



Some readers might be surprised to see an article about young people in this journal, but dementia can impact on people of every age. Most often, young people under 25 are affected when a grandparent develops dementia, but some must live through the challenge of their parent developing younger onset dementia. This diagnosis is devastating for the person with dementia, but how might it impact their child?

There are noticeable gaps in the literature about the outcomes for young people living with a parent who has dementia (Svanberg *et al* 2011). Most of the research to date has investigated the impact of younger onset dementia on the person living with the condition and their primary carers, often their partners. Worryingly, a recent report looking at caring responsibilities of young carers across a broad range of situations not specific to dementia has found that young carers' mental and physical health deteriorated over time. Importantly, the authors noted that this deteriorating health seemed to get worse as young carers moved to adulthood (Cass *et al* 2011). As dementia can impact families with children and young people it is important that we as a community understand the experience of these young people.

Based on data from our qualitative research project, *The impact of younger onset dementia on the person and their family*, we would like to take you on a journey with three young people who have lived with a parent with younger onset dementia. This is an ongoing project collecting the stories of young carers. The experiences of these three people are representative of the larger group involved in our research project. To date, we have interviewed 12 young carers, and hope to interview two more aged between 10-18 years, particularly male young carers. We have also interviewed two people with younger onset dementia and three carers and parents to get the family perspective on these situations.

The young people's stories

Bryan*, Timothy* and Morag* come from three separate families, each with a parent who was diagnosed with dementia when the children were in their teens. They are now all young adults. Looking back, all of them acknowledged that some changes in their parent's behaviour were apparent for quite a few years before diagnosis.

Bryan was nine when his mother first showed signs of what he much later knew to be cognitive decline. Timothy was 11 when he had to start cooking, claiming that even the cat wouldn't eat the food his father was serving up. Morag was 13 when she was first told about her mother's diagnosis.

Invisible carers

Karen Hutchinson, Chris Roberts and Susan Kurrle discuss a research project recording the difficult journeys of young people caring for a parent with younger onset dementia



The social discrimination and exclusion often experienced by young people caring for a parent with dementia can have devastating effects on their mental and physical health

Both Bryan and Timothy were only-children and lived mostly with their parent with dementia. Morag lived with her two siblings and both parents. The diagnosis of dementia in parents with young children and teenagers sends shockwaves through the family as well as the local and wider community. However, the focus of service providers, health professionals, as well as family and friends has not necessarily been on providing support for the young people involved.

Bryan and Timothy became their parent's main carer from a very young age, with little support until they turned 18 and became their legal guardians. Until then, life was very challenging. These young men simultaneously dealt with a very unpredictable situation at home, while also coping (or not coping) with their own issues of growing up. They knew their home life was different from others in the communities in which they lived, and found themselves isolated. For many young carers the general lack of knowledge about dementia leads to discrimination. These young people discovered that many friends and family just disappeared from their lives.

With the deterioration in their parent's condition increasing the stress, a full-blown crisis was almost inevitable at some point. What triggered this crisis was different for each individual and family.

Bryan

For Bryan, the crisis hit when he was studying for the Higher School Certificate (HSC), working part-time, caring for his mum and trying to obtain a university music scholarship. His stress level was high and life was challenging. He was completing his education with minimal support. Many of his friends were planning to leave the area to start a new life, gaining some freedom and independence from their parents, but he knew in his heart he could not leave home.

Bryan was in Year 12 when his GP recognised his crisis and counselled him to move out of home for the sake of his health. However, there was no financial support to make this a realistic plan. Bryan developed severe depression and his negative emotions drove him to self-harm.

He was successful in receiving several offers of music scholarships but declined these to remain near his mother. He admits that his mother would have been very upset if she had been aware of his decision, as she had recognised his talent and supported him from a young age.

Having made the decision to remain nearby to care for his mother, Bryan still needed to escape from the situation so he moved out of his mother's home and lived locally. However, life was a blur trying to save his own life while caring for his mother when he was physically and emotionally able to manage this. The guilt





of not being able to care for her upset him greatly, but he was not emotionally stable enough to do so, even when on medication. His future seemed bleak with the knowledge he was losing his only present parent.

Bryan describes attending counselling sessions where the counsellor was almost brought to tears by his situation. Bryan pointed out how sympathy was not what he wanted, but rather guidance. He experienced feelings of increasing hopelessness after each session failed to provide the necessary support. The counsellor's inability to provide tangible support just added to Bryan's despair and sense of exclusion from society, causing him to feel more of an outcast. Bryan's perceived unfairness of the situation was intensified by the lack of understanding from a professional who was supposed to help him.

