



# Dealing with Death

In the past, people with Down syndrome were denied the right to grieve because others mistakenly assumed that they had no capacity to do so. It was thought that people with Down syndrome did not experience grief, or recognise or comprehend loss.

The following three real-life stories clearly show grief felt by children with DS and this adaptation of an article from the DSA of the UK (Stuart Mills, April 2002) gives more information.

## Bereavement

- Bereavement literally means to be deprived by death. When experienced after the death of someone loved, bereavement is perhaps one of life's most stressful events.
- In the past people with Down syndrome would often die before their parents. Life expectancy for people with Down syndrome has increased dramatically, so now many adults with Down syndrome experience the death of their parents, who in many cases have been their main carers.
- When people with learning difficulties are bereaved, their reactions to the loss are frequently misunderstood.
- Grieving is a highly individual process and people respond to bereavement and express their grief in different ways.
- The person with learning disabilities experiences the same processes as the rest of the population.
- The grieving process for those with learning disabilities may however take longer.
- Grief may manifest itself in ways that are not instantly recognisable.
- Usually people with Down syndrome can work through their feelings about an unhappy event and come to terms with it, but will probably need help to do this.
- Bereaved people with learning disabilities may find that other people make decisions that affect their lives without any warning, or any element of personal choice or of control.

## Common responses

- Whether or not they have learning disabilities, people react individually to grief.
- Most people experience at least some of the common responses to bereavement. These are summarised below:
- An initial sense of shock, numbness, disbelief and denial accompanied by one or more physical symptoms such as lack of energy, trouble in concentrating, remembering, making decisions, hyperactivity, thinking about wanting to die and a sense of unreality.
- As the early shock wears off and the impact of the reality of the death is felt, people may experience the following reactions:
- **Emotional:** Anger with the deceased or with those who it is believed could have prevented the loss. Guilt, anxiety, fear, panic, depression, despair, mood swings, irritability, crying, sadness, yearning and pining, sense of being abandoned.
- **Physical:** Symptoms such as pain, appetite disturbance, breathlessness and illness. People with learning disabilities, who are less able to express themselves verbally, may experience and exhibit increased physical symptoms of grief.
- **Behavioural:** Low vitality, need for more sleep, sleeplessness, hyperactivity, withdrawal and a lack of interest in normal activities.
- **Mental:** Confusion, hallucinations, nightmares, insecurity, searching for the deceased, poor concentration, regression and loss of skills.

## Resolution

- Resolution occurs when the bereaved is able to think of the deceased without pain or anger and can recall the times they had together in a positive way.
- The journey towards resolution is not always a continuous or direct one. It may take a considerable time.
- Not everyone will experience all of the symptoms detailed above.

## Depression

Sometimes grief can continue into depression and this may well show itself, in someone with a learning disability, in unexpected forms.

However, not everyone will get depressed.

Sometimes one loss can then lead on to other major changes that may result in depression.

For example, after parents have died, people with a learning disability are often moved to emergency residential care. This means that they lose their home, their familiar possessions and routines, as well as their parent and carer.

Sometimes a more serious and persistent depression develops.

This is a particular risk for people with learning disability because carers often miss the early signs of depression.

The time to get help is when any changes in behaviour or mental state persist for a lengthy period of time.

You should then seek professional help for further information.

pain, appetite disturbance, breathlessness and illness may occur

## How to help

- Always give the news of a death with honesty and at a pace suited to the individual. The news of a death should not be kept from an individual in an attempt to protect him or her.
- Always use straightforward language in order to avoid misinterpretation by the person with learning disabilities. The use of terms such as 'death' and 'died' are preferable to terms such as 'passed on' or 'gone to sleep'.
- The person with learning disabilities should be given the choice as to whether or not they wish to take part in the rituals associated with death.
- If the person is unable to choose directly, it is advisable to involve the person as fully as possible.
- Non-verbal rituals may be particularly helpful to people with learning disabilities.
- It is important to allow the bereaved person to have the opportunity to choose a memento by which to remember the deceased person and to act as a focus for their feelings.
- Avoid major change at this confusing and distressing time. Many people with learning disabilities find change of any kind difficult to cope with.
- Routine can be particularly important, providing an important sense of order and structure. The person with learning disabilities may find it comforting to take refuge in their daily routines and familiar surroundings.
- Helping the bereaved person to maintain some continuity and connection with life before the bereavement is essential to recovery.
- Always give the individual with learning disabilities space and time in which to express their feelings.
- If the deceased is a family member, it may be helpful to create opportunities for the person with learning difficulties to communicate his or her feelings to someone outside of the family.
- You may wish to consider specialist bereavement counselling for the person with learning disabilities.

