



Dementia Toolkit – Stay positive

The role of the carer



Dementia Toolkit
Living your life with hope



Stay positive

The role of the carer

Caring for a person with dementia has its ups and downs. We want to explore the experiences of carers and offer some ideas for how you can look after yourself.

In this booklet you will:

- hear carers speaking from experience
- learn about our research findings which emphasise the importance of carer wellbeing
- hear about the positive experiences of caring people have told us about



When the activities stopped, I felt guilty that I should be trying harder.

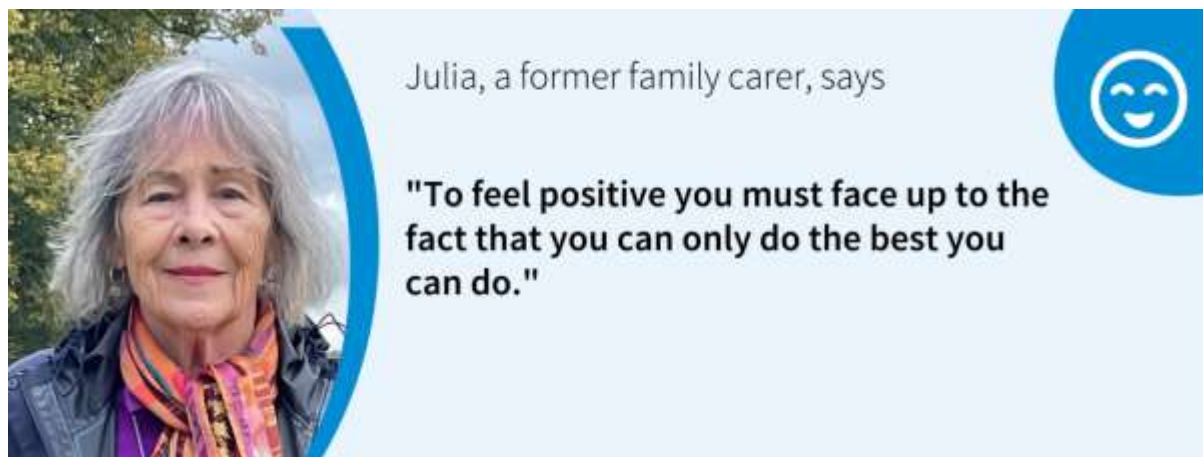
A carer talking to our researchers about the impact of the COVID-19 pandemic



How do people think about caring?

On our webpage you can watch three videos in which different people share their experiences of caregiving.

In the first video Julia discusses the realities of caring for someone with dementia and how to stay positive.

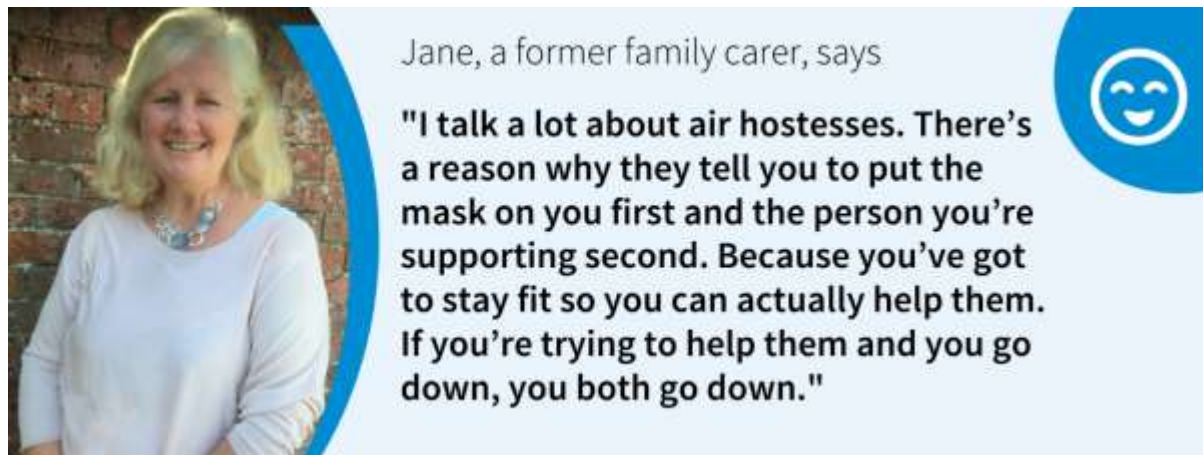


In the second video, Suzanne discusses her personal and professional experiences of caring for a loved one. Among the topics she covers are:

- the progression of care needs
- the emotive aspects of caring
- the importance of open and honest conversations



In the third and final video on our webpage, different people offer their suggestions for how to approach the role of carer.



Looking after yourself helps both of you

Many of the people we spoke to mention feeling guilty for taking time out of caring to look after themselves. Guilt is a natural impulse for carers, but as Jane points out looking after yourself helps not just you but the person you're caring for.

Some of our research has looked at how the overall wellbeing of the carer can have an influence on the wellbeing of the person with dementia.

We've found that:

- How the carer experiences caring makes a difference not just to them, but also to the person they are caring for. For instance, if a carer thinks of themselves as stressed, then the person with dementia rates their own wellbeing less positively.
- If either the person with dementia or the carer is struggling with depressive symptoms, then this affects the other person. So it is important to look at the combined effect of depression in caring relationships.

- If either the person with dementia or the carer views the quality of their relationship as low, they have poorer quality of life. How each individual views their relationship really matters, and we need to support people to maintain positive relationships.

All the evidence tells us that carers need to take care of themselves, and that this has benefits for both of you. Setting in place what you need to stay well as a carer is a form of caring as well as being important self-care.

You can read accessible summaries of all our research on the IDEAL project website: <https://www.idealproject.org.uk/activities/papers/>

Positive experiences of caring

We have been speaking to carers about what makes a difference to their lives since 2014. We know that being a carer can be a challenging role and that carers need supporting in this role.

However, we also wanted to understand which aspects of the caring role people found positive. We asked 900 carers ‘What is your greatest satisfaction in caring?’

They identified the following 8 topics:

- I have ‘grown’ and learnt new skills through caring.
- I enjoy spending time with the person with dementia.
- I am making a difference to the life of the person with dementia.
- I find it satisfying that I am fulfilling my duty by caring.
- I am helping the person with dementia to keep some of their independence.
- I feel I am providing good quality care.
- I am helping to improve the well-being of the person with dementia.
- I enjoy my relationship with the person with dementia.

The findings show that carers can identify positive experiences of caring. The list above may help you identify your own satisfactions.

We hope that you will find lots of examples of ideas on our website for things to try or useful information.

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
IDEAL@exeter.ac.uk

If you prefer to write to us, then please address your letter to:

Living with Dementia Toolkit

PO Box 616

Exeter

EX1 9JB



www.livingwithdementiatoolkit.org.uk