Article by Jane Powell published in

Complicated Grieving and Bereavement - Understanding and treating people experiencing loss

Published in 2000, by Baywood Publishing Company. Inc, Amityville, New York. IBSN 3 0-89503-213-9(cloth)

CHAPTER 8

Grieving in the Context of a Community of Differently-Abled People: The Experience of L'Arche Daybreak*

Jane Powell

At the very beginning of this chapter, I want to take a risk and put forward the proposition that people with a developmental disability, far from experiencing complicated grief, may actually have much to teach the rest of us about grieving in a healthy way. There are, of course, exceptions. But the world of death and bereavement is a world of intuition, symbolism, and ritual, and people with disabilities tend to be much more in touch with these domains than some of the rest of us. I believe that it is precisely because of the lack of cognitive ability that people with developmental disabilities can live more spontaneously from their emotions and, because of this ability, can even give leadership in the work of grieving. But this can happen only if these people are actually enabled to know about terminal illness, to be close to their friends and family members as they approach death, and to participate in the normal expressions and rituals of grieving.

My own learning in this area has taken place in the context of the L'Arche Daybreak community~ intentional faith community where I have lived for many years. Daybreak is a member community of the International Federation of L ' Arche Communities, founded by Jean Vanier . In North America, L ' Arche communities are predominantly Christian, but other faiths are also welcomed. In L ' Arche, people with developmental disabilities share a life together with those who come to assist them. We live together in households, and while some members of the community have employment outside the community, others spend their days together in day and seniors' programs or working in the woodworking shop. Mutuality is a fundamental principle of community life in L'Arche. We believe that each person both gives to and receives from others in the course of our community life. All that I say in this chapter is based on the experience that "care-giving is not a one-way street," and on the assumption that caregivers have the courage, humility, and insight to receive from those whose care is entrusted to them at some more formal level. Particularly in this most universal realm of death and grief, barriers fall away and we become aware of our common humanity.

Our community of L'Arche Daybreak is rich in diversity of age, intellectual level, religious background, and means of communication. In recent years we have grieved the deaths of several community members, family members, and friends. Because many members of the community have an intellectual disability and some have multiple disabilities, we have needed to find ways to deal with death very concretely and creatively. We have seen the importance of involving each member of our community in the grieving process, whether labeled "disabled" or not. This concrete and shared involvement has greatly facilitated our walking through grief to acceptance and consolation. I share some of our experience here, believing that it can be generalized to other situations.

I will deal with the three stages in the grief process-anticipatory grief, intense grief, and bereavement-describing the steps we have found important to take before the death occurs, the actions we take at the time of death, and the ways in which we facilitate the grieving process after the loss. I give the greatest attention to the first stage because I believe that if it is lived with depth, the actual death and later bereavement is much more likely to be smooth. It will become clear that in each stage, while some steps may be particularly helpful for someone with an intellectual disability, many can be of value to the so-called "normal population" as well.

---

*This chapter has been developed from a practice report presented at the conference "Understanding and Treating Complicated Grief," hosted by the University of Western Ontario, London, Ontario, Canada, in May 1998.

WHAT CAN WE DO BEFORE A DEATH OCCURS?

Drawing from our experience at L' Arche Daybreak, I will suggest seven steps that can help the person with a disability prepare for the loss of a loved one. Everything I say here treats as fundamental that honesty will be the rule in communication about illness and impending death and all that ensues. We need to be committed to keeping members informed frankly and clearly of the progression of their own or someone else's illness. In the past, a somewhat patronizing attitude and perhaps fear of unexpected, possibly embarrassingly emotional responses, and also the mistaken assumption that people cannot understand, fed into a tendency to want to shelter people with disabilities from the truth about painful situations. It is now well known that such "sheltering" does much damage that is very difficult to undo later. What I am saying assumes also, of course, the exercise of sensitivity in communication, as would be the case in communicating with any other person about the illness and death of a loved one.

Create a Support Group

At Daybreak, most of the seniors with disabilities belong to the Seniors' Club, which meets Monday to Friday as a social club and peer support group and to engage in various recreational and social service activities. It is the peer support aspect of this group that has proved especially important at times of loss or anticipated loss. This is a group of people who are aging together. They have known one another for some years, and, with good facilitation by a small team who knows the seniors well, they are able to share their fears, sorrows, and frustrations. It is a group where the seniors can gently cope with the variety of losses that accompany aging, and where they can prepare for their own dying and the deaths of others. It is a place to be cared for emotionally and spiritually while becoming more fragile physically. And it is a place to give care to friends and to be respected as a wise elder .

