

Someone to come alongside

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I think as a couple we were very similar to many couples in our Baby Boomer lifestyle where we tended to work through the issues of life together and get through without looking for help or advice. That wasn't being foolish and it's not an indictment on those who are quick to seek help – it was simply that life had taught us to work towards overcoming the expected hurdles as we faced them.

Neither Graham nor I had chronic or ongoing medical issues which needed regular medical monitoring or intervention; physically we were both fit and healthy. So, when I found myself in totally uncharted waters, managing Graham's everyday activities and functionality, I simply put in my best effort to continue to keep our life moving along as smoothly as possible. We didn't have a diagnosis at that stage, nor were there any suggestions coming from our GP for sources of helpful advice.

While I was managing from day to day, I was also beginning to feel the stress. The reality of the disease often remains hidden: friends would say how well Graham was looking and how well he seemed to be functioning when the reality behind closed doors was becoming more disturbing and confronting, sometimes alarming. Still, there was no advice forthcoming from anyone as to how I could be helped with managing our lives as the disease progressed relentlessly.

In April 2012, a little over a month after we finally got a definitive diagnosis of young onset Alzheimer's disease, friends told us about an organisation called Alzheimer's Australia which was about to start their next course on Living with Memory Loss. Our friends also wanted to attend but were unable to at that time. I called Alzheimer's Australia and discovered that the course which would commence the following week would be focussed specifically on couples affected by young onset dementia in all its forms. There was a screening process which saw us being accepted and so began our association with the organisation and people who have had an invaluable and irreplaceable impact on our journey, all the way through to equipping me to advocate for Graham through his end of life experience.

The truth is I didn't know how much I didn't know!

The course equipped me with a lot of basic knowledge about the disease, as well as helpful suggestions for negotiating all the rough spots we were to encounter along the way. No two people living with dementia will have the same experience and, therefore, the caring role in each case will be very different. Despite this, there was so much information we were given which had a common thread applicable to the dementia journey. I learned how to be assertive and how to advocate for Graham in all the environments where we would find ourselves – medical, government, hospital, care facilities, our community, even our family.

But education wasn't the only benefit: we discovered during the course that we weren't alone in what we were experiencing. Yes, our stories were different but each of the participants in the course, both carers and those living with dementia, found an immense release in being able to discuss our experiences and our journey with like-minded people. For the first time we realised that we weren't alone.

The course finished but we continued to meet as a support group once a month, learning more and sharing more as the disease progressed and our caring role evolved and changed. At the end of the six months, the formal structure as a support group came to an

end, but some of us decided that we wanted to keep in contact and support each other and we have done this ever since, for almost six years. There have been many late night emails downloading or crying or relating milestones of achievement – such an important thing to do but it really only becomes liberating when you know you're sharing with someone who completely understands what you're going through. There's nothing more reassuring than a voice at the other end of the phone or out there in cyber space letting you know that you're not alone, encouraging, affirming or commiserating.

Aside from the support group though, there has been ongoing encouragement and acknowledgement and validation in being involved with Dementia Australia (formerly Alzheimer's Australia) as a Dementia Advocate. This has taken many forms, including attending functions; fundraising; contributing to research; sitting on consumer forums; acting as a public voice for those no longer able to do so for themselves; contributing to media stories and generally feeling valued and appreciated both as a carer and as a consumer and advocate for those living with dementia. While we never actually accessed the Helpline, we were aware that it's available 24/7 and that the counsellors on the other end of the line are highly trained and thoroughly equipped to be a source of guidance and knowledge, as well as a compassionate listening ear.

Often I meet a carer who is under great stress, as I was, and I gently encourage them to make that phone call. I know it will lead to a sense of relief to find someone walking alongside them or perhaps just giving them that tip or contact details which will provide what they need to continue caring for their loved one well. Sometimes the encouragement they need will simply be a reminder to care for themselves. I'm not always successful, but I respect that each person has their own idea of "help organisations" and some people want to "be strong". The truth is that just a little guidance and support can be a huge help in seeing their loved one continue to enjoy life as well as possible.

When you walk side by side with those who are passionate about changing our community so that people living with dementia can continue to live fulfilling and rewarding lives, there's a sense of purpose and achievement. In fact, this can transform something that is incredibly sad – the Graham and Imelda Gilmore walk through dementia – into something positive that can be used to encourage and affirm those who follow us on the journey. I'm immensely grateful to God for setting us on this path initially and to our friends for their kindness in pointing us towards Dementia Australia, and I look forward to continuing to be involved with the organisation in making our society a more welcoming place for those living with dementia.

Imelda Gilmore

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