

Helping children and young people isolated by young onset dementia find a voice

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A pioneering study led by researchers from the University of Sheffield is helping to give a voice to children and young adults who are living with a parent with dementia.

There are estimated to be at least 42,325 people in the UK under 65 living with a variant of young onset dementia.

Many of those affected by the disease are parents of children and [young people](#) who are left feeling isolated and afraid as they try to cope with the loss of their mother or father.

For the first time, researchers from the University of Sheffield's School of Education have examined the perceptions and experiences of children and young people who have a parent with dementia by giving them the opportunity to tell their stories.

The ground-breaking project aims to raise awareness of the impact the disease has on the youngsters – especially their education and schooling – and to highlight the fact there is now a growing number of under 25s living with a parent with dementia due to improved diagnosis and demographic changes such as people choosing to have children later in life.

Professor Pat Sikes, whose own children's father began showing symptoms of young onset dementia when they were just 13 and 15, is leading the project which is being funded by the Alzheimer's Society.

"Before and after diagnosis my children had to experience the police being called out to find him when he slipped out of the house and went missing, many tantrums, obsessive hoarding, violent episodes, verbal abuse, falls, unpleasant incidents around his failure to find the lavatory, and countless sleepless nights due to his constant wandering," said Professor Sikes.

"The children involved in our study all had similar stories to tell including a little boy whose father was eventually diagnosed with dementia after they sat down together on Christmas Day to play with his new Lego and his dad simply don't know what to do with it.

"Another girl who had always been very close to her dad was devastated when he began accusing her of stealing things and became very aggressive towards her – something which is not unusual behaviour for someone with certain forms of young onset dementia."

Professor Sikes and Dr Melanie Hall spoke in detail to 22 young people aged between six and 31 years-old. Because of the age profile usually associated with dementia the assumption is that partners or middle-aged children are the family members most affected but this is certainly not the case.

"Many of the children we spoke to had 'cancer envy' because they believed that if their parent had cancer at least there was hope of a cure," said Professor Sikes.

"With cancer people offer sympathy but with dementia people often say unhelpful things like 'they are still the same person' or 'at least they can still be at your wedding' but it's not that simple and bodily presence alone is not enough - if the parent is unaware of what is going on, they can't share. And if they were 'still the same' they wouldn't be being violent or shouting or swearing at their child.

"Dementia is different from other diseases and grieving typically goes on for a long time as the parent progressively loses abilities. People mourn the loss of variety of things: for some it is when their parent can no longer walk, for others it is when they don't recognise them anymore."

Professor Sikes added: "As one young woman put it, 'I get used to it and then she gets that bit worse and I get upset. Every few weeks, or even less, there's a new normal and it's so unpredictable.

"One of the participants who was at University whilst their parent was diagnosed said they didn't like going home in the holidays because they knew every time he saw his dad it would be the worst he'd ever been, and the best he'd ever be."

Although children and young people living with a person with dementia have similar experiences to older relatives, the impact on their lives is

arguably much greater. Young onset dementia is likely to be diagnosed when someone is still working. Many will have significant financial commitments such as a mortgage, children to care for and dependent [parents](#) too.

Olivia Barnett was just 19 when her mother was diagnosed. Now 21, Olivia decided to take part in the project because she felt she had been left in the dark about her mums condition.

"I felt like I trawled through the whole of Google and couldn't find anything that related to my mum's condition or my experience aside from medical journals", said Olivia.

"It was very upsetting feeling so alone, especially when you're a teenager and your friends can only relate to you by referring to a grandparent with dementia. I was keen to take part in this project so that other people know they're not alone – and so that there is a wider awareness that dementia isn't just an "old person's disease".

She added: "I think there is definitely a need for people to be more aware of [early onset dementia](#) - if only for the fact that people are still shocked that my mum, now 60, has it.

"I've encountered countless people over the five years that she has been living with dementia who are still left stumped as to what to say when I tell them.

"I feel that if people were more aware of early onset, they wouldn't be so hesitant to talk about it. I also believe that services for people living with early onset dementia and their families would be improved (or even created!) if the general public knew it was actually an issue - as people with [early onset](#) are typically of working age, the impact on their family financially is huge - and their [children](#), who are often teenagers, are left

without any resources (be that financially or emotionally)."

Dr Melanie Hall, Research Associate on the project, said: "We were absolutely overwhelmed with the response from young people wanting to take part in the project.

"Everyone who shared their story discussed how desperately isolating it is to have a parent with [dementia](#) and how you become marginalised from your friends and society.

"Going through secondary school, college and university can be a challenging and stressful time for anyone but to have to deal with slowly losing your parent to such an debilitating disease at the same time is unimaginable.

"Through this project we want to show young people that they are not alone in this awful situation."

More information: For more information about the project visit www.sheffield.ac.uk/education/...groups/ccpe/dementia

Provided by University of Sheffield

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