Many in the group have lost parents, siblings, and friends; and with the aid of good facilitation have learned to support others in this situation. George knew that when his sister died too far away for him to attend the funeral, he had a safe group with which to share the story of their relationship and to help him to try to make sense of the loss.

He knew others in the group had been through similar experiences and that the moment had come for him to receive the type of support he had offered to them. When she died he brought a photo of his sister and some letters she had written to him, and the others listened sympathetically as he spoke about what she had meant to him and remembered some of the good times of their childhood. At the suggestion of one of the group, he decided to have a memorial prayer service for his sister. All his friends in the Seniors' Club and others who were close to him came to support him at the service.

This group of seniors is able to participate in rituals and to celebrate together. Milestone birthdays and their silver anniversaries of coming to Daybreak are big occasions. It is an environment in which care for others is fostered. When one of the regular recipients on their meals on wheels route died, they sought out the family and sent condolences. The seniors hope for and savor together the many little moments that keep their lives rich and meaningful. For instance, Peggy's being able to go to her family cottage one last time before it was sold, in spite of her increasing problems with mobility, was acknowledged for the significant event that it was in Peggy's life.

A death or approaching death of a significant friend or family member can bring the loss of other activities and contacts very important to an individual's well-being, quite apart from the actual loss of relationship with the loved one who has died. Such loss can be especially pronounced when the individual is already more dependent on these others for support than might be the case among ordinary members of society. And in the senior years this experience of loss and anticipation of further loss can continue to grow over a period of months or years.

One member of the Seniors' Club, Alfred, became depressed when the death of his mother led to his no longer being able to visit the family home for weekends. Over the ensuing years, as his father became less and less able, even visits at home for a meal became impossible. Gradually, Alfred's father began to lose both his hearing and his memory and Alfred's previously consoling phone calls to his father became a source of pain and disappointment. Meanwhile, Alfred himself, who formerly had traveled independently by public transit to visit his parents, became physically disabled and dependent on assistants who were willing to drive him to see his father. Alfred displayed understandable anger, impatience, and frustration during this time. The team in the Seniors' Club facilitated his expressing his feelings to the others and eliciting their understanding, sympathy, tolerance, and forgiveness.

His senior friends helped Alfred not to retreat into sad isolation but to share his sadness and loss with them. Finally, Alfred's father moved to a nursing home and the beloved family home was sold. Alfred continued to be able to visit his father with the aid of assistants, but the loss of the family home was so traumatic that for a time he became quite psychologically disoriented and spent some time in the hospital. Through all this, Alfred's friends in the Seniors' Club remained a constant, kind source of support. Some of the others were experiencing similar diminishment of contact with their families and similar losses of mobility, and as the others spoke about their frustrations, the mutuality of this experience seemed to help Alfred cope. Finally, when his father died, the others rallied around him in friendship and attended the funeral to show him their support. Over the ensuing months some of the seniors joined him when he visited his parents' grave and spent time drawing him out in conversation as he processed the loss and all that his parents had meant to him.

With her friends in the seniors' group, Peggy was able to speak clearly of her hesitations about moving to a new house and to think out loud about the features she would need to help her to maintain as much independence and privacy as possible in the new home. In turn, the group was able to encourage her to ask for what she needed. She can no longer manage stairs, but she wanted, for example, to be able to get to the basement to do her own laundry. After some discussion, she decided to ask that the new house have an elevator and this, in fact, proved possible.

With some team facilitation the group can speak together about Roy's heart being weak, and how this tires him and means he frequently needs to rest or have an easy afternoon clambering in and out of a vehicle, for instance. With this understanding, they are more able when necessary generously to let go of their own plans to accommodate Roy. And the other seniors can help each other understand why Roy is not always in the most cheerful of moods. The Seniors' Club is a place other than Roy's home where he knows he is loved and cared for.

Undertake Life Review and Life Story Work

Life review and the preparation of one's life story is becoming increasingly recognized as important to maintaining good mental health as one ages and as helpful in coming to terms with one's own mortality and preparing for death (Butler, 1963). Life review can be facilitated as people share about their lives and family histories with a close friend or counselor or in a small group with others whom they know and trust and where a safe atmosphere can be established.

The preparation of a life story book can be a therapeutic project during the time of anticipatory grief. It can also be a very good way for a terminally ill person to integrate his or her life experiences and the book itself can be a wonderful legacy for friends and relatives.l The therapeutic effect may actually be experienced both by the helper and by the one being helped, as together they examine the many ups and downs of the subject's life journey and the experiences that have shaped who the person has become. And the book itself can be a wonderful legacy for the deceased person to leave behind for family and friends.

