

‘Supporting people with learning disabilities through a time of bereavement and loss’

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In this paper I hope to present a programme of bereavement aimed at supporting people with learning disabilities who have a loved one who is ill and approaching death. The programme aims to prepare the person with the disability spiritually, and practically, for the death of a loved one.

Death is a difficult concept for a person with a learning disability. It can sometimes seem that the person is not aware of what is happening and yet it is a grave mistake to think that this is so. Bereavement is a universal human experience; we will all experience bereavement at some time in our life. 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. This can at times manifest itself in challenging behaviour or total withdrawal from all that the person may have been involved in. When a loved one is ill and approaching death we often find comfort in communicating with others and sharing stories about the person who is ill or dead. For a person who has a learning disability, communication, cognitive abilities and emotional relationships with others can be difficult. Their ability to communicate their concerns and fears, therefore, can be impaired. Often the need to prepare for the loss of a loved one, by finding a method of expressing their feelings, is overlooked by those who care for them due to a desire to protect them from pain.

It is very important that the disabled person is not excluded either from the illness or death of a loved one. 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. Research has also shown that putting bereavement into a meaningful context helps people with a learning disability to cope.²

As an adviser within the Christian church, I have been privileged to have raised disability awareness and promoted the creation of a ‘culture of inclusion’ within the Christian Church of England and Wales. During this time many pastoral issues have arisen. I have noted that disabled people and their families often exist on the margins of the Church and that, when in need, there is very little support available for them as people which includes their spiritual and religious development. The need for the spiritual support of people with learning disabilities during the illness and death of a loved one is vital.

I have recently been engaged in providing support for a young person with a learning disability within a family who were approaching the death of an important member of the family unit, the mother. It seemed, as the mother

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

² Oswin 1991 in article : How far are people with learning disabilities involved in funeral rites : Dr Oyepeju and Sheila Hollins Department of Psychiatry of Disability : St George’s hospital Tooting.

was told of her terminal illness that she was not only facing her own mortality, but also the main fear that most parents of disabled people seem to voice within the lifetime of their child, ‘*What will happen to my child if I die?*’

Due to a lack of appropriate support in bereavement counselling for disabled people, I was privileged to be able to offer some support to the family by developing a ‘parish programme of bereavement’. I will not comment on the specific case of the family involved but present a general overview of the programme that I have created. It is important to highlight the fact that the following programme has been written from a purely Christian perspective as this is the faith community for whom I work. However, it can be adapted and differentiated to meet the theological, social and spiritual concepts of any specific denomination and indeed can be applied within a secular / community setting with careful replacement of scripture and parish activities. It is important that a person with a disability is able to share the suggested programme within the context of a family (be that within residential care or not) and the wider parish family (community based setting). The final outcome of the programme is the development of a scrap book which will provide the disabled person with a tangible object filled with memories, prayers and important moments that they have shared with the life journey of the person they love who is dying. Professor John Swinton in his research report ‘*Why are we here?*’ has suggested that ;

‘people with learning disabilities should be allowed to express, through words, music, pictures, drama, gestures and actions how important spirituality is and what it means for their lives (2002:12)’.

This programme, therefore, focuses on providing a space for the disabled person to consolidate the lived experience of loss and bereavement whilst identifying, expressing and recording their feelings. At the core of the programme ‘*Sharing my loved one with Jesus*’ lie three main objectives; 1) the opportunity to look over the events in a personal and differentiated manner, so that the disabled person can make sense of all that is happening within their life during a time of loss 2) the development of a specific role for the disabled person within illness, death, burial and loss of their loved one and 3) a heightened awareness of self worth and independence for the disabled person and the knowledge that it is necessary for them to express how they are feeling during difficult life experiences.

‘*Sharing my loved one with Jesus*’: A programme of bereavement within the setting of a family and a wider Christian parish community.

The programme relies upon two volunteers who agree to commit time to accompany the disabled person and develop a personal, supportive relationship with them and their family. The volunteers should encourage all members of the family to join in with activities. The programme is divided into 6 sections. Each session ends by sticking images, photographs in the memory book and consolidating with prayer. The volunteers are encouraged to create prayer space, suggest some prayer activity for the week based on the session’s theme so as to encourage personal reflection .

Session 1: I am (*name*) 'Jesus loves me'

This session reinforces the disabled person's sense of worth and purpose whilst building a relationship with volunteers. The idea is that they meet for refreshments. The disabled person is host. The emphasis of the session is to encourage the disabled person to understand that they have something important to do for the person who is dying and for Jesus. The session also aims to develop the spirituality of the person by celebrating who they are and their purpose in the world. The activities should develop their understanding that God calls people to help build his kingdom and that we do this through showing love and serving each other, we are all important. Volunteers should:

- Share the story of the calling of the twelve (MT4:18 -22) link with personal vocation and purpose
- focus on remembering their baptism and begin to develop a concept of there being a time for everything, that time turns and life has a beginning and an end.

