

Spiritually Accompanying People Living with Dementia

Rev. Dr. Joseph D. Cortis

Every human person is seen as equal as he/she is lovingly and beautifully made in God's image and likeness.

The basis for the theme of **Human Dignity**, the bedrock of Catholic Social Teaching, is that we were created in the image and likeness of God. Regardless of any factors or reasons we can think of, individuals have an inherent and immeasurable worth and dignity. Each person is unique and special. Human life is considered sacred. This theme is about our radical equality before God that leads us to think no less of somebody because they are from a different place or culture, because they believe something different to us, or because of their work or employment situation or indeed because they have changed due to dementia and so has our relationship with them. Another great thing to remember is what Tom Kitwood, a pioneer in dementia care, once said: **'If you've met one person with dementia, you've met one person with dementia'**

The other principle I would like to focus on is **Subsidiarity**: to make common decisions at the lowest practical level. Every person, family and intermediate group has something original to offer to the community. *'Every person's contribution should count'*. It is important to realize that mental capacity is situational.

In the midst of the creation account in Genesis, God says *"it is not right that man should be alone"*. We do not flourish as people by being isolated and living by ourselves, but by engaging as full members of our community. We have an obligation to help and support those around us while at the same time allowing ourselves to be supported. The place most of us first experience a community in our lives is in the family, and so it is here that the themes of **Community** and **Participation** have their roots, and in the context of the family that these principles have developed.

Spirituality

There is a saying that it is only with the heart that one can see rightly; what is essential is invisible to the eye.¹ Spirituality is essential to every person, though it is often invisible. The visible aspect of spirituality can be found in its link to a particular religion or to spiritual practices such as daily prayer, reading scriptures etc. and doing works of charity. However, all human beings are spiritual beings whether they belong to a particular religious tradition or consider themselves to be religious.

Spirituality's invisible aspect can be described as that turn inwards, the inner life that people have. It is important to make a distinction between two aspects of the inner life: first, the inner life that is a **human life**, enjoying activities in the world, for instance the need for relationships, music, art, poetry, joy of creation and the world around us, finding beauty in the world; and second, **the inner life** that is spiritual yet also human life. Living fully with dementia reminds us all of the importance of fostering and encouraging this first aspect of the inner life.

However, the second aspect of the inner life, spirituality, is that relationship a person has with God. And whether or not the person is religious, the person does have a relationship with God.

¹ Antoine de Saint-Exupéry, *The Little Prince*.

After all, to say that God does not exist is to make a statement about one's relationship and attitude to God. The invisible inner life of spirituality is often described as the way in which a person finds meaning and connection or finds sources of hope in the world. If we think of spirituality in terms of finding meaning then it is all too easy to make the mistake of thinking that the person in the last stages of dementia is no longer a spiritual person, especially if the person no longer seems to relate to an inner human life of enjoying activities in the world. However, once we realize that spirituality is as much, if not more, to do with God than our own abilities, then we can understand how it is that every human being, no matter their situation, is a spiritual being.

Assessing spiritual needs

First, we can identify a basic approach that simply gathers essential information about the person. If someone is already involved in parish life or in another faith-based community life, then their faith affiliation will be clear.

However, there may be situations, for instance when a person is new to a care home, when this is not so clear. In any event, it is helpful to have this basic information:

a) determine a person's faith affiliation and b) determine whether the person has particular religious or cultural needs such as diet, religious observances, or certain restrictions.

However, this basic spiritual information provides quite a static view of the person's spiritual life. In addition, it is useful to look deeper and build up a spiritual history with the person.

A spiritual history is more dynamic because it seeks to identify ways in which a person's spiritual or religious life affects their care, and this can change as the challenges the person faces also change. Unlike the basic spiritual approach that is usually done only once, a spiritual history can be added to as the person's situation changes and as ongoing relationships with carers and professionals develop. A spiritual history can also help with identifying changing needs. It is important to remember that spiritual histories are:

- not so much about what a person believes but rather how their faith and beliefs operate in helping them to cope;
- are about respect for the person's faith and beliefs even if they differ from the beliefs of the person who is doing the assessment;
- are not about judging or trying to fix a person's beliefs.