Life story work may be particularly important for people who are devalued in our society (Porter, 1998). It provides an opportunity for them to realize how many lives they have touched and been touched by. People with developmental disabilities, of course, are not likely to be able to write down their own memories. An approach that has been used effectively in Daybreak is to assist individuals to write letters to friends and family asking them to send letters with special memories of the person, perhaps humorous little stories or anecdotes, and pictures. We ask that the letters try to highlight the gifts of the person. Tape recordings are also an option if letter writing is difficult. Most recipients are delighted to respond. Often the letters that are sent back to the Daybreak member tell the person of his or her importance in the lives of others. Hearing and discussing these often quite beautiful letters helps the individual to integrate their life history and to see the fruitfulness of their life in their relationships with drive in the country with no others. It is generally a very positive experience for people to work on their life story book with someone they trust. At Daybreak, these books are so sacred that some people have asked to have them blessed.

I The Hospice Foundation of America provides a Life Story kit with a video tape and fill-in-the-blank workbooks for the various stages of a pcrson's life. The Foundation's address is 777 - 17th Street, Suite 401, Miami Beach, FL 33139.

Find Ways for People with Disabilities to Help Their Dying Friend or Relative

When someone we are close to is living their last months, we can feel very helpless. This can be particularly true for people with disabilities, who may experience even greater powerlessness. They are often assumed to be less able to contribute in difficult situations and may in fact be unnecessarily sheltered or thoughtlessly shut out at such times. We have found that it is important to discover a way for people to be involved directly or indirectly in helping provide care for a dying person. When Helen developed Alzheimer's disease and was having difficulty going upstairs, Gord, a man with a disability who had shared Helen's home with her for a number of years, suggested that he trade rooms with her so that she could have a main-floor bedroom. This was a generous offer on Gord's part and, in fact, one that others in the house quickly saw would benefit Helen. The team in the house ensured that Gord was pointedly credited with making a very real contribution to improving Helen's situation. George, another house member, offered to sit in the living room with Helen on certain afternoons and call for assistance if Helen was about to wander out of the house.

When Adam was being cared for at home, John, a man with Downs Syndrome, was able to help. John was not working at the time and could actually travel to doctor's appointments with Adam and Ann, who was responsible for the home. John was able to lift Adam's wheelchair in and out of the car and to help transfer Adam. Ann speaks very clearly about the great practical and emotional support John gave to her and to Adam. Unfortunately, people with disabilities rarely experience being thanked and feeling deeply appreciated. Such opportunities to give and to be thanked for giving can be very healing when someone is grieving.

The Daybreak members with disabilities are often very generous and quite emotionally mature. The challenge for us is to be creative in involving them in safe ways that they can provide support. Then people can feel they have done what they are able and this can ease the grief when someone dies.

Help Those Who Will be Facing a Loss to Visit the Dl Person in Hospital

Both Helen and Maurice lived their last months on the chronic care floor of our local hospital, much diminished by Alzheimer's disease. We found it very important to convey to the nurses and other staff what we could about Helen's and Maurice's life before they became ill, so that the staff would have some sense of the richness of their lives and their delightful personalities. One way of doing this was to leave their photo albums and life story books by their bedside. Another was to use opportunities to chat with staff about our friendships with their patients when we visited. The Daybreak community set up a roster so as to have someone to give support at mealtimes, since they needed help eating.

Friends with disabilities could readily be included in these visits by planning that we visit in pairs. Gord, a fairly independent man who had lived with Helen, usually walked over to the hospital to help her with dinner on Saturdays. The seniors took responsibility for one lunch each week.

A journal was placed by Helen's bedside, with the request that visitors enter a note or draw a picture about their visit. Since eating was difficult for Helen, the note was to include information as to how she had eaten". This book provided a way for visitors to feel a little more connected with Helen's care and was also an additional, more personal and comprehensive means for us at Daybreak to monitor Helen's condition. The Daybreak nurse coordinated Helen's and Maurice's care with the doctors and hospital staff, who, we discovered, were glad to have our support with the patients. Our nurse also helped the rest of us in the community to understand Helen's and Maurice's medical condition and what we could expect would happen to them as the disease progressed.

Our nurse's involvement allowed others of us to be free to be present as friends and family rather than primarily as medical liaisons.

All of the Daybreak members with disabilities were encouraged and supported to visit Helen and Maurice if they wished. This meant that all were able to see their decline and when death came, it was with less of a shock. Some of those who visited do not have verbal skills. I believe they were able to grasp intuitively that Helen and Maurice were going to die because they saw them getting sicker, whereas they might not have grasped a merely verbal explanation.

