



“A little burdensome”: stigma and fear around dementia

I opened a letter today, addressed to my mum who was diagnosed with Alzheimer’s ten years ago. The letter happened to be from a ladies committee that my mum was a member of some ten years ago. A letter of thanks for her contribution to the society over 50 years of her life and, at first, I was pleasantly surprised that someone had taken the time to send it. But then I started to think about how much my mum had enjoyed this social circle over the years and it reminded me that the entire group of lifelong friends had simply abandoned her following her diagnosis!

I remembered one of the ladies committee had phoned me around this time to say they just didn’t have time to deal with my mum’s behaviours and that due to her memory loss she was becoming a little burdensome at their meetings, and would I mind asking her not to attend any more? They didn’t even have the courage to speak to her directly – they left it to someone else!

To me, it sounded like they had decided that Margaret had lost her ‘usefulness’ within the group and they simply could not or would not put themselves out to accommodate her changing personality. Of course, over the years since then, they would always stop me in the supermarket to ask how mum was getting on. Although that was nice of them they didn’t take up my suggestion that mum would be overjoyed to see them if they could find time to visit her at home. Over the next few years mum became sadder, lonelier, and even depressed by the lack of company and support from her friends. It was hard enough for her to come to terms with this very scary diagnosis and she often expressed her deep-seated fears that somewhere down the line she would by degrees, lose her mental capacity and be treated as if she had ceased to exist in the real world!

My dad also struggled with the transition. Whilst he was grieving at the loss of his wife (as the person he once knew) he became more and more embarrassed to talk about mum to his friends and even stopped taking her out in public. He was afraid that her behaviours would be irritating to others. When I suggested that mum could make new friends and get the support and attention she craved by going to a day centre he commented that he didn’t think they would like her very much! He said that she would be too annoying to others. (Smile!)

And all of this has come flooding back ten years later, prompted by this well-meaning letter of thanks. A tad late, don’t you think?

So here am I lying awake in the middle of the night, trying to make sense of it all and searching my soul to find some forgiveness for those who abandoned my mum so many years ago and left her to face her dementia journey alone. And now it is too late to let my mum know that at least she was appreciated ten years ago, as she just couldn’t take it in.

I find myself thinking: "Let's hope this doesn't happen to them!" And I wish I could find a way to let them understand the hurt they inflicted on my mum. Perhaps they perceived mum as not knowing what was happening at the time? Well I can assure them that she did. She was devastated!

I believe that they made their decision to leave Margaret out of their group due to the fear and stigma about dementia. They anticipated that they would not be able to meet her needs. They had no experience of what it might be like for someone newly diagnosed with dementia. They didn't know what to say to her or how to handle it. If they had they might have acted differently.

And this is just one of many similar stories I have heard over the years spent caring for others in the same situation. I have been my mum's advocate for so long now – trying to anticipate her needs and desires and to speak out for her as she is now non-verbal. Trying to remember what my mum would have liked back in the days when she could make her own choices.

I am so very proud to say that it was our early experiences of living with my mum's dementia that was the inspiration we needed to start up regular Memory Cafes and now a full time [Activity Day Centre](#). My friend Pam (whose dad also lived with Alzheimer's) and myself saw the need and did our best to fill the gap in services.

So now we offer a 'safe haven' where people who live with dementia can feel a sense of normality and be engaged in meaningful and empowering activity. Keeping the brain active and happy can help to slow down the progress of the diseases of the brain and bring a sense of "normality" to their daily lives. We also strive to counter some of the stigma associated with dementia by inviting members of the public, and sometimes schoolchildren, to join in with our activities so that they can gain a better understanding of the disease and help people to have a sense of purpose; and hopefully this would lead to people being able to stay in their own homes for longer as opposed to having to go into full time care too soon. We also provide much needed support and respite to those carers and families who are also living with the disease through their loved one.

It has been extremely uplifting to see so many people helping others and coming to understand what it is like for those living with dementia. It is very easy to perceive someone's dementia behaviour as irritating or negative but if we all had just a little more empathy, if we could just stop for a moment and try to imagine what it may feel like for those people. Understanding their fears and anxieties can be marvellous healing - a medicine for those who need to be understood and not just shunned.

So next time you are in a queue in the supermarket behind the lady who has forgotten her pin number or is taking too long to pack her shopping, don't be so impatient and try not to show your frustration - try to have some empathy for how she is feeling about it. Put yourself in their shoes and wonder how you might want to be treated if that was happening to you!

Empathy is the route to ending stigma. One of my clients is in the habit of calling me "an angel without wings"! "No!" I say to myself, I am not an angel, I simply feel your pain, and I will treat you as I would like to be treated if I were in your shoes!"

Finally, I would like to express my gratitude to my mum for drawing me into this caring pathway, where I feel so able to help others just like her.

"Thank you mum for teaching me so many valuable lessons, even today as you are approaching end of life, I remember you just as you were, and I know that you are still there, just the same person on the inside and I will always be there for you, whatever happens. x"

Amanda Botterill
[Memory Lane](#)

This is one of [a series of blogs published by the Age Proud Leeds campaign](#).