

Ashamed By Dementia?

Written by K B Napier

Monday, 20 September 2010 09:47

The police contact you - Dad has been found wandering along a busy dual carriageway, in a dressing gown, at two in the morning. Or, you come to hear gossip from neighbours, that Mum has been seen, stark naked, pruning the flowers. Or, Dad, a staunch deacon who is well known in the area, has taken to swearing at people. Mum might accuse visitors that they stole her diamond ring when they went upstairs to the toilet. There are countless variations of these stories. Each of them brings devastation to families. They are typical examples of the onset of dementia, and of the onset of shame within families. But is this shame justified? I hope to show it is not. For a more detailed examination of dementia, see other articles).

Whilst working as Head ('matron') of a Dementia Unit, I was walking down the corridor and thought I heard a female voice in a room nearby. It was early evening and dark, but I could not see any lights on in the rooms. I retraced my steps and yes, a female was definitely talking in room 46, even though it belonged to a male resident. The voice was speaking in the Welsh language and although I have a very limited knowledge of my own language, I realised that the female was not engaged in conversation, but was making some kind of speech.

Intrigued, I quietly opened the door. There, in the dark, standing in the middle of the room, was the diminutive figure of one of our elderly lady residents, an ex-teacher. She was facing the window, and her arms and hands moved expressively, as she delivered her speech. As she spoke, she moved her head, looking from one side of the room to another, she also moved her whole body around, as if she was in a very large auditorium. As I watched and listened I managed to interpret some of her words and found out that she was making a speech at a Welsh Eisteddfod (the annual national cultural event of Wales), to an appreciative 'audience'!

I watched for about 20 minutes as she spoke in beautifully modulated tones and with perfect timing. At times she interjected with portions of scripture and poetry (she had also been an Eisteddfod entrant herself in the past, winning prizes for her verses). She was evidently thanking the audience for their support of the children from her school, who had won the event, and she gave several anecdotes about individual members of her school party. She even listened to questions asked by the imaginary audience and answered them!

All of this was in her own mind, but do you know, I was deeply moved by what I saw and heard. She was *there*, in the flesh. The audience was real to her. When she turned and saw me, she obviously incorporated me into the same hallucination, and treated me as one of the audience. Clinically, this was fascinating. When she finished, I clapped, as did (I think) the 'audience'! I worked with dementia sufferers as a nurse, 20 years before. Then, I returned to the same work,

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out of choice. I cannot work in acute psychiatry, because I disagree with the theories and practices. But, working with dementia sufferers is worthwhile. If dementia was shameful, I could not do the work.

The same lady depicted above was a lot less than five feet tall, but she could deliver verses in English or Welsh that moved the soul! Through her confusion I even heard evidence of a saved woman, as she spoke affectionately of Jesus Christ! Often at dinner, she would stand and recite entire poems, retaining all the dramatic presentation qualities of timing and pathos found on the Eisteddfod platform. Residents and staff alike gave her an ovation, such was the quality of her delivery. And that was just *one* of the residents!

There were a number of fairly eminent people amongst the residents, from police superintendants to teachers and ministers of the church. The rest were ordinary folk, all of them someone's Dad or Mum. Each had his or her own traits and ways. They ranged from mildly confused to more severely demented and the work is harder than in an ordinary nursing home unit, but staff loved it! This is because the residents were real characters, every one of them.

On the Unit there was much laughter and very real fun, but we did not laugh *at* residents - they were simply such good fun to be with, and the laughter was spontaneous. We all laughed together. On occasions, dementia can cause people to act outside their normal character. Thus a pastor might curse, or a perfectly respectable person will utter obscenities or act lewdly. But, none of this is the 'real person'... it is all the result of dementia, so no shame is attached to it. (However, it is also true that certain personal traits can sometimes be highlighted and made far worse, because the person no longer has control).

Really, dementia (there are different kinds, but the most well-known is Alzheimer's disease) is not a mental illness at all. There are certainly 'mental' problems, but these are due to changes and damage in the brain itself. Thus, when a devoted deacon, husband and Dad, begins to expose himself, or curses, one should understand that this is due to a physical illness, and NOT to some hidden desire or character!

During our lifetimes we all hear and see sinful activity and words. Normally, we dismiss them and never bother to take part in, or repeat, them. The same happens in the lives of many non-Christians, too, who would never dream of uttering obscenities, exposing themselves, beating their wives, or otherwise embarrassing their families. There is a part in the brain that controls inhibition. Once this part is destroyed, any sense of propriety also goes, and that is

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when we see and hear things we could not associate with our loved ones. And that is why many anxious families are shamed by dementia.

There is also shame attached to the stigma of 'mental illness'. But, as we have already seen, the process is entirely physical - as with any other physical illness. When my own mother was in the terminal stage of cancer, her entire character altered and she said and did things alien to her, as well as to us. In such cases, the cancer manufactures toxins which produce confusion and other marks of temporary dementia, even though there is no actual dementia. Many other things can cause dementia or dementia-like symptoms, and the sufferer cannot be blamed for what he does and says at such times. The family must try to remember the essential character they once knew and not dwell on what the dementia is doing, because the 'real' person has been overtaken against his/her will by a physical disease (we are not talking here about self-induced dementias, through, say, drug abuse).

So, if your loved one has dementia, do not be ashamed, whether or not he or she is a Believer. And do not be ashamed by anything that is done or said, if it is out of character. The disease unlocks words and activities that have filtered in to the memory over the years, but which normal Christian processes discard. It also causes one to react to the present in a different way.

A progressive dementia can last many years (depending on the type) and it can produce some terrible effects. One of the worst is the inability of the sufferer to recognise his or her own relatives. This is why some have called dementia a 'living death', where one mourns the sufferer as if he has died, but the mourning does not cease, because although the brain and memory are severely disrupted, the body remains fairly intact. It is, to me, one of the saddest and most emotive of illnesses. But, as I have said, it can also produce much laughter and joy!

A spouse, however, or a very small family, cannot look after a dementia sufferer at home for long, unless they can provide 24 hour a day care, non-stop. Even then, there will come a time when the strain and the inevitable inability to cope with the many symptoms, forces the family or spouse to approach a nursing home, or other agency, for help. There is no shame in that, either.

Looking after a dementia sufferer is harrowing, and because dementia is a progressive condition, it will require specialist care at some point, just as other diseases require specialist doctors and hospital care. Often, relatives feel a deep guilt and shame when they hand over relatives to such care. Sometimes this guilt turns to over-protectiveness or undue criticism of

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care staff. Just remember: dementia is a physical illness and it needs specialist attention. Professionals understand how you feel, and why you over-react. That is why they will support you, if you allow them to.

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