Engage the Person with a Disability in Helping to Plan the Funeral

Early funeral planning, when death is not imminent, helps to ensure that the needs of all parties involved are met as well as possible.

Obviously, we include the person who is ill as much as is possible and to the degree they desire. We have found that people with disabilities who are aging or in failing health but mentally able, often want to express their preferences for their funeral and burial, when the subject is introduced gently and by a trusted person at an appropriate time. Some Daybreak members are very clear about their wishes-for example, that they be buried with their parents or in a particular cemetery , or that they be cremated. And they may even want to choose favorite hymns or the leader and readers for their funeral service.

Of course, pre-planning is not always possible. It is helpful to be prepared to include friends or family members with disabilities in arrangements even when such arrangements must be done quickly. When George died suddenly, his family were glad to have his house-mates involved in choosing the casket and contributing to the funeral as readers, ushers, and pall-bearers. This was possible because the family had already become acquainted with George's Daybreak friends and trust had been established.

The need to plan ahead is even greater if the dying person is of an unfamiliar culture or religion and customs and expectations might be very different. Alia, a woman with whom I lived for some time at Daybreak, is of the Moslem faith. In a way, because her needs are great, she is at the center of our community. Doubtless, when she dies everyone in Daybreak will miss her deeply and want to grieve her in some formal way. To prepare ourselves in the event of Alia's death, we asked to meet with her family. We wanted to be aware of and sensitive to their traditions regarding death, and we also wanted to plan ways in which we non-Muslims can join in grieving her. A plan that is acceptable to and t4at will be consoling for everyone emerged as Alia's family were able to share their wishes concerning Alia's care with us. A "living will" was signed and a copy placed in Alia's file. It is helpful that this discussion took place in a less stressful and emotional way than would have been the case if Alia's life had been in immediate danger. The discussions were precipitated by Alia's needing a feeding tube. Looking back we are grateful that we took the opportunity to have those discussions, as now we can approach the time of Alia's eventual death with clarity and peace of mind, having the assurance that we and her family have the same expectations. The need for this type of dialogue will only increase as our society becomes more diverse.

Encourage Conversation about the Deceased and about Feelings

We intentionally create opportunities to talk about the dying or deceased person. We have found that, particularly for people who have limited verbal skills, it is helpful to have a picture of the person who is ill in a prominent place in the home. We may sit in a circle and perhaps light a candle and pass the picture around, inviting each person to share a memory about the deceased as they hold the photo. The presence of a picture often seems to give people permission to talk. At other times we may notice someone pausing to look at a photo or other object associated with the deceased and take that as a cue to spend time with them. When Lloyd died, his favorite chair at the Seniors' Club looked dramatically empty. Then Francis, Lloyd's closest friend, decided to sit in it. This seemed very appropriate to the others and they affirmed that Francis should have Lloyd's chair and spoke to Francis about the importance of his friendship to Lloyd. This exchange allowed Francis to express his feelings a little more and seemed to be quite consoling for him.

Our experience at Daybreak is that people with disabilities are capable of anticipatory grief, but as caregivers we need to be in touch enough with our own feelings that we do not inhibit this opportunity for those whose grieving we should be facilitating. It is wise to assume that the friends of the dying or dead person understand what is happening, even if they do not seem to be expressing what we would consider to be associated feelings. People who are very limited are also often very sensitive to the feelings of those around them. If nothing else, they will be aware of the concern, anxiety, and tension of their caregivers. It is much easier if the truth of an approaching death is known by all. In the talking together or even in listening to others talk about the person who is dying, their friends may recognize the value of this person and also, perhaps, sense the sacredness of life in general and, by extension, of their own life.

Patrick had a very strong relationship with his mother and found it difficult to make decisions of which he thought she might disapprove. His mother was ailing and Patrick and those around him were concerned about his ability to cope when his mother died. Patrick chose to take part in a special grief-sharing group geared to his needs before his mother died.

At the time of his mother's death, Patrick experienced many different feelings but he had a sense that they were not totally abnormal. He was also aware that he needed extra support at this time and was able to seek that out. Our experience with Patrick taught us that someone with a disability such as Patrick's is able to process to some degree what will happen in the future and to develop strategies to use during the difficult period.

Help people to Say Good-by When Death is Imminent

It is important for caregivers to remember that, regardless of the type of service they are helping provide, the people with disabilities who are involved will usually have very long-term relationships with one another. This is true in both residential and work settings. We, as care providers, cannot overestimate the importance of people having a chance to say good-by to their friends when they are actually nearing the point of death.

This may mean working closely with people at the hospital or home where the dying person is being cared for .

