groups where you could meet fellow carers

> **Talking to someone that knows what dementia is. My friends have backed off as they can't cope with it.**
>
> **If I had access to someone who understands dementia as well as caring.**
>
> **Access to a support group and talking to people in the same position as us.**
>
> Three carers responding to the question 'What would make you feel more supported?'

Blogging about caring: DementiaWho!

We are delighted to bring you the voice of seasoned blogger DementiaWho! on the topic of Sharing is caring. You will find extracts from her blog below, as well as links to her website where you can read much more of her blog!

I've been caring for my mum who has Alzheimer's for the last 10 years. She was diagnosed with dementia in 2012, but it took almost 2 years to try to persuade her to visit a memory clinic for more tests. My mum is a proud African and our culture doesn't recognise the term dementia and isn't really spoken about. Most families don't discuss it, so it was extremely difficult to get to the diagnosis stage. Even now, when I describe it back to mum we just refer to it as being forgetful.

Mum is in the mid-stages of Alzheimer's, and her symptoms present mainly as fluctuating memory impairment, anxiety, repetitive behaviours and sleep disturbance. I gave up work to become her full-time carer. In the beginning, it was overwhelming learning about the disease and dealing with the day to day issues. I felt I was drowning at times so to change the focus I started to write and share our experience in a blog.

Blogging became a release for me. It helped to separate what I was going through because by writing our experiences I could see it more clearly without emotion clouding my understanding. It gave me a purpose and helped define me as being more than a caregiver.

It helps me to problem-solve and then I share what I've learnt, hoping that it will help others. That makes me feel good, knowing that our struggles are useful to others.

For you, your thing could be joining a local carers group, craft groups, expressing yourself through art or music, writing poetry or taking photographs etc. It's whatever helps you and your loved ones live with dementia in a way that replenishes you again and again so that you can continue to care. There are always going to be good and bad days. If we have support, ways to share or release tension and things that enrich us then this will allow us to move forward to continue to care with purpose and love.

I reflected on what I'd learnt in a recent blog post I wrote called **22 Things I Wish People Knew About Dementia Caregivers In 2022.** Here's an extract - and a question for you - what would you wish people knew about caring for someone with dementia?

#1 – Dementia is more than…

It's not quite that stereotypical picture of dementia that you imagine, that's for sure! There are at least 100 different types of dementia, and they present with various symptoms. So, it's not just memory loss that you have to learn to deal with as a caregiver.

You may be dealing with vision loss, spatial awareness, coordination, mobility issues, loss of taste, increased sensitivity to touch, anger or sorrow, and personality changes. For a caregiver (as well as your loved one), it can be a rollercoaster of emotions and issues to deal with. You're not just dealing with a memory issue.

#2 – Love & joy

Caregiving can bring this closeness that maybe you didn't have before. You get to be right there in the details of your loved one's life, experiencing their enjoyment, their accomplishments, their love 24/7. You learn from each other. You realise what's important in life and put aside relationship difficulties you had in the past.

It's not a burden. You feel lucky that you get to experience this time with them. It's not all sunshine and roses, but when those moments & days come, especially at the beginning, you revel in them.

#3 – We're resilient!

Dementia Caregivers are resilient. You have to be. You do things that you never thought you were capable of. You get knocked down but get back up. You build this inner strength, learn to fight & advocate for your loved one despite the obstacles put in your way.

You learn to deal with the daily challenges of caregiving for someone with dementia, building new skills whilst living with someone you know but don't know anymore.

One of the hardest parts is dealing with role reversal, especially when taking care of a parent. You become the parent protecting, loving, caring for them.

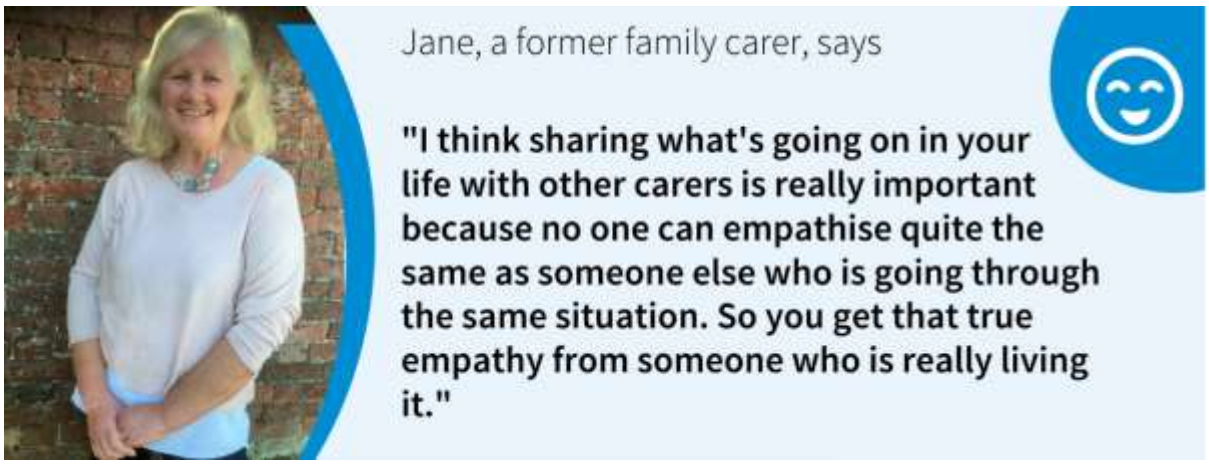
To read the rest of this blog post go to:
https://dementiawho.com/22-things-dementia-caregiver/