# “Dad’s Got Gone”

*“At a time of loss and grief and sorrow, there is no one way. There is no right way and no wrong way. This is part of our journey. It is not a work of research, rather some words from the heart and born of great love.”*

***Written in memory of a very special father, husband, friend and mentor, Brian Shaw***

*A large part of parenting involves preparing our children for important life experiences. Preparing them for the first day at kindergarten, the first day at school, the first day at college, and ultimately, helping prepare them for living as well-adjusted adults in society - and the myriad of smaller events inbetween.*

*Along the way, as part of family living, we also model behaviours, reactions and interactions according to our personalities, family structure, faith, culture, past experiences and personal creeds.*

*However, when the sudden, the tragic and the totally unexpected happens, disrupting the rhythm of everyday life, you can find yourself fighting a desperate rear guard action of trying to support those you love during a time of shock and bereavement, with little or no preparation.*

*I would like to share with you, my family’s story and, in particular, how we helped and supported Kendall during a time of great sadness and confusion in her life.*

*At a time of loss and grief and sorrow, there is no one way. There is no right way and no wrong way. This is part of our journey. It is not a work of research, rather some words from the heart and born of great love.*

*They are written in memory of a very special father, husband, friend and mentor, Brian Shaw*

For the funeral, Kendall wrote a special ‘story’ for Dad and read it out. It was rather short “I love you Dad. Goodbye”

It seems these days everybody knows about Nelson. Two years ago, when we decided Auckland was no longer where we wanted to live, Nelson was still relatively ‘undiscovered’. After a long successful banking career my husband chose early retirement, and we decided to return to his hometown of Nelson. We found our dream home, complete with its own small olive grove, in the foothills of Ruby Bay. This was to be our little piece of paradise. However much it was a diamond in the rough, we saw the potential and planned, plotted, dreamed and schemed of how to make our dream a reality.

Realistically, we were fully aware relocating our family was going to involve sacrifices. We were all leaving behind close friends, and living at Ruby Bay meant adapting to a completely different life style. We discussed this as a family and included the children in our planning. Kendall was going to get a flying fox and a swing - two of her passions - and a puppy. Kendall and her Dad had even drawn up a shortlist of names for their ‘brown dog’. We were all excited and looking forward to a new stage in our lives. The only challenge we faced in the immediate future was farewelling Chris who was leaving home to commence tertiary studies - and the multi-syllabic word ‘university’ entered Kendall’s vocab.

Tragically, it was only one month after our arrival in Nelson, and just four days after Chris’s departure, that our lives took a sudden, tragic and totally unexpected turn. From Kendall’s perspective she went to bed one night and her life was everything it had ever been; she woke up to an entirely different world, a world that no longer held her father. He had died suddenly during the night. Surprisingly, Kendall, a normally light sleeper, had slept through the noisy arrival of ambulance officers, police, doctors, neighbours and family

members. In those first hours one of my foremost concerns was, how do I tell Kendall? How do I put the unspeakable into words? I can’t now recall the exact words I used when she woke, and I don’t think Kendall could fully grasp the meaning of my message anyhow, but she did understand something of our grief and our tears and she did realise her Dad was not to be found.

Later that morning the funeral director returned to our home. I asked him for help and his words and guidance formed the cornerstone for what was to follow. I will always be grateful to Stephen Day for the compassion he displayed, the wisdom he shared and the care and respect he showed my family.

He suggested that I break everything down into very simple steps and explain in words that Kendall would understand exactly what we were doing and why. In retrospect it sounds so sensible but at the time shock seemed to rid me of coherent thought. All I could think was that the old euphemism “Daddy’s gone to sleep” was not at all appropriate and was simply an evasion of the painful truth.

So, we told Kendall that the part of Dad that walked and talked and played games and gave Kendall prickly kisses and hugs and laughed and sang and read stories, that part had gone to heaven. We then went on to tell her that when people go to heaven we don’t get to see them any more, they can’t come home on holiday and they can’t phone home, but we still love them and they know we still love them. And they still love us just as much as ever. We told her that heaven was a good place to be.

We were careful to differentiate between Chris leaving home and going to university and her father dying. Both events, superficially at least, had a similar impact on Kendall’s daily life in that neither lived at home any more.

Kendall's carer family, the Giddeys from Auckland, with whom we share a very special, very close relationship, flew down to be with us and we discussed what we were telling Kendall so she was getting the same, consistent message from those close to her. This proved to be of immense value to Chris and Jenah (Kendall's siblings) and Steven and Laura (Giddey), none of whom had prior experience of funerals. Explaining the service in uncomplicated terms made it easier for them to prepare, in part, for the funeral service.

At this time the thought occurred to me that we have no control over some things that happen to us in this life but we do have control over our reactions and responses. It followed therefore and was important to me that we honour Brian in a personal and positive manner, worthy of such a kind and gentle man, and in a way that celebrated his life and his many fine attributes.

We all made contributions to the funeral service. Kendall for some time had had a piece of what we called her 'comfort' music - 'Hallelujah' by Rufus Wainwright. Whenever she got angry, was told off or scolded, off she would storm to her bedroom, on would go Rufus, way too loud, and she would emerge a little later, calmer and comforted. So it seemed appropriate that 'Hallelujah' was her contribution.