Certainly, this farewell visit may be an emotional one, but I believe that it provides a healthy way to begin the more intense phase of grieving.

Our experience has been, as well, that even for the dying person there is a peacefulness that comes when loved ones come to say good-by. Again, clear communication is very important. Visitors should be prepared as to what to expect. They should know how the dying person will look and be helped to understand that he or she may not be able to respond to them.

Mention should be made beforehand of bandages, tubes, machines, or noises that may be alarming. Good preparation will help to make the situation less frightening and the person will be able to focus better on the actual visit. The visitor may choose to make a card to leave behind, or if the visit proves too much at the last minute, to substitute for his or her presence. Visitors can also be helped to thin}t ahead about what they would most like to say to their dying friend-perhaps, a simple sentence like "I love you" or "Thank you for being my friend." During the actual visit it may be important to help visitors make a connection with the dying person, perhaps by enabling them to stand close to the bed or to hold the person's hand. It may be necessary to work with hospital staff to get permission for people to visit. When Lloyd was dying, many family and friends were able to visit him because he was placed in a separate corner of the ICU. This opportunity to visit was especially important because Lloyd became critically ill quite suddenly and we were not prepared for him to die. Even though he was not able to respond at all, it helped all of us who were his close friends to at least see him, to lay gentle hands on him, and to say a prayer together.

WHAT MIGHT BE HELPFUL AT THE TIME OF DEATH?

Share the News Fully and Clearly

Again, as with anyone, it is very important to be honest and to use clear language in speaking about a death. Ideally, the language used is language with which people have become familiar over the duration of the illness. If a family member of a person with a disability dies and the person needs to be informed, it is best that this be done in private by someone who is a strong reference for the person. Meanwhile, it may be helpful to see that other people in the bereaved person's house are also informed, so that they can be sensitive and give support to their friend.

Some excellent illustrated materials are available for people who have difficulty grasping verbal information.2

When a member of Daybreak dies, we have discovered that the support of the community leaders (administrators) and the pastor is often helpful. As soon as possible after word of the death is received, these "outside" people visit the houses in which the deceased lived or was most connected. They are present to give security and reassurance and also practical support to both the assistants and the people with disabilities.

They can encourage the members of the household to ask questions and ensure that they grasp what has happened.

It is often important to share information about the death a number of times and in different ways, to ensure that each person has fully grasped what has happened. Supplying concrete details is more helpful than it is disturbing. People seem to need to know what happened at the actual time of death. Details such as who was there with the person and whether or not the person was in pain are important.

Sometimes, the fact that the information is given seems somehow more important than the details themselves. But generally, people will be less confused and afraid if they know where and when and under what circumstances the person died. It may be helpful to describe how the deceased person looked after he or she died. The bereaved friends will also want to know where their loved one's body is now and what to expect in the ensuing days.

Staff or friends who were very close to the deceased will need extra support. Often many phone calls must be made and practical arrangements undertaken. It may be comforting for those closest to be involved in these arrangements but not to have to make decisions alone. They will also be coping with their ordinary responsibilities and dealing with their own emotions.

Gather Together Soon After a Death

As soon as possible after we have received news of a community member's death, we gather in our chapel. It is important to be together, to hear once again what happened, to ask questions, and to express our feelings. If possible, someone who was with the deceased when they died speaks of what actually took place at the time of death. As we speak about the person, share our memories and perhaps various anecdotes, we may cry, laugh, pray, and feel angry or numb, but the experience of sharing together our sadness about our common loss is a great source of strength in the difficult days to come. I have noticed that people with disabilities are often quite uninhibited about expressing their emotions and in this way may help the rest of us. A gentle embrace can give much comfort. This time together gives all of us permission to grieve and alleviates some of the loneliness and fear that often accompanies the news of death.

Help Those Who are Grieving to be Involved in the Rituals

It is good to encourage people to participate as much as possible in the rituals that are customary at the time someone dies, but also to be very respectful of each person and where they are in the grieving process. We try to provide the necessary accompaniment and support for each one who is grieving so that each may participate as fully as possible. We especially need one another at this time. Linda, a young woman who has suffered many losses, can be quite emotional when someone has died. But her crying and wailing show me that it is all right to be vulnerable. We can cry together. There is a wonderful mutuality because neither of us have any control over the reality that someone we love has died.

At the visitation or wake we find it helpful to call those present to focus together for a time. We gather in a circle to listen to a comforting reading, perhaps to sing, to say a prayer, and allow those present to tell some stories about the deceased. People with disabilities can be helped to prepare, so that they can contribute. This may require asking someone who knows the history of the person's relationship with the deceased to help. At Daybreak, we tell stories about special times we spent with the deceased, about significant moments in the deceased person's life, about turning points in our relationship with the person, and about what we see as the fruitfulness of the person's life.