Bryan eventually returned to caring for his mother after leaving home, but reached a point where he had to organise nursing home care for her. He described this as a challenging, difficult process due to his mother's age and his lack of knowledge and understanding of the procedures.

Morag

Morag's family situation was quite different. Her father worked full time and was also her mother's main carer. Morag felt that, as she was the youngest, she was shielded from a lot that was going on. However, not long after her mother's diagnosis, Morag developed a mental health condition.

She concealed her emotions, hiding behind a façade of what was expected of her in the family and community. She was a bright girl and well liked. She did well enough in the HSC to go to university. As her father was her mother's main carer, she was able to live at home and attend university while providing back-up support for her father.

Morag was 20 when her crisis hit. Her mother had to go into a nursing home for respite, with plans for her to become a permanent resident. Morag was not prepared for how emotionally difficult this would be. She was distressed at the thought of her mother living in a place with people at least 30 years her senior. Her emotions built up to the point where she self-harmed. Things were getting worse. She told us that she felt life was not worth living, but luckily, a supportive friend stepped in to help her regain perspective.

Morag's life had been totally derailed by her mother's deterioration. The enormous sense of guilt she felt was focused on the belief that they, as a family, had failed her mother. She felt they should somehow



Children and teenagers affected by the need to care for a parent with dementia need support from service providers, health practitioners and the community

have managed to keep her at home even though rationally she knew this was not possible – not without a huge amount of support and commitment from the whole family, which was not available. Community support services could not provide enough care at home, and because of an incident in the dementia day care centre, Morag's mother was not allowed to return. Her father's health was deteriorating and he needed to take care of himself.

Morag described the grief of losing a mother who was still physically present but out of reach emotionally. Most of her friends did not understand at all and not being able to talk about it made her feel very alone. She missed her mother immensely and cherished her memories of her, which she desperately held onto.

Timothy

Timothy grew up in a regional beach-side community where his father, who had undiagnosed younger onset dementia, was labelled a drug addict because the community could see no other reason for the change in his behaviour. At the age of 12, and an only child of parents who were living apart, Timothy was unable to give his friends and their parents a name for his father's condition. Consequently, they were both socially ostracised and discriminated against, causing his father to withdraw further from social activities. His father no longer met up with friends and started drinking more at home. This affected their relationship as well as leaving them with little or no money for food and to pay bills.

This socially isolated life drove Timothy to hang with 'the wrong crowd' where skipping school was common. He stayed away from home at nights and slept on the streets. For Timothy, the crisis came when his father became increasingly stressed and

his extended family intervened. They labelled Timothy as the troublemaker and separated the two of them. Timothy was sent to live with his grandparents. Denied contact with his father, Timothy eventually ran away from his grandparents' home and returned to his father to care for him. He was only 14 at the time.

Timothy cared for his father for many years. His father continued to deny his diagnosis and Timothy worried that they would end up being separated if he let anyone know his real home-life situation. Although academically bright, Timothy struggled to get good grades. He was his father's full-time carer, worked to pay for food and bills, as well as studying at school. He described the stigma of being poor and having a parent with dementia: he certainly did not feel like he belonged in the same world as his peers.

After leaving school, Timothy reached an emotional crisis point when he was juggling work and caring, under increasingly difficult circumstances, while trying to maintain some normalcy in his life. He too had to leave home, forcing other family members to care for his father. Timothy was very angry and depressed, which negatively affected his relationship with his father. He knew he probably had many years of caring ahead of him, but he needed some time out to recover emotionally in order to keep going. After Timothy left home, care services for his father were put in place, but the service providers struggled to manage his father at home and he was admitted to a nursing home shortly after Timothy's departure.

The first aged care facility was not equipped to care for people with dementia and struggled with caring for someone as young as Timothy's father. Timothy also wanted to have his father closer. Whenever issues arose, he had to keep travelling back and forth to deal with them. Timothy tried to find a more appropriate facility, but because he was living and working in a different area, he had to spend many nights sleeping in his car as he travelled back and forth. Though he was successful in finding alternative residential care for his father, it proved to be an arduous process requiring substantial time and energy with considerable financial stress for Timothy.

The decision to move a parent into an aged care facility can be traumatic, as was the case for Morag. However, both Bryan and Timothy acknowledged that it also lessened some of their responsibilities, which in turn, actually improved their relationship with their parent. With the strain of being a carer removed, they were able to reconnect with their parent and spend valuable quality time with them. Morag agreed with this too, but for her, it





meant she was also able to improve her relationship with her father now that he was no longer caring for her mother full-time.