I decided to speak at the service and as a mark of solidarity, which I greatly admired and appreciated, Chris and Jenah also decided to pay tribute to their father. I asked Kendall if she would like to write a special 'story' for Dad and read it out. She did. It was rather short "I love you Dad. Goodbye" but she did it.

About the same time she drew a picture of her father with some balloons sailing overhead so we incorporated that theme into the service and we each released a helium balloon at the conclusion of his burial, symbolically sending our love heavenwards.

Kendall was remarkable during the church service and again at the burial. She wanted to stay by the grave for sometime after the burial and so she and I sat close together, hugging, until she was ready to leave. Not perhaps the most orthodox behaviour but her needs at that stage were more important.

Sadly, several weeks later Kendall's Nan,

my husband's mother, died. She had become very ill and frail and her passing was not altogether unexpected, so I had been able to prepare the children for the possibility of this sad event occurring. Nan's funeral service was held at the same church and conducted by one of the priests who had led Brian's service. Kendall knew what to expect, she sang with gusto (without knowing the words of the hymn), screwed up her eyes very conscientiously in prayer at the appropriate times and I later came across her telling the priest that, "Dad and Nan were in heaven together eating sausages". Our message about heaven being such a good place had obviously made its mark!

The period following two such close bereavements was, naturally, very difficult for us all. Kendall found it extremely difficult separating from me and became very insecure about leaving home. There was an unfortunate incident at school in the first week of term so I removed her for two weeks, reason for considerable concern at the time, but in hindsight, a wise thing to do.

I was worried about Kendall's insecurity and separation anxiety and sought help through the paediatrician at the local hospital. Being in new territory I was totally without a support network and hadn't had the opportunity to meet the health care personnel who would supervise Kendall's ongoing medical care. I was referred at that time to Christine O'Neil of Tautoko (a community based organisation which assists people with intellectual disabilities) who has been of immense practical support to Kendall throughout this year and who has liaised with both school and home.

Early on, I put together a book entitled "Kendall's Dad" and for a time, Kendall read this again and again. For Kendall, understanding comes through repetition. The message of the book reinforced what we had been telling her. It talks about sad things happening, how people react, how we can remember happy times and how it's okay to feel sad and to cry. I described the funeral service and the burial and explained words like coffin, burial and cemetery. Kendall also unearthed an old 'You and Me' videotape where Suzie's gold fish dies and gets a dignified burial in the garden and for a while that was played and replayed.

Sadly, I realised our beautiful lifestyle

section was much too large for one person to maintain so I decided to sell and move into Richmond. This decision was not made without a great deal of consideration and soul-searching as I was very aware I was disrupting our lives at a time when we were all still so very vulnerable. One night, shortly before we left Ruby Bay, Kendall collapsed emotionally. All she would say is "Dad's got gone. Dad's got gone". It was as if the ghastly realisation of her father's death had finally touched her soul. It was heart wrenching holding her little body as great sobs wracked her. She was inconsolable.

During the first two terms Kendall literally fell apart, school became a nightmare and I watched helplessly as the daughter I loved receded behind some truly horrendous behaviours. Lacking the skills to verbalise her feelings and emotions, Kendall's grief and sorrow found outlet in extreme behaviours. Realising this was beyond what I could cope with, I again called in Christine O'Neil who set in place a behaviour plan. Term three saw a marked improvement and term four has seen Kendall emerge the calm, happy, contributing, amusing, sometimes obstinate student she always was. At the same time, she is different. The sad events of this year have left a mark; she appears sadder and quieter at times but she had also developed a new maturity.

I wish I could end this with a happy ever after paragraph but we have some way to go before any happy ever afters. Our journey through grief is not yet over. My two girls and I are trying our best to adjust to a very different life. It isn't easy. We have had all those 'first' birthdays without Dad and, at the time of writing, we face our next big 'first' - Christmas.

I choose to focus on the positive and remember what we had and the love we all shared rather than focus solely on our loss. I believe by showing my children how to do this, together we can look towards a new tomorrow albeit a very different tomorrow from what we had ever hoped for. We can learn to accept what life gives and what life takes away and value each day and each person we meet along the way. Together, we have discovered the power of love and how it is all that really matters when life is indeed, harder.

*Diane Shaw,  
mother of Chris, Jenah and Kendall  
Nelson*



# “Grandma’s not *really* dead?”

I’ve written about our experiences helping our daughter Biddy to understand death, and process and cope with the loss of a Grandma. My partner Paul and I have two children: Biddy aged 11 who has Down syndrome, and Laura aged 8.

My mother died in May 2003, and for the final five months of her life needed someone with her all the time. I am the youngest of eight children and we all felt strongly that we wanted to keep Mum at home. At the end of January we employed a carer to look after Mum from 8am – 5.30pm Monday to Friday, and the family covered the rest of the time.

The girls had visited Grandma lots when she was more able, when she would whip up a batch of scones or pikelets if she knew you were visiting. There was always a warm quiche if we visited near lunchtime. From when Mum began deteriorating we visited two or three times weekly. This enabled the girls to slowly adjust to the changes in her health. I was often staying the night and occasionally the girls would stay on a weekend or holidays. I spent quite a lot of time away from home during this period. I was still working as an independent midwife, helping to care for Mum and trying to keep things going at home.