When it is a family member of a person with a disability who has died, we may need to encourage the family to allow the person to participate as much possible, supplying accompaniment so that he or she can attend the visitation time and the funeral. When Michael's brother, Adam, died, their parents thought, naturally enough, that going to Adam's burial might be too difficult for Michael. They were gently encouraged to allow Michael to join them and others at the graveside.

Once there, Michael seemed interested in the priest's sprinkler with which he planned to bless Adam and the casket immediately before the burial. Recognizing this, friends arranged that Michael be allowed to help sprinkle the casket with holy water during this final blessing. For Michael, this proved a wonderful opportunity to express a last gesture of love for his brother. It also helped Michael afterwards to be very clear about what had happened: Adam's body was in the ground; his spirit was with God.

When Henri, our pastor and a much-loved member of our community died, people working in the Daybreak woodworking shop helped build his coffin. Some also drew pictures which were then painted on the coffin lid.

At the wake, community members were invited to place a small token in the coffin with Henri. Some people contributed pictures or notes; others, a flower or something that symbolized their relationship with Henri. This was a chance to offer a final farewell gesture and to say thank you to Henri. Everyone who wanted was able to participate regardless of intellectual or physical abilities.

People who may never have been to a funeral home or a funeral should be helped to know what to expect. If the casket is closed, it may not be evident to the visitor that the body is in the casket. A photo of the deceased placed on top of the casket can be of help in grasping this reality.

If the casket will be open for the body to be viewed, the visitors should be told, so that they are less afraid. In either case, they should be helped to approach the casket and make some gesture-to touch it gently or say a prayer, perhaps. If possible, the funeral should be planned with a concern for both accessibility and participation of people with disabilities. At Henri's funeral, the Scripture reading was mimed while it was being read, for instance. Others participated in a reverent dance. And the eulogy was prefaced by one of Henri's close friends with a disability.

When possible, it is usually helpful for people with a disability to be able to go to the cemetery and see the interment. We have found it good to participate together in shoveling the earth down onto the coffin after it is lowered. This may be a painful experience but it gives a sense of completion and makes the reality quite clear . When going to the interment is not an option, we have developed a custom of filing past the casket for a final brief good-by just before the casket is taken out and the service ends. In Daybreak funerals, time is allowed for being sad and serious, but the emphasis is put on giving thanks and celebrating the goodness of the deceased person's life. Usually, there are moments both of laughter and of tears.

Be With One Another

Almost all people wish to have another person whom they trust simply be present with them at a time of intense grief. When Henri died suddenly of a heart attack it was difficult for all of us at Daybreak. He had helped many of us in the community when other members had died, so that we especially missed his comfort when he himself passed away. I had the privilege of sitting at his wake with Tracy, a woman who needs much support because she has profound cerebral palsy. We sat together in silence on some cushions on the floor near the coffin containing Henri's body, with Tracy leaning against me. We had no words to share that would comfort us because Tracy does not speak with words and because my words would not have made our grief any easier. But being there quietly with Tracy was very consoling for me. We needed to be together. It was one of those privileged moments when our common humanity is evident and differences fade away.

We should not assume that someone with a disability has feelings different from our own. People who have a significant loss will be grieving in their own way, even if they are not expressing their grief in identifiable behaviors. We are likely mistaken if we think they do not understand or do not care. The person's feelings need to be acknowledged and attended to for healing to take place. It can be important to ask ourselves who it is whom the person with a disability might be able to talk to at a time of loss.

It is good to remember also that a death, for any of us, may trigger memories of other significant losses. For instance, some people with disabilities have been rejected by their families and bereavement may reawaken these feelings of abandonment. Over time, I have noticed that people with disabilities are able to develop skills during a period of struggle or loss that they can then generalize to other experiences of grief.

Sitting quietly with a friend over a cup of tea, or with a lit candle, can lead to the gentle sharing of tears. One person I know used relaxation techniques which he had learned for stressful times at work, to help him deal with grief. Others have asked for some warm milk or herbal tea to help with sleep. These are only a few examples of the types of self-care that all of us, disabled or not, can practice when we are coping with intense grief and, perhaps, feel we have little control over a situation.

HOW CAN WE SUPPORT ONE ANOTHER AFTER SOMEONE HAS DIED?

