



‘The experiences of children and young people with a parent with dementia’

Participant report

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We are Pat and Mel and we work at the University of Sheffield. We research with children and young people about important things in their lives.

When Pat's children were growing up, their father was diagnosed with young onset dementia. Pat learned the hard way that there wasn't much support for young people with a parent with dementia. Most of the support available was for older people who have the condition and for their partners. She wondered how it was for others like her son and daughter and what might be done to help them so she put in a proposal to the Alzheimer's Society for funding to meet with children, teenagers and young adults to ask them what it is like to have a parent with dementia. The Alzheimer's Society were aware that there were gaps in understanding around young onset dementia generally and particularly regarding the needs of children and young people whose parents were affected – and they awarded the money for the study.

Pat employed Mel as the researcher on this project. Mel has spent three years travelling around, meeting many lovely people, who have been so generous to talk to her (there was also tea, cake, biscuits and ice cream).

We would like to give you some feedback on what we found.

There are other people in your situation

People told us that they thought they were the only person their age to go through this. Between 2014 and 2017, Mel met with 24 people who have experienced having a parent with dementia. Including:

- children of 7, 8 and 9
- those who were of secondary school age
- young adults
- people in different situations:
 - some whose parents had died;
 - some whose parents lived with them;
 - some whose parents lived in a home;
 - some who lived in different towns after going to University or moving for work
- Everyone's families were different:
 - some had divorced parents
 - some had brothers and sisters
 - some had no brothers and sisters

One of the things we heard over and over again was how lonely it could be to have a parent with dementia. Even after the research has finished, we have people writing to us to thank us for sharing your stories, that they have helped

them feel less alone. *Your stories have made a difference. They will continue to do so.*

What did people tell us?

We must highlight that not everyone felt all of these things. Some people feel okay some of the time, but had bad days. Others felt down about the situation a lot of the time. There is no 'right' way to feel when your parent has dementia. You are allowed to feel as you feel. These are some of the things that came up:

- **Frustration!** It was annoying that everyone (friends, teachers, the general public) seemed to think that dementia was something that happened to grandparents. *It is different when your Mum or Dad has dementia!*
- **Dementia is a difficult illness.** There is a long period of strange goings on, without explanation. People asked 'what on earth is happening?'. Everyone assumes that dementia = forgetful. Your stories told us it was more than that.
- **Dementia changes people.** People told us about how their parents' interests changed. Some talked about their parents becoming violent. Some had parents who accused them of hiding the remote control or their car keys. Some found their parents stopped being interested in them. People described how their parents were unable to care for them. *Your Mum or Dad might not feel like the same person that they were.*
- **Dementia affects families.** When your parent has dementia, it disrupts day to day family life: meals out and holidays might become more difficult, or even impossible. It can lead to role reversal, where the child feels like the parent. People were comforted when 'normality' happened: if their parent made them a cup of tea, or said something nice out of the blue. *All family members need support.*
- **There is a grieving process.** Grief is often seen as something that happens when someone you are close to dies. People who have a parent with dementia grieve while their parent is alive, as well as when they have died. It is hard when your parent changes. When someone can no longer talk or walk, and so on, this is a loss. It happens on an ongoing basis: people talked about having to adjust to 'new normals' and feeling sad about them. *It is normal to feel sad about this.*
- **There are lots of emotions going on.** People loved their parent. People sometimes felt angry with their parent. They felt angry at what the dementia had robbed them of. Then they felt guilty for feeling angry. They felt jealous of their friends who had parents who were not ill. Some felt that it would be easier if their parent had died. Then they felt guilty about that. Some felt it must be easier for those who had parents with cancer, because at least other people knew that cancer was bad, or that there might be a cure. Then they felt horrible for saying that. *Having a parent*

with dementia is a difficult thing to go through. It is okay to feel different feelings.

- **It affected their lives significantly.** Getting on at school/university could be difficult. Some were bullied, or found it hard to concentrate because of problems at home. Some brought forward weddings or having children, while others put off having a family. Some purposely remained close by to their parents, even though they wanted to move away. Some postponed plans to travel. Some had inherited money and been able to buy houses, but this set them apart from their friends. Many described feeling 'in limbo'. *Planning could be difficult.*

Having and losing a parent to dementia can be a difficult thing to go through. We believe much more support is required.

What happens to the research?

We have been talking to lots of people about our research. This has helped raise awareness of the issue. We have argued that there is a need to support those who have a parent with dementia. Our audiences include:

- people who work in dementia services
- the Alzheimer's Society
- Young Dementia UK
- Channel 4 News
- Radio 1 Newsbeat

We are continuing to work with the Alzheimer's Society and Young Dementia UK to help them support children and young people with a parent with dementia. We are advocating for targeted support services. We are hoping there will be a specific website in the future. In the meantime, our research findings are available here: <http://cypdpd.group.shef.ac.uk>

Although this project has drawn to a close, Pat and Mel will continue to undertake research that supports children and young people in the future. We are looking to obtain funds to make an animated film.

We will continue to raise awareness that dementia doesn't just affect older people. We will continue to tell people that it is difficult for those who have a parent with dementia.

If you need any support, the following organisations may be useful:

Alzheimer's Society Helpline 0300 222 11 22

Samaritans 116 123

Young Dementia UK lists support groups at:

<https://www.youngdementiauk.org/support-friendship-online>

If you would like to keep in touch, we can be contacted at:
p.j.sikes@sheffield.ac.uk or Melanie.hall@sheffield.ac.uk (Mel is likely to move Universities and may lose her Sheffield address so do try the Hotmail one).

We cannot thank you enough for helping us with this important research.
Thank you!

Mel & Pat