Life was quite disrupted at this time for Biddy and Laura, but my partner Paul was

fantastic and coped with home life when I was working or at Mum’s.

From when Grandma began to ‘slow down’ and need assistance, we began to discuss that Grandma was getting old and unwell, and that she may die soon. Each time we went to Grandma’s we would talk about her in the car on the way home. I would point out the changes and encourage the girls to ask questions. I would explain each time that life wasn’t much fun for Grandma, that she couldn’t eat much, that she couldn’t see her garden so well [she had cataracts] and that movement was painful.

Biddy loved helping. She used to jump on Grandma’s bed and talk to her. It was difficult to explain that she needed to be careful, as Grandma was very thin and quite sensitive to movement and touch. [She had lost about 15 kg over 5 months.]. Grandma had a soft spot for Biddy. Some days Biddy would be the only one to get a smile from her.

In addition to frequent visits to Grandma, we would talk about age and dying. We talked about our cat that had died a couple of years previously, ‘Winnie One Eye’ as the girls fondly knew him. He was old and developed a large tumour and died at the vets. We brought him home and the girls decorated the box and wrote a message for Winnie on it, then we buried him in the garden. We had said at that time that Winnie was old and it was OK for him to die.

In early March we had some devastating news. My twenty-two year old nephew John had been killed in a climbing accident on Mt. Rolleston.

This presented another challenge. We had been preparing the girls for Grandma’s death and now trying to get Biddy to understand that John had fallen on the mountain and died, was difficult. I found I had to repeat the same thing in different ways to get Biddy to understand.

John was at his home for a few days before the funeral. Biddy saw John and touched his hand. She told everyone in the room that “John’s died. He fell down a mountain and hurt his head. He’s got a sore head.” I think she wanted to get reassurance that she understood things correctly. I used these times to explain in more detail.

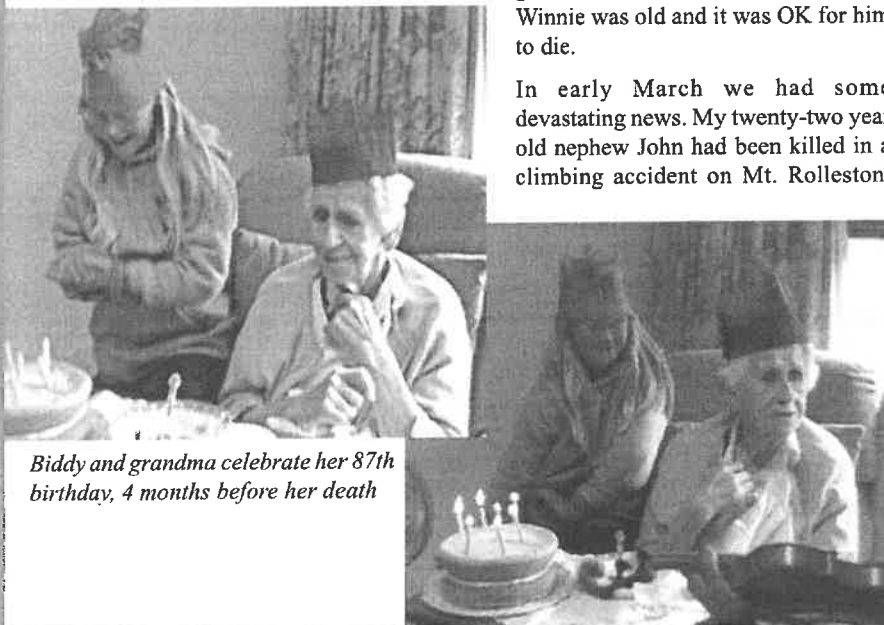
I’m aware that some people can’t cope with seeing dead people themselves, but it certainly helped Biddy to understand death. All my family talked to Biddy over this time and helped her to understand.

Laura (Biddy’s eight year old sister) responded quite differently to Biddy. She didn’t share her feelings at all. She also chose not to see John.

The girls went to the funeral and burial. Family and friends filled in the grave and I thought Biddy was going to fall in at one stage. All the children seemed to find helping quite therapeutic and fun. Children certainly provided some distraction and humour at this sad time [especially Biddy]. After the funeral we went back to my sister’s house and the children had lots of fun with their cousins, and it extended to a barbeque and late night.

Laura and Biddy found that week very difficult and it made me realise that death is a very difficult concept for ALL children to cope with. They are trying to understand what has happened, while coping with their routine being shattered and us being upset.

Mum died on May 4<sup>th</sup>, 8 weeks after John’s death. I had been away for the weekend and went straight to Mum’s house. Paul hadn’t said anything to the girls so we told them together the next morning.



*Biddy and grandma celebrate her 87th birthday, 4 months before her death*

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I told them that we had some sad news for them. That Grandma had died yesterday and that it's really sad for us because we are going to miss Grandma lots. I also said that life was no fun for her anymore, and it's OK for people to die when they get old.