Session 2 'My Family'

This session moves from a focus upon the personal worth of the disabled person to a celebration of their life within a family, especially with the person who is dying. The main purposes of the activities in this session are:

- Remembering good and difficult times in the family and remembering how the family overcame the pain of these events (finding a job, wondering about residential care, loss of pet etc.)
- Focus scripture story: The boy Jesus lost in the temple (LK 2:41-49), linking to Jesus and his family having difficult moments too.
- Seeking comfort and support. Like Jesus in the story we can turn to each other and God.
- The memory book could include pictures of family events, baptisms, holidays together past and recent memories.
- Always referring to the person who is dying, their importance and how God is close to us in good and bad times, when we are together and when we are apart (no mention at this point of the dying person departing).

Session 3 'My Church Family'

Links from session one and two: All people have a special place within the family of God. As individuals and as families we all have a place within a wider family, a place of belonging in which we all have a special role to play and the ability to serve/support God and each other. Volunteers are encouraged to:

- Arrange visits to the church, smell oils and get up close to altar, explore symbols that remind us that God is close. Explore what it means to belong to a church community, in church and at home.
- Organise a house Mass/liturgy/ worship with the disabled person, developing and applying their ideas. Consult with the person who is dying and priest/minister. Sensitivity is paramount. Develop the idea of sharing liturgy in church and at home.

- Visit respite centres as well as home; this creates a bridge between home, parish and residential care and helps the disabled person to feel they have not been sent away. They can also soothe any concerns about how their loved one is and reinforces the sense of belonging to wider family of church.

Session 4 'My loved one is not well'

As the illness of the loved one worsens, an important role for the parish community is the support of the volunteers as they grapple with the reality of supporting the person with the disability. The volunteers are encouraged to:

- Take photographs of the disabled person and their loved one together, of the bed in which the loved one is not well (consent of person must be obtained from initial meeting).
- Pray together more frequently and for a longer period (if desired). The focal point should have a picture of Mum as it is she we are praying for. Important never to pray for healing but for peace and closeness to and from God, Jesus.
- The disabled person is given a specific role: making tea, coffee etc for visitors, nurses and loved one. Encourage them to spend moments together thus providing memories and giving reassurance to both.

At this point the book should be filled with photos, images of their lives together. They should listen to poems and music together (i.e.: Psalm 23 The Lord is my shepherd)

Session 5 'My loved one is with Jesus'

Sensitivity and pace is very important as the disabled person faces the reality of death. The volunteers should:

- Judge when to share, pray together, visit, help in preparing something for funeral and encourage family to include disabled person in the planning and funeral arrangements.
- Enforce the memory of the loved one but be clear that she has died and will not be coming back.
- Continue to talk about being with Jesus in a special place. The disabled person has done a good job and has helped their loved one prepare to die, now it is Jesus' turn to look after them now.
- In the scrap book place pictures of the disabled person helping, of Jesus, and very importantly use a feelings sheet that is made of pictures of 'feelings'. In this way the disabled person can point to the picture and express pictorially the way they are feeling. This overcomes barriers of communication.

At this point the page in the scrap book might appear as below:

yesterday my mum died

I miss

Insert image of loved one

I am feeling sad

Jesus, please look after my mum

Session 6 'My Family'... remembering, looking ahead.

This is a time for reflection and remembering. The volunteers are encouraged to:

- Share scripture: The story of Pentecost (Acts: 2:1-11)
- Link personal experience to how the disciples felt without Jesus, but that their lives carried on without him and they were to do a special thing for Jesus. Their mission began.
- Help the disabled person choose a new ministry in the parish. The support of the parish is vital now and remembering happy moments with loved ones and within in the parish could help ease the sadness of loss.

This section of the book should be filled with images chosen by the disabled person, some from the past, the funeral, Jesus and a prayer from the parish community that shares their support and commitment to the whole family. Images of new ministry could be included so as to demonstrate looking forward. The time that is taken for this last section of the programme depends upon the volunteers and their judgement of the level of support that they feel the person needs. They must also help him/her understand that life is an ever turning series of events, that everything has a beginning and an end but that God is with us throughout our life journey. The book should, when completed, be kept in a special place and also be taken to respite. It is to be a tangible way of recording and remembering their own life journey and expressing feelings to all with whom the book is shared.

This programme was designed to be a prayerful and spiritual experience which would assist with the pain that is associated with death and loss. The scrap book aims to be a source of reflection for the disabled person. A faith community has a very limited voice within the social and emotional well-being of disabled people and yet, as a resource, it has great potential in supporting a person spiritually and practically during a time of bereavement.

In this family that I was working with, I feel the above programme could have been enhanced by the presence of a support team that included the family social worker, a member of the medical service and the educational psychologist who may have been supporting this family. The programme was created due to the absence of help for a family in need. On reflection, my questions are, 'how many more families have experienced the same difficulty?' and 'how many sad and bereft people with learning disabilities continue to wait for their dead loved one to return; bewildered at where they might be?'

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