

~ Chapter Eighteen ~

Spiritual care of dementia

Dementia is often seen as a medical illness. But it is much more than that. Most of all, dementia is in fact a social and a spiritual illness; it is, for everyone, about a profound change in life and also part of a journey towards God. So if we neglect the spiritual dimension, then we fail our patients and loved ones.

In fact, health services frequently forget the spiritual aspect and will very often only send for the church at the last moment, if at all. They fail to see the social and spiritual realities of illness. While we focus often upon the medical issues, dementia brings about a profound change in all aspects of life. As mentioned above, dementia is also unquestionably about the final journey of individual sufferers towards God. So if we neglect the spiritual, we fail people with dementia.

Worse still, priests and church visitors are often excluded from the confidential network of hospitals. Church workers are therefore never told there are Catholics or non-Catholic Christians in hospital: the patients must tell us themselves. People with dementia cannot do this, and nor can other very sick individuals. It is really important therefore that churches

are informed when these people go into hospital and when they go into care so that the right input and right support for them can be provided there. It is a real tragedy when the sick and vulnerable members of our society are denied access to the spiritual care that they should have a right to receive because of a lack of information about them.

Dementia also brings the opportunity to think and pray about these changes. Given that someone with dementia is no longer as able to practise their faith by themselves, it is really important that we provide them with the opportunity to do so by other means. By doing so we will help to value and respect them as we should. If we leave them alone, we neglect our Christian duty.

She stilled and became calm at the moment of Holy Communion.

Two of the old ladies on the dementia ward in a long-stay hospital were Catholic. So one weekend we thought that they might like the opportunity to go to the hospital Mass. Jean was still able to take part in the Mass. She did so with some effort and some lapses in concentration. Ethel, who had a very severe dementia, sat in her wheelchair and chatted all the way through Mass. But at Communion she stilled and became calm and serene, seeming to pray for a while. We all looked on and marvelled a little. Yes, she recognised Jesus, she saw him, and she knew him.

Those brief moments when it is clear that someone with dementia recognises and understands more than we thought they did are uncommon, but they can be very beautiful and special.

Prayer is a central part of our lifelong relationship with God as well as of our understanding of ourselves. Of course, we usually think that our “faculties” and mental abilities are at the very core of what it is to be ourselves. And being able to see and recognise the eternal and the reality of our creation is an important gift at all stages in life.

Some people find themselves unable to go to church for decades at a time, perhaps due to some impediment, or even because of an interfering mother-in-law or other relative. Others just stop going and forget. And some simply find themselves unable to see the signs of the Creator in the world around them.

Whatever their background, almost all humans naturally seek meaning and hope. And that lifelong search and yearning means that almost everyone with dementia has a spiritual background which they bring with them to the illness.

But one of the mysteries of us as people is the extent to which our eternal soul and spirit is one and the same as our mental faculties. We often think it is, while in fact we recognise that tiny children and those with learning difficulties are no less human than the most able president or world leader. And while we see that those who are disabled have unique gifts and charisma, bringing real change and love to those around them, we still struggle to grasp what we are without our faculties.

Clearly we do not know what we will be like in heaven (or hell), but we are confident that those who have died (as well as God) can hear our prayers, and we have good evidence that those prayers are often answered. Therefore, we think that in heaven, we will have our faculties in at least some form, while

at last seeing the glory and joy of the Resurrection. But we also then feel confident that our human soul consists of more than just thought processes and ability. The precise nature of it all remains a mystery. With confidence we predict that it will remain a mystery!

As dementia strips us of our intellectual abilities, therefore, we think in part that humanity is compromised. And yet we also see accentuated into stark relief the gifts that come with that disability. Sometimes, as we have said, people with dementia are happier than they were before they had it. Very often we see that Grandma or Grandad remains just as real to the little ones until the day they die. To some degree, therefore, dementia can help us to see that we are more than the abilities we have. Even in severe disability we are fully human and able to give to those around us. And when finally people with dementia have died, there is still a great emptiness in the house and hearts of those left behind.



Grandma came to stay, and gave us so much

With cancer and severe dementia, Grandma was doing badly in a home. She and Grandad came home to stay while she died. She had been very distressed and challenging, but as she got worse she settled somewhat, needing full care support and feeding, etc. Soon she was bedbound. Her pregnant daughter became critically ill and had to go to hospital, leaving her son-in-law and the rest of the children at home. As things progressed it became clear that the baby would die soon after birth. But somehow, Grandma, strengthened by the sacraments of the Church, hung on till after the baby had been born and died.

And in the middle of all that, her son-in-law (still doing the full-time day job) realised that even in her extreme illness, she was somehow helping to keep her whole family going. And for the children, Grandma was there, a gift and a real asset at a time of crisis.

It is a fundamental claim of person-centred dementia care that people with dementia continue to have “agency” – which means that they have worth and continue to give to those around them. They have that worth even in the most severe inability. Grandma gave so much, even at the end.