Visit the Grave and Celebrate Anniversaries

Helping the bereaved person to visit the grave of a loved one periodically can help bring solace and aid in the journey through grief. It is usually helpful for the individual to bring along something to leave at the grave, even if just a single flower or, in the Jewish tradition, a pebble to place on the headstone. We find this is a good time to invite the grieving person to share a few memories of the deceased and perhaps to hold hands and say a prayer together. Expect that some tears may be shed and welcome these.

The seniors at Daybreak have a custom of visiting the graves of friends around the time of the anniversary of the person's death. On some occasions they have invited siblings of the deceased to meet them at the cemetery and have followed the visit to the grave with a lunch or tea outing to renew contact with the family members who have come. This gives opportunity to reminisce further and gives the comforting experience of being together with others who knew and loved the deceased friend. When they visit Lloyd's grave, the seniors invariably recall that Lloyd loved Holsteins, and they recount some of the teasing that they engaged in with Lloyd about his preference for these over Jersey cows.

Usually, his sisters will then share about their family life on a Holstein farm before Lloyd moved to Daybreak. Before long, various members of the group have fondly mentioned several favorite stories of Lloyd and the whole experience becomes one of treasuring Lloyd's memory in a way that allows the gift of his life to continue to unfold for each person. I believe this experience also may give the seniors some reassurance that they will be remembered after they die.

The members of the house where Adam had lived decided to mark the first anniversary of Adam's death with a memorial mass and dinner to which they invited Adam's family and a few of his closest friends. The setting was beautiful, with flowers and pictures of Adam arranged around the coffee table altar . It was also a moment for those present to realize they had gotten through the year even though it had been difficult, and to give thanks for Adam's life and all he had meant to them. Adam's parents were grateful to see how much Adam continues to be loved by those with whom he had lived.

Give Permission to Grieve

We have found it helpful to continue displaying pictures and mementoes of the deceased person and to continue telling stories about them for weeks or months after the person has passed away. These items make it clear that those who are bereaved are not expected just to forget about the one who has died and that it is alright to grieve. After some time it may finally feel right to put some of these away and to choose one special photo to display. We find this decision is best made by the members of the household together. A discussion can follow as to how to dispose of the items that will no longer be displayed and perhaps a small ritual created for this changeover, but it is wise not to put a timetable on grieving. People will each grieve in their own way and in their own time. Sometimes the behavior of someone with a disability may change and caregivers may see this as a behavior management issue or merely as attention-seeking. It is important to recognize that the problem behavior may in fact be a way that the person is trying to express grief. We may not be able to see an obvious connection between the behavior and the loss, and the person him or herself may be unable to name this connection, but kindness and patience and the professional help of a grief counselor may be the answer at such times. It may be that unresolved griefs from long ago have been awakened by the more recent loss.

I assist with bathing and personal care for some of the Daybreak members who have profound disabilities. I have discovered that it is important to pay special attention to the body of a person who is grieving.

The tension in the person's body may be expressing what they are unable to express in words. People may need to get extra rest and greater care at anniversaries of the death of loved ones. During these difficult periods, often lasting for a few weeks in the vicinity of the anniversary , individuals may be more vulnerable to illness and less resilient. Alia, in my home, expressed what she experienced partly through her appetite or lack of appetite. For a number of years after her mother's death one January and Alia's subsequent placement in an institution, she ate very poorly during the month of January. People can continue to feel the sad effects of losses at anniversary times for the rest of their lives. Probably few of us realize how much the pain we have lived is written in our body. Again, it is important to recognize that individuals may be grieving even if the manifestations of grief are not obvious or typical.

Grief may be especially present at holiday times, when we may expect the opposite. It can help to acknowledge the absence of the people who have died. When Ann said to the others in her house, "It's hard this first Christmas without Adam," everyone seemed to relax a little. They felt they had permission to be sad and the opportunity to express what they may have been feeling. As well, some people recognized that they were no longer feeling quite as sad as they had at Thanksgiving or some of the earlier holidays in the year and this was reassuring. For me, today, nearly three years later, Michael's periodic reminders, "I miss my brother, Adam . . . he is right here in my heart," help me to not forget Adam and to keep him alive in my heart as well.

Name the Gifts and Also the Difficult Realities of the Person Who has Died

When someone has died it is important to ponder the value and meaning of their life, but it is also important to be honest and not to gloss over the pain that may have existed in the relationship. The time spent telling stories is significant in that it helps us to name more clearly the gifts of the deceased person, and also to put in perspective the difficult times. After Maurice died we spoke of his life as being epitomized in his frequently asking friends to "have a cuppa tea," enunciated only as Maurice could enunciate it. Maurice's invitation to a cup of tea very clearly said, "I like you and want to spend some time with you." His invitation was a way of helping the rest of us to slow down, and we loved him for it. But that is not to say that we were not frustrated at times with his attraction to cups of tea and his slowness in partaking of them, especially if it happened to be an occasion when one of us was trying to get Maurice settled for the night. Recognizing this mixture of feelings we sometimes had about Maurice's gifts and his slowness helped us to laugh at ourselves and the situations we recalled and to move realistically toward gratitude.