Looking to the future

At this point in the research project we have analysed the data from the perspective of emotional trauma. The more we listened, the more we realised that these young people had experienced significant difficulty due to the consistent lack of support and understanding by their communities. While we were not surprised by their deteriorating health (Cass *et al* 2011), the severity of that deterioration and the degree to which they were stigmatised by their own families and local communities was surprising. Equally challenging was the way that fragmented service provision consistently let them down. These young people were living with their own grief and trauma as well as struggling to support their parent's mental health, but society seemed to be making things worse for them.

In order to further understand the experiences of the young people we interviewed and to be able to formulate a framework within which to develop further research and recommendations for support and service delivery, we looked at our research participants from the perspective of the Social Model of Disability. This model helps us understand the experiences and truth of disability as a social problem rather than an individual or family issue. It draws our attention to the real problems of disability, the attitudes which disadvantage people and the social barriers that affect full participation in society (Barnes & Mercer 2011).

From this perspective, these young people were at a greater disadvantage because society failed to support their emotional well-being and engagement in the social, educational and economic opportunities relevant to their age. This caused them unnecessary isolation and exclusion from fully participating in society. The diagnosis of dementia created social stigma, discrimination and lack of understanding. Because that stigma is common in the community, this only added to their family's difficulties. We began to ask whether young people living with a parent with younger onset dementia – in experiencing similar discrimination by society as their parent – are therefore, in effect, disabled themselves.

As a wider community we need to ask questions like this and have these conversations so we can understand what social factors impact on the lives of these families and young people. We can see this personal tragedy of social discrimination



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and exclusion happening not only to the person with dementia, but also to their families and dependants. We need to understand that changes must be made to prevent social isolation and to promote emotional and physical well-being by providing adequate and age-appropriate support, thus avoiding the 'derailment' of the entire family at times of crisis.

A common issue revealed in our research was that young people found that service providers were so overwhelmed by the young person's situation that they inadvertently contributed to their despair and were unable to help them move forward. This indicates that professionals need more training to be able to support younger carers and children of people with dementia. Almost all services are focused on aged care and the common situations of counselling partners and adult children or relatives. Dealing with young people in the context of a family affected by dementia requires specialist knowledge and expertise to provide effective intervention and support that meets their needs: empathy, services and practical advice.

Supporting young people

With the new Australian Government funded key worker roles for people with younger onset dementia and their families (Alzheimer's Australia 2013) there are opportunities to help prevent some of the consequences of long-term emotional trauma in these young people. Paying particular attention around the vulnerable time when young people move from youth to adulthood is important.

Service providers and health practitioners can develop positive action towards monitoring the situation to

prevent a crisis. As soon as a formal diagnosis of dementia is made, programs and support need to be put in place to reduce the caring responsibilities of these young people, as well as to control the amount and intensity of their caring roles. The provision of immediate support is important as issues have often existed for a long time prior to diagnosis.

For some young people over 18 years of age, the Alzheimer's Australia (NSW) young people support group has provided an opportunity for them to meet others in similar situations and share experiences. A feeling of belonging is important for these young people to give hope for the future. Alzheimer's Australia (NSW) runs the young people's support group every second month at the Sydney Dementia and Memory Community Centre in North Ryde.

We must support the development of more services like this and help to make the children and teenagers affected by the need to care for a parent with dementia more visible to service providers, health practitioners and the community. With this aim, we are planning a workshop this year with relevant organisations to look at the issues and highlight opportunities for working together.

By doing this we may identify better ways of meeting the needs of these young people. In the meantime, we are still planning to recruit a few more participants in the 10-18 year age group for our research and run a focus group with some of the young carers who participated, to learn more about their experiences. We are continuing with the data analysis and further analysis of the emergent themes from the data is ongoing. ■

For more information on the young people's support group, call (02) 9805 0100 or go to: <http://www.fightdementia.org.au/services/support-groups.aspx>

* Names have been changed to protect privacy

References

- Alzheimer's Australia (2013) *National Younger Onset Dementia Key Worker Program*: Available at: <http://www.fightdementia.org.au/services/younger-onset-dementia-key-worker-program.aspx>.
- Barnes C, Mercer G (2011) *Exploring Disability* (2nd ed). Malden, MA: Polity Press.
- Cass B, Brennan D, Thomson C, Hill T, Purcal C, Hamilton M, Adamson E (2011) *Young carers: social policy impacts of the caring responsibilities of children and young adults*. Report by Social Policy Research Centre, University of NSW (LP0755940).
- Svanberg E, Spector A, Stott J (2011) The impact of young onset dementia on the family: a literature review. *International Psychogeriatrics* 23(3) 358-71.