I then told them that we would go and see Grandma that morning.

The girls reacted quite differently. Biddy asked lots of questions and made lots of statements. She repeated what I told her. It was like she wanted me to say it wasn't really happening. Laura was very quiet and I had to keep asking if she was all right and did she understand what was going to happen.

We are lucky in that my brother in law is an undertaker and I asked that Mum be left at home on her bed until the girls had seen her. We spent some time alone as a family with Grandma. The girls then played around and came in and out as family visited. Biddy insisted on helping when Grandma was taken to the car to go to the undertaker's.

Also I thought it would be helpful for the girls to be there when Mum was brought home again, and requested that Mum go back onto her bed, as I felt the girls would find that better. [My thirty year old niece commented that she found it much nicer also.]

There were some hilarious moments when Biddy would copy people's behaviour. We were sitting in Mum's room, talking about when we were children. There was lots of talking, laughing and crying. I looked over

Biddy would often say, "Let's go and see Grandma". I would have to remind her that Grandma was dead. She would then suggest we could take some flowers to her grave.

and saw Biddy dropping her glasses and dabbing her eyes. Initially I thought she was sad, but I soon realised as I watched her, she was copying everyone's behaviour and emotions – it certainly lightened the moment!

She seemed to sense when we needed to laugh.

Biddy didn't understand totally. On one stressful trip home from Mum's Biddy commented "Isn't it sad Grandma died". "Yes Biddy. It is sad, but Grandma wasn't well and she needed to die". Silence for a few minutes and then "Grandma's not dead". "Yes Biddy Grandmas dead." A few repetitions later, she finally said, very distressed "Grandma's not really dead?" I needed a stiff gin by the time I got home!

I found it very draining having to repeat everything. It wasn't easy trying to cope with my emotions and remain patient with Biddy. Laura was really helpful with reinforcing the message, but at 8, was struggling to understand it all herself.

The girls both saw Grandma go into the coffin and put in a special flower for her.

The funeral had lots of family involvement. My brother is a priest and conducted the service. He talked about Mum and Grandma, which made it more relevant for the girls.

At the cemetery Biddy was standing near the hearse "keeping an eye on Grandma"[her words]. She heard my brother in law say we should start soon. Biddy hopped up and in a very loud voice said "Let's get this show on the road". As we carried the coffin over she called out to everyone "make way for Grandma". This certainly lightened the moment and caused everyone to laugh. As soon as the burial was over Biddy said, "Right - now we can have a barbeque." She had remembered what had happened after my nephew's funeral.

I have tried to decide what helped Biddy most. I think the repetition, and explaining in different ways to try and ensure more understanding. Biddy would often say, "Let's go and see Grandma". I would have to remind her that Grandma was dead. She would then suggest we could take some flowers to her grave. I commented on January 13<sup>th</sup> that it was Grandma's birthday, and made the mistake of saying that if Grandma had been alive she would have been 88 years old. Biddy thought about it for a minute and said "When Grandma becomes alive we could have a surprise birthday party for her".

I have worked in the past as a nurse and am presently a midwife and have seen the importance of talking openly and honestly with children about death. I have used opportunities to discuss death with the girls, for example newspaper articles, and friends' grandparents dying. Both girls have accepted old age and dying as a natural process. For Biddy, conceptualising death has been harder than for Laura, and repetition seems to help the message get across. Biddy still has limited understanding of the finality of death – perhaps as time passes, and with repeated discussion, she will understand that Grandma won't come back.

Anne O'Connor  
Christchurch

# “Dad goes in a heaven car.”

Hamish and his dad, Alistair, had a great relationship. They watched the rugby together, fished off the boat together and played cricket together. They laughed together, they joked together, they sat in church together, they prayed together. Hamish and Alistair loved each other dearly.

Those days are gone now. On November 1<sup>st</sup>, 2002, Alistair was diagnosed with a brain tumour. The doctors hadn't been concerned that Alistair's headaches were anything serious, but thought at CT scan would soon dispel that theory and then they would find the root of the problem. Hamish and I visited Alistair that evening to see how the scan had gone. As soon as we walked into the room and I saw Alistair's face.... I knew he had some news for us. He patted the side of the bed and asked me to sit down. "I've got something to tell you ....they found something on the scan. I have a brain tumour." Our world suddenly turned upside down, never to be the same again. Changed forever. We sat in shock, not really comprehending what was truly happening.

Hamish, at 17 years old, sat silently in the hospital room. As yet

he didn't understand or have any knowledge of what we were talking about and even in the days ahead, as we told family members, cried, talked, prayed, Hamish seemed to be unaffected by what was going on. The tumour needed immediate surgery, so within a few days, Alistair was sent to Wellington hospital for the operation. The morning he was due to be taken to Wellington, Alistair phoned me early. He asked me, with emotion in his voice, "Could you please bring Hamish in to see me before I leave for Wellington. Also would you bring a cauliflower and mushroom for me." I didn't ask the reason why, but felt I knew....