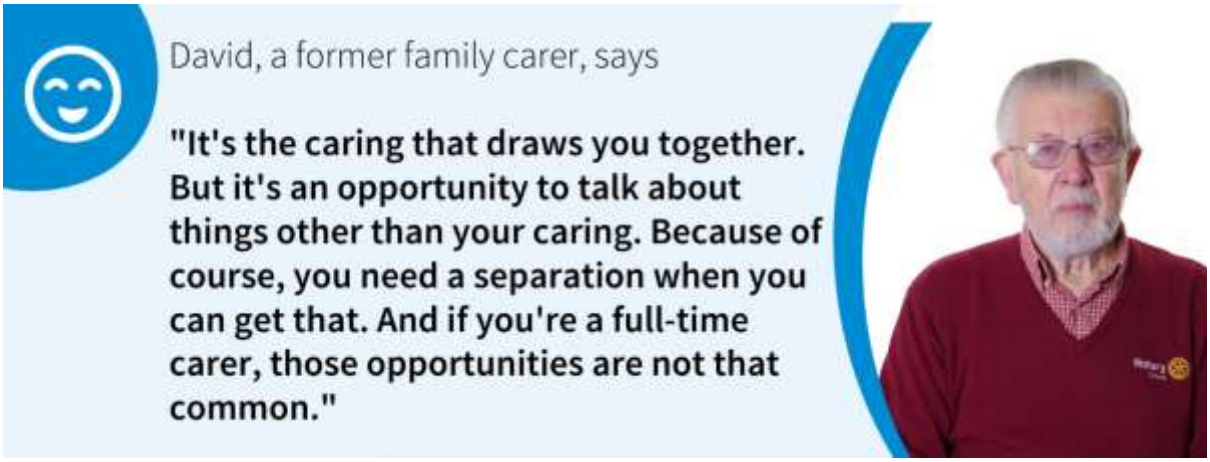
To visit DementiaWho!'s homepage go to: **https://dementiawho.com/**

Sharing with others

We spoke to a number of different carers to understand why they think that speaking with fellow carers is important. The video is available to watch on our website. Among the key points in this video are:

- how other carers understand what you're going through and can offer tips from their experience
- the chance to have social time of your own
- gaining perspective: sharing with other carers can help you to overcome negative emotions like guilt





We worked with Chinese Wellbeing, a charity in Liverpool, to understand the views of the Chinese community. They asked their Dementia Network members 'Do you find it helpful to be able to talk to other people about caring for a family member with dementia?' This is what they said:

It is very helpful for us to share our feelings and difficulties with others. Specially to share with those who are in similar situation and share the same language and culture. They can understand our feelings more easily.

Sometime I am burn out when I take care my mum with dementia! But after talking about my situation in Chinese Wellbeing group, I feel recharged.

The active listening in the dementia group is great for me and to be able to express my feeling.

We think it is helpful to hear about the difficulties from other members in order to equip ourselves to prepare for the future as we may be in a similar situation sometimes later..

Four members of Chinese Wellbeing's Dementia Network members sharing their views

Connecting carers virtually

Over the next few pages, DementiaWho! shares her knowledge of online carer groups you could join. It's important to look out for local in-person sessions near you, too, but these options can be accessed from anywhere.

TIDE - Together In Dementia Everyday - National Chat and Change Group

This is a fortnightly informal national chat with other dementia carers. It's a very relaxed session and happens every Wednesday morning. These are not themed on any topic, just what the group wants to discuss or get advice from current and former carers of people with dementia. Sharing and hearing from others can help with feelings of isolation and loneliness. This is a small group setting with a facilitator to help initiate the discussion. Very friendly, encouraging sessions and newcomers are made to feel extremely welcomed.

You need to register with TIDE to join the session, but it's a one-time thing then they'll send you an introductory email with all the upcoming session dates and one zoom link to join any of the sessions.

To sign up for TIDE's National Chat and Change Group go to:
https://www.tide.uk.net/national-chat-and-change-group/

Mobilise Cuppas - Join other carers for a virtual cuppa

These cuppas are aimed at all types of carers from all backgrounds, ages, and experiences. They publish a timetable of their weekly cuppas on their website so you can take your pick as to which sessions you want to join. The groups are small (up to 10) and the sessions are facilitated by a Mobilise team member. Most sessions are very natural, people keep their microphones open to freely chat, it's non-judgemental. You don't need to register beforehand just click on the link on the day on their website to join the session.

To watch members of the community discuss what the online cuppas mean to them visit: **https://www.youtube.com/watch?v=GtFe9VbIxz0**

To view the Mobilise Cuppas timetable visit:
https://www.mobiliseonline.co.uk/cuppa

Care for a Cuppa - Carers UK

Carers UK 'Care for a Cuppa' sessions happens weekly every Monday afternoon between 3-4 pm. You need to register for each session at least a week in advance as that's when they send out the confirmation email with the zoom link. Their sessions are slightly larger as up to 20 carers can join, but again it provides a supportive network for carers talking openly and honestly to each other facilitated by Carers UK.

To find out more go to: **https://www.bit.ly/CarersUK_Cuppa**

We now use a WhatsApp group to support each other.

A carer explaining to our researchers how their group adapted to the COVID-19 pandemic when in-person sessions stopped.

This resource is on the internet. Use the camera on your phone or tablet to scan the QR code below to visit the webpage.

Contact us

We would love to know what you think of the toolkit. We want to improve it based on your feedback.

Please get in touch with us by emailing
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If you prefer to write to us, then please address your letter to:
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