A spiritual assessment is designed to take a deeper look into a person's spiritual outlook so that appropriate care can be planned. This means looking together with the person and if the person agrees, with family and/or carers, at the person's needs, hopes and resources. A good spiritual assessment values the person as a real individual who comes from a particular culture, country and faith tradition, and who has their own background and experiences.

One key element of any spiritual assessment is the conversations we have with people. Hence when we are assessing spirituality we need to explore that person's current **Image of God**. This can tell us a lot about how the person faces up to their new reality as a person living with dementia. For instance, if a person has a view of God as a supreme judge, then the person may become worried about things that they have done or failed to do in the past and this may cause considerable distress. If a person has not thought about God except in terms of an impersonal being or an abstract figure, they may find it difficult to relate to another person's image of God as a loving and forgiving father. And if a person has had poor or abusive relationships in the past, a

view of God as Father may be a trigger for serious distress – even saying the Our Father may present them with real difficulty.

Practical spirituality

- What seems to be clear is that despite seeming to ‘withdraw’ into another place in their minds, many people living with dementia are still able to pray and their spiritual lives are still present. Hence we must presume nothing about what the person can and cannot appreciate spiritually.
- Never underestimate the power of Our Lord to bring comfort to people in any situation or the value that frequent, reverent words have for people with dementia and their families and carers.
- Getting to know the person living with dementia and the family as early as possible is crucial to establish a healthy relationship.
- Clergy have a responsibility to raise their own awareness about the different types of dementia.
- Crucially important is to hold regular dementia awareness session for the parish
- Both above points help to reassure the person and their family that he/she still belongs to that faith community
- At the early stages of dementia keeping to the same routine of the person is important e.g. attending the same mass, sitting in the same area of the church, allocating a responsible parishioner to look out for the person living with dementia unaccompanied etc.
- It is particularly important that if the person with early stages of dementia was an active member of the parish e.g. doing flowers, catechists etc such situations are dealt with in the most sensitive and caring way. Whenever possible support needs to be offered so that the person continues to fulfil their roles as long as possible.

What can be done when engaging with parish life is no longer possible.

- Here a good relationship with the family in order to get to know what the person’s favourite prayers and hymns are, favourite devotions, favourite saints etc.
- Assessment of spiritual needs is also important including the role of faith and prayers in that person’s life.
- What may be challenging but needs to be addressed in a sensitive way could be if the family’s praying practices are not strong and they do not seem to understand that this aspect of life is still important to the person living with dementia.

Some practical suggestions

- Be prepared to be flexible in administering spiritual care as responses and behaviour may be very different even from the last recent visit.
- Read the non-verbal signs of communication e.g. person is restless, uncomfortable etc.
- Wear clericals as this will signify that you are an ordained member of the clergy.
- Use familiar prayers and scripture readings, may be those you have discovered in dealing with the family members.

- Engage family members in these sessions as much as possible even if they do not practice or of no faith.
- Take your time in praying with the person concerned.
- With memory loss there cannot be confession of sin, but the healing through this sacrament is possible.
- There is a need for visible, tangible, audible signs of God's love when visiting a person at home or care home or attending a service of reconciliation.
- When appropriate physical touch can be healing.
- Prayer is a practical thing that we can do and even in very advanced dementia people may still be able to somehow respond to familiar devotions.
- Even when people are unable to respond they may well hear and understand what is happening.
- Singing a hymn can also bring healing and comfort.
- Prayers need to be greatly simplified as a response from the person may not be forthcoming, depending on the stage of the condition.
- Use of symbols such as a statue, rosary beads, cross can be very effective.
- We cannot however simply assume that a person wants to pray or indeed wants to attend a religious service. The individual experience of dementia may bring about a change in the way that person practices their faith.
- A person may no longer be able to read and may have forgotten the words of cherished prayers. Trying to make the person remember may cause distress.

Christine Bryden, who lives with dementia once said *'I may not always remember who you are, but I will always remember how you made me feel.'*

I would suggest that this encapsulates what accompaniment really means.

Rev. Dr. Joseph D. Cortis

October 2024

Resources:

Caritas Leeds: <https://www.dioceseofleeds.org.uk/caritas/our-resources/>

'Journeying together accompanying people living with dementia' 2023 Joseph D Cortis and Pia Matthews, Redemptorist Publications. The book is available for purchase for £11.95 [here](#).