We arrived at the hospital and Alistair asked Hamish to come and sit up on the bed with him. Alistair, a primary teacher for many years, explained how his brain, the cauliflower, had something growing in it, the mushroom, that shouldn't be there. "The doctors are going to try and take the mushroom part out." Alistair worked away at the cauliflower with his Swiss army knife. "But when they try and cut the mushroom out they may take out little bits of the cauliflower, so when I wake up again, I may not be able to walk or talk or even know who you are." He told Hamish how much he really loved him.

The operation was initially considered to be very successful and most of the tumour had been removed. But within a week we were told that the tumour was "Glioblastoma Multiforme", grade IV malignant and the operation had only removed about half the tumour. We were told Alistair's prognosis was 8-10 months. With weeks of radiotherapy, dreadful headaches, dizziness and appointments, our lives revolved around Alistair's illness. Hamish just kept being Hamish. He watched his videos; he talked about his birthday and asked what was for dinner. But slowly, he began to take it in. I remember so clearly a night when Alistair and I were sitting on the sofa. I started crying as we talked and without a word Hamish walked out of the room, I thought to leave us alone. But not at all, hearing his footsteps and heavy breathing return, he had the box of tissues in his hands. He lay the box down and then proceeded to pull a tissue from the box and began to wipe my eyes. "You sad because dad is sick", he said. He repeated this many times over the next months.

By March 2003, Alistair's health had deteriorated to the stage that he was admitted to the hospice and we were told that there was nothing more they could do. The pain of loss and grief was extreme as we faced a future without him. Did Hamish really understand that his dad might die? I sat on his bed one night and said to him that dad was very sick and could die. Hamish had prayed, and did so every morning and night. Hamish had watched his dad on the radiotherapy machine, seen his dad in hospital, but did he really understand that dad could die? That night, the reality of Alistair's illness was beginning to sink in. We talked, cried and prayed together. Yes – he asked God everyday to please heal Dad, and also talked about the reality that Dad might be going to heaven soon. Heaven, death, grief.... they were all things we were well accustomed to talking about. Close family friends had died in the previous few years and we had talked a lot to Hamish about what happened. He'd seen our friends after their death and he'd been to their funerals. Death was not a stranger to him.



Hamish with dad Alistair before the brain tumour was discovered

Death had been a much talked about subject for us as a family, as from when Hamish was just 2 ½ months old, we were told of his heart condition (Eisenmenger syndrome). We knew that everyday with him would be a bonus. Yes- we'd lived with a death sentence over Hamish all his life. But not Alistair. Not Dad, the big strong one, the hunter, the fisherman, the teacher, the principal....we'd never talked about him dying.

The months went on, and Alistair's health stabilized for a few months. He spent his days either sitting or lying down. His ability to do anything physical was minimal.... he could walk around the house and go for the occasional walk pushing his wheelchair. Hamish thought it was cool because now dad had a wheelchair too! But Alistair was an invalid. Seizures, headaches, tiredness, vomiting, shakiness, dizziness.... all became part of our normal life. Hamish continued to do all the things he'd always done. Off to school in the morning, calling out to Alistair as he left - "Bye Dad." Arriving home in the taxi.... "How's Dad?" he would ask. "Go and see him and tell him about your day", I'd respond. It was routine for us. Dad was sick. Hamish would get him a drink and have a little talk to him, but often the headaches or tiredness meant even the talks they used to have diminished.

As Alistair's eyesight deteriorated, he could no longer watch the rugby. He began to become confused about whether day was night or night was day. Hamish went into our bedroom less. Alistair didn't often talk when Hamish spoke to him. The headaches became more and more severe. Another admission to the hospice. Alistair was sleeping most of the time by now and when he was awake he was often confused and disorientated. Hamish went to stay with his "second parents" for a few days. I was exhausted from caring for Alistair. Alistair had short times of being very coherent, but mostly was highly drugged and asleep. Hamish would visit his dad at the hospice, and watch him try to feed himself, but need help; watch him try to stand up, but fall over; hear him speak but not make sense; watch him sleep and not talk. As the days went on Alistair became more and more ill. By the middle of November we were told that Alistair only had 2-3 weeks left. Over the months, I told Hamish that Dad might die, Dad probably will die, Dad will die soon, Dad will die very soon. Hamish was not protected from the truth but rather we faced it together. He never judged the situation but accepted it as part of life.

Alistair's 47<sup>th</sup> birthday was the 22<sup>nd</sup> November and we wanted him home. He came home in the ambulance, confused and very ill. He managed to stay awake off and on, all day for his birthday and we sang happy birthday, talked to him, held his hand, loved him, knowing that there was only such a short time left. Yet Hamish took it all in his stride - never asking why, just like his father.... Alistair never asked why, but rather made the most of the life he had. Like father like son!

