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Coping with death

Accompanying a person with a learning disability who is dying

I have been disability adviser in diocese of Southwark for ten years and it has been a wonderful journey into the lives of people with disabilities. For the past ten years we have been steadily building up the theology and awareness within the church of the important and valued role of people with disabilities within her life and mission. The church teaches that every life has value and that all equally contribute to the building up of the Body of Christ in the world. Sadly, in the past, people with disabilities have been mostly absent from our communities and even more so have experienced a lack of resources and pastoral activities... It is true to say that we have experienced a hierarchy of ability within the church, as all that we produce and provide is geared to people that can read, write and process information in a mainstream way.

The good news I am happy to share is that this is changing and the life stories and witness of disabled people are enthusing the church to make positive changes and embrace diversity. It seems that the increasing presence of disabled people in the church is calling us to authentic love of the neighbour and to creative ministry and again, I am happy to say that we are beginning to respond to that call.

For the past two years I have been working with Professor John Swinton, a leading voice in the field of the 'theology of disability'. We have been conducting some action research focused on enabling the voice of people with disabilities to guide us in finding ways of meeting their expressed spiritual and religious needs. It has been a truly enriching experience. The outcome will be a practical resource that encourages religious and non religious communities to meet and experience the incredible wisdom that people with disabilities have to share (please see <http://www.abdn.ac.uk/cshad/Gangemi.htm>)

The theme for this year's Day for Life is a very important and emotive subject. Fr James Hanvey's reflection on Christian death and care for those who are dying is a very important issue for people with a disability and those with whom they share their lives. In his reflection Fr Hanvey gently speaks of the physical and spiritual reality of life and death. It is often the case that people with learning disabilities are deeply spiritual people but that they have not always had the opportunity to explore personal spirituality or be supported in understanding the reality of their inner life.

This could mean that, as a person with a Learning Disability becomes ill or approaches the end of their physical life, the language and the tools that are used within the church may be of no use and be outside their life experience. Therefore, when the need arises to accompany a person with a disability in approaching death, the church may not be ready nor have the knowledge to support them in their personal journey or when they face the loss of a loved one. Within the secular and medical world there is an ever increasing amount of research in this area and most of it suggests that a common practice within the palliative and bereavement care of a disabled person is to hide or avoid the reality of death. Indeed this



has been highlighted by the Foundation for People with a Learning Disability in their research 'Death matters'.

Death is a difficult concept for all of us but one thing we know is that it is a universal human experience.

It seems that a common misconception is that a person who becomes ill or who has a person close to them who is dying, is not aware of what is happening and yet it is a grave mistake to think that this is so.

There are stories recorded where the person with a learning disability has been experiencing immense anxiety due to the physical changes resulting from illness and that they have been told to 'cheer up' or 'it's ok it will stop hurting soon'. This practice is often due to the need to care for a person who is considered to have an inability to understand.

All people, at some stage in their life, encounter the loss of a person they have known. This loss, left unexplained, can result in confusion and psychological anxiety thus building up inner fears that, due to differing forms of self expression, remain unexplored and unexplained.

A person with a disability is also aware of loss and it may often be very difficult for them to show the confusion that they are experiencing. Indeed Dr Oyepaju and Dr Sheila Hollins from St Georges' hospital in London write; 'Research and clinical experience both suggest that people with a learning disability, who have not been fully involved in time of illness and funeral rituals have delayed or prolonged grief reactions and it can sometimes lead to psychological and emotional complications¹. Often the language we use to explain death and loss can add to this confusion. We can sometimes say ' the person has gone away, or sorry for your loss' Both suggest an implicit message that there is the chance of the person returning, or, if lost can be found.

An example of this is the story of a young man with Down syndrome who would sit outside the cemetery every morning at ten o'clock and wait for an hour. When he was asked if he was ok he answered ' Yes I am waiting for my mum, one day at ten O'clock they took my mum in there and they said she had gone away..I am waiting for her to come back'

For sure, the reason we explain in this way could be to keep the person with the disability away from the reality of death is because we do not want them to suffer.. Often it is true that the person is also kept from attending the funeral for the same reason. That very action, however, may be the cause of an inner suffering that the person with a disability finds difficult to express. We all need to grieve the loss of a loved one,

It is also true, that having to find ways of hiding the reality that someone who is close to them is dying, places a strain upon those who are supporting and accompanying them.

¹ General information extracted from article : How far are people with learning disabilities involved in funeral rites : Dr Oyepaju and Sheila Hollins Department of Psychiatry of Disability : St George's' hospital Tooting.



A different story... accompanying Samantha

A gentle yet powerful experience I have had of supporting a person with a Learning disability to understand death is that of Samantha Mizzen after the tragic death of her brother Jimmy in 2008. Immediately following his death, through actions, pictures and symbols, we helped her to understand the concept that his physical body that was gone and his spirit, which was now with God. On asking where Jimmy's favourite place was, Samantha took us to the garden and there we invited her to release a balloon and to watch it rise as his spirit had done. This journey of understanding death and remembering Jimmy's life resulted in Sam sharing her own creative and personal memories of her brother.

At the funeral Sam was able to share a symbols picture that she had made and whilst not verbal, through the voice of a supporting friend, she told the whole church of all that she had loved about her brother, that he was not coming back and that she remembered and loved him. As she finished pointing to the images she turned to his coffin and gently and lovingly waved farewell... This was Sam's way of expressing her sadness and love. In the months that followed, she was able to return to the picture and the places she had identified as his 'favourite'... there, in the reality of the situation she expressed the fact that she missed him and was able to be enfolded in her friend's and family's love as they supported each other in their grief.. it was a powerful and privileged experience.

Something that really struck me from Fr Hanvey's reflection for this year's Day for life was his comments that 'in moments of sorrow we are not alone; We are enfolded in the community of faith which carries us in this world and in the next.'

For a person with a disability this is not always so and they often face life being marginalised. The parish community is vital in the caring for a person who is dying or who has experienced loss. This is especially so for a person with a learning disability. As they prepare for or experience loss the parish should offer an alternative to that of the world, where they often experience loneliness and exclusion..... I would like to suggest that 'accompaniment' offers a welcome and loving alternative.

Having had to respond to pastoral needs over the past ten years, I have created a resource that *practically* sets out this journey of accompaniment. It encourages people with and without learning disabilities to remember, make sense of and celebrate their life; using pictures and meals together, symbols and house liturgies, those who are ill and those who are experiencing loss are invited to share time together and make a tangible book of memories, which will showing tokens of love to those who prepare to meet God or assist in the process of letting go of those who have gone before them.

An alternative way forward

Death is never easy to experience or understand. As a church we have the responsibility to share our life and our death with each other in celebration and thanksgiving for all that we have been called to be during our physical presence on this earth. Letting go of physical existence, through meaningful and creative accompaniment, can give us the opportunity to walk in Christ's footsteps as he accompanied and loved those who society excluded and marginalised.



If, as the people of God, we accept to give of our time and together to gently translate the human and Christian reality of Death we can experience a journey of mutual love and respect that can be treasured forever.

In Noelle Blackman's book on Loss and learning disability² a story was shared of a person with a LD who asked, *'Will anyone care when I die?'*

Friendship, company and using differentiated and carefully crafted resources, that build a tangible memory book, will mean that they person with a learning disability will not experience the isolation in death that they may have been forced to experience in Life. This communal journey of accompaniment will say 'yes we do care and 'In so many ways, hidden and seen, at the hour of your death, the Church is quietly and prayerfully present.

² Blackman Noëlle (2003) Loss and Learning Disability