It is a natural human desire to want to keep the essence of a deceased person's spirit alive. Obviously, naming the gifts of the person helps us to do so. While some of us may think in more general and abstract terms, people with disabilities are likely to recall very concrete moments with the deceased: He liked apple pie. She took me to the exhibition. We remember special qualities of each one who has passed on. As Helen's friends, we want to keep alive Helen's wonderful authenticity and lively energy. We remember Lloyd's gentleness, and Adam's silent gaze that called people together around him. Each of these qualities is tied for us to concrete little stories that we can all share together. This process of sorting out and talking about our special memories of the deceased can also help us to become more conscious of our own gifts and the gifts of those around us, and perhaps to think about the legacy we are leaving.

A memorial book at Daybreak provides a place for community members to memorialize family or friends who have been close to them.

Individuals are assisted to prepare a page about their loved one. This activity can allow the grieving person to step back and extract from their many memories the qualities they most want to remember about the one who has died. It can be a wonderful way to move a little further through the grieving process, and it may provide an opportunity gently to hold at a little distance some of the more painful memories concerning the person.

CONCLUSION

I hope that it has become evident that people with development disabilities, given the opportunity and support, can grieve in a healthy and transformative manner. Indeed, because they are often much more in touch with their hearts and sometimes are less inhibited than many so-called normal people, they can call the rest of us to take the time we need to grieve, and to express our feelings in ways that can bring healing.

When I give time to someone with a disability to grieve I am more able also to give myself permission to take time. The needs and gifts of people with disabilities in the area of grief and bereavement challenge the attitude of many in society that three days' compassionate leave should be enough and then one should get on with one's life as though nothing has happened.

In some ways, people with disabilities are better prepared to cope with death than are the rest of us. Often they have spent much of their life "being" rather than "doing." When someone is dying, there is usually not much that caregivers can do except to be with the person. People with disabilities may be more at ease in this situation than others. Of course, the dying person does need good care, but mostly he or she may need others to be there and present. The gift of people with a developmental disability often, both explicitly and by their own need for accompaniment, is to call others into relationship around the person who is ill or who has died.

Hospital staff and funeral directors have remarked on the quality of presence Daybreak people bring to the person who is dying and to the visitation and funeral. They have commented that they have never seen the dying person so well "sent off," nor have they seen people, especially people with disabilities, so involved in the rituals and so able both to weep and to talk about the life of their loved one. I believe this is possible because we have touched deeply into one another's common humanity at these times of loss, and from there has grown our sense of mutuality and of honoring the experience of each person.

Wendy, an Anglican priest at Daybreak, tells of being amazed when she arrived in the community at how freely people were able to talk about death and specifically at that time, about the fact that our friend Maurice was not going to get better. This was three weeks before his death. During her time in parish ministry she had found most people less willing to face the reality of a loved one's approaching death. The way that we are able to look at the person's whole life including their suffering and name their gifts while not idealizing the person after their death, seems very healthy to her. The gatherings after a death are times of mourning but also of true, hope-filled celebration. Wendy feels also the "hands on" elements in our celebrations are especially helpful.

It is the people with disabilities who have led us in the community to find ways to be concrete and to use simple rituals. Above all, they point to the centrality of relationship while providing care for someone who is dying or grieving and what we have discovered as a community is our great commonality in the grief process and that the gestures that are very important for a person with a disability in the grieving process are also very helpful for the rest of us. It is a great privilege to walk this journey with people who are differently abled and to experience together the gradual transformation of grief into gratitude and joy and new life.

Acknowledgments

I thank the members of the L'Arche Daybreak community who allowed me to share their stories. In the original presentation of this material, Ann Pavilonis contributed reflections on Adam and her house. I am grateful to Wendy Lywood, Ann Pavilonis, and Joe Vorstermans for helpful preliminary discussions on this topic. And I thank Beth Porter for her encouragement and editorial assistance.

REFERENCES

Butler, R. N. (1963). The life review: An interpretation of reminiscence in the aged.

Psychiatry, 26, 65-76.

Porter, E. (1998). Gathering our stories; Claiming our lives: Seniors' life story books facilitate life review, integration, celebration. Journal on Developmental Disabilities, 6(1), 44-59.