Alistair was nearly blind, unable to do anything for himself, needing 24 hour care. Then he stopped eating. On Wednesday 3<sup>rd</sup> December, Alistair only had hours left. He was deteriorating very quickly. The boys and I sat and held Alistair and we were with him as he passed away. I was aware only that Hamish was hugging and supporting others as we had an outpouring of grief, realizing Alistair had taken his last breath.

The hospice nurse arrived, the pastor, the funeral director, family and friends. Hamish remained open and honest. "My dad died." He cried with us when we cried. He knew his dad had gone even

though his body still lay on the bed. Hamish accepted death as part of life. We had Alistair's body brought home for the days between his passing and the funeral. Hamish saw him, Hamish touched him, Hamish wrote him a long letter and put it beside his dad. Hamish spoke to his friends on the phone and told me they were sad because his dad died.

The day of the funeral came. Although Hamish is much shorter than Alistair, at 5 ft, and Alistair was 6ft 1", Alistair's suits fit Hamish well in width! Hamish wore Alistair's college tie. Alistair would have been so proud of him as he stood in his suit and tie. Hamish attended the funeral in full confidence... even greeting people with handshakes as he entered the church. More than I could do by far! He sat quietly as the service commenced but each time he looked and saw me crying, an arm would come over towards me and rub my shoulder, then a tissue. Looking at the white casket, the photo of a younger, healthier Alistair, some McNeill tartan fabric and a floral tribute of red and white roses, we listened as people gave their tributes to a life well lived. After our older son, Callum, spoke, he called Hamish up. Hamish spoke into the microphone clearly but with emotion...

"Dad is go to heaven. God is good. Dad is a good father."

There may have been dry eyes in the church until then, but there weren't any after Hamish had spoken. He returned to his seat with tears in his eyes and a sad but proud look on his face. Alistair would have been so proud of him, as I was that day. As the casket was carried from the church with Renton(17) and Callum (21) as the leading pall-bearers, Hamish held my hand and supported me, as we left the church. Without his heart condition, Hamish would also have been a pall-bearer. But he did a great job of looking after his mother! At the graveside, Hamish again attended to me and mixed with our many friends. Hamish, Callum, Renton and I knelt and prayed as the casket awaiting lowering. Together we farewelled a dear and well-loved father and husband. "Loved and cherished husband of Christina, patient, humourous and much loved father of Callum, Hamish and Renton." The death notice words were so true.

It's not long since Alistair passed away. It is still very very fresh and new for us. An empty seat at the table, an empty place in my bed, his voice no longer heard, his presence no longer physically felt... a huge emptiness in our lives. As I continue to grieve the loss of my husband and soul-mate, Hamish continues with me in my journey. In his acceptance of death, he is able to support and care for those around him. He cries sometimes, he talks about his dad, he hugs me when I need a hug, he wipes my eyes with tissues and says - "It is too hard for you. You miss Dad." And he counts down the days before his birthday. He plans his birthday, he talks to his friends on the phone, he watched his videos, and he asks me what we're having for dinner tonight. He loves his life. He loves his dad. He never asks why but makes the most of each and every day.

In Hamish's own words... "I love Dad. He is cool. He goes in a heaven car. Dad is alive in heaven. I will see him again. We'll all die."

*Christina McNeill  
Palmerston North*





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No. 1061474

## People with Down's syndrome

### Bereavement

#### Myths:

People with Down's syndrome do not experience grief

People with Down's syndrome do not recognise or comprehend loss

#### Facts:

The loss of a loved one is perhaps one of life's most stressful events. After the death of someone you love you experience bereavement, which literally means to be deprived by death. For example, you may experience bereavement at the loss of a family member, a friend or a pet.

In the past, people with Down's syndrome (DS) were denied the right to grieve because other people mistakenly assumed that they lacked the capacity to do so. The life expectancy of people with DS is steadily increasing and as a result of this, many are experiencing the death of their friends and parents. When people with DS are bereaved, their reactions to the loss are frequently misunderstood.

Grieving is a highly individual process and people respond to bereavement and express their grief in different ways. The person with DS experiences the same processes as the rest of the population. The grieving process for those with DS may however take longer and it may manifest itself in ways that are not instantly recognisable. Usually people can work through their feelings about an unhappy event and come to terms with it. People with DS will probably need help to do this.

Many people with DS find change of any kind difficult to cope with. Routine can be particularly important to people with DS providing individuals with an important sense of order and structure to their lives. However, it has often been the experience of people with DS that other people make decisions that affect their lives without any warning, any element of personal choice or of control.

#### NATIONAL OFFICE

1st floor, Down Centre  
20 Langdon Park, Tring, Hertfordshire  
SG13 7PL  
Tel: 01494 471024 (England & Wales)

#### DOWN'S SYNDROME ASSOCIATION

Tel: 01494 471024 Fax: 01494 471025  
e: [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)  
w: [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

## **Common Responses To Grief**

Whether or not they have DS, people react individually to grief, but most people experience at least some of the common responses to bereavement. These are summarised below:

An initial sense of shock, numbness, disbelief and denial accompanied by one or more physical symptoms such as lack of energy, trouble in concentrating, remembering and making decisions, hyperactivity, thinking about wanting to die and a sense of unreality.

As the early shock wears off and the impact of the reality of the death is felt, people may experience the following reactions:

**Emotional:** Anger with the deceased or with those who it is believed could have prevented the loss, guilt, anxiety, fear, panic, depression, despair, mood swings, irritability, crying, sadness, yearning and pining, sense of being abandoned.

**Physical:** Symptoms such as pain, appetite disturbance, breathlessness and illness. The person with DS, who is less able to express himself or herself verbally, may experience and exhibit increased physical symptoms of grief.

**Behavioural:** Low vitality, more than usual need for sleep, sleeplessness, hyperactivity, withdrawal and a lack of interest in normal activities.

**Mental:** Confusion, hallucinations, nightmares, searching for the deceased, poor concentration, regression, loss of skills and insecurity.

Resolution of grief occurs when the bereaved is able to think of the deceased without pain or anger and can recall the times they had together in a positive way. The journey towards resolution of grief is not always a continuous or direct one. It is also a journey that may take a considerable period of time. It is important to note that not everyone will experience all of the symptoms detailed above.

## **Depression**

Sometimes grief can continue into depression and this may well show itself, in someone with DS, in unexpected forms. Although depression sometimes strikes out of the blue, it is often triggered by some unhappy event such as bereavement. These unhappy events affect most people with DS at some stage of their lives. However, not everyone will get depressed.

Sometimes one loss can then lead on to other major changes that may result in depression. For example, after parents have died, people with DS are often moved to emergency residential care. This means that they lose their home, their familiar possessions and routines, as well as their parent and carer. Sometimes a more serious and persistent depression develops. This is a particular risk for people with DS because carers often miss the early signs of depression. The time to get help is when any changes in behaviour, withdrawal or gloom persist for a lengthy period of time. You should then seek professional help. You may obtain a copy of a publication entitled 'Depression in People with Learning Disability' from the Down's Syndrome Association or you can download the leaflet free of charge at the website of The Royal College Of Psychiatrists ([www.rcpsych.ac.uk](http://www.rcpsych.ac.uk)).

## **Helping the person with Down's syndrome through the process of Bereavement**

- Always give the news of a death with honesty and at a pace suited to the individual. The news of a death should not be kept from an individual in an attempt to protect him or her.
- Always use straightforward language in order to avoid misinterpretation by the person with DS. The use of terms such as 'death' and 'died' are preferable to terms such as 'passed on' or 'gone to sleep'.
- The person with learning disabilities should be given the choice as to whether or not they wish to take part in the rituals associated with death. If the person is unable to choose directly, it is advisable to involve the person as fully as possible. Non-verbal rituals may be particularly helpful to people with DS.

- It is important to allow the bereaved person to have the opportunity to choose mementoes by which to remember the deceased person and to act as a focus for their feelings.
- Avoid major change at this confusing and distressing time. The person with DS may find it comforting to take refuge in their daily routines and familiar surroundings. Helping the bereaved person to maintain some continuity and connection with life before the bereavement is essential to recovery.
- Always give the individual with DS space and time in which to express their feelings. If the deceased is a family member, it may be helpful to create opportunities for the person with learning difficulties to communicate their feelings to someone outside of the family. You may wish to consider specialist bereavement counselling for the person with learning disabilities. You can obtain further information about this from your local Social Services (Learning Disabilities Team) or from an organisation called CRUSE (see Useful Organisations). CRUSE should be able to provide you with an appropriate local contact.
- Remember that everyone with DS is different. It may take many months for some people to realise that the dead person will not come back. For some people life will get back to normal very quickly after someone dies. This might be because they knew that the person was going to die and had worked through their feeling before the death. Some people may experience strong feelings of loss for months or even years. As time passes, as with all of us, the person with DS should reach a point where they can remember good things about the dead person without being very sad at the same time. Naturally, dates such as the dead person's birthday or the date when the person died will sometimes bring back the feelings of sadness. Memories are important and it can help for the person with DS to talk about the person who died, what they were like and what they used to do together when anniversaries arise. Non-verbal rituals and visiting familiar areas or the place where the person is interred can be helpful.



## **Resources**

### **Literature**

#### **Loss And Learning Disability**

By Noelle Blackman (Worth Publishing Ltd, 2003)

ISBN 1-903269-02-4

(£12.00)

The emotional life of people with learning disabilities is a subject that has only begun to be thought about during the last decade. This book by Noelle Blackman addresses the central issue of how people with learning disabilities can be affected by bereavement

#### **Am I Allowed To Cry? : Study Of Bereavement Amongst People Who Have Learning Difficulties**

By Maureen Oswin (Souvenir Press Ltd, 1991)

ISBN 0-285-65096-3

(£9.00)

A practical guide with plenty of facts and advice mixed with real life stories and experiences. This book is a definite must read for all those working with people with learning disabilities. Although staff attitudes to people with learning disabilities have vastly improved since this book's publication, bereavement of people with learning disabilities is still often overlooked.

#### **Talking Together About Death - