



Dementia Toolkit – Stay connected

Involving family and friends



Dementia Toolkit
Living your life with hope



Stay connected

Involving family and friends

Many people affected by dementia find that their social circle can get smaller. Family and friends might be unsure of how to approach the situation after a diagnosis of dementia. We want to encourage family and friends to remain involved in the lives of people affected by dementia. Our research shows the many benefits of maintaining these relationships for both the person with dementia and the carer.

In this booklet we:

- consider why it's important to maintain contact with family and friends
- offer strategies for how to involve younger generations in the life of a person with dementia
- share a meeting between Year 10 and 12 students and the Toolkit involvement group – find out what they wanted to know about dementia!



The emotion you feel from a visit far outstrips any good news that might have been imparted because you won't remember that. But it's the emotional feeling that you are left with.

A person with dementia speaking to our researchers about the importance of seeing people



How can we involve family and friends in the lives of people with dementia?

We spoke to a range of professionals from dementia care and research about involving friends and family in the dementia journey. Among the things they discussed are:

- a common experience that people affected by dementia say that friends have dropped away
- the importance of continuing activities you did together before, but perhaps with slight adaptations
- the importance of being realistic about what you can do and what you would like to do



Hayley, from Alzheimer's Society, says
"Yes, dementia brings changes, but it's about family and friends coming together as a unit, having that communication about what that dementia means for that person, with the person, and how they still want those family and friends to be involved."



Tips for remaining connected:

- have an activity or a goal for your interaction. It can be as simple as having a beer together and discussing a rugby result.
- encourage younger children to involve older relatives in their activities, such as by reading to them.

Why and how to involve all the generations

It's important to involve younger people in conversations about dementia. 6 members of the toolkit involvement group met with Year 10 and 12 Health and Social Care students from South Devon UTC. You can see the full video on our website. Here are the questions that the students asked people with dementia and carers:

- What would you like us health and social care students to know about dementia?
- What other hardships come with caring for those with dementia and how can you deal with it?
- Are there any common misconceptions people make about dementia?
- [for people with dementia] If you're having a bad day, what would your coping mechanism be?



We also have a video where former family carer Jane explains the importance of having a wider social network and offers tips for involving young people in the life of a person with dementia.



Jane, a former family carer, says

"An adult child could look at Playlist for Life with the parents and then the teenagers could go off and actually source the songs and put them together. That would be a wonderful multigenerational project."



Young people might be able to help with:

- digitising old photos
- collecting the stories behind photographs for a memory book
- creating a personal playlist for the person with dementia



We'd like more help from friends – we feel a bit abandoned – not physical help, just someone to chat to.

A carer speaking to our researchers





This resource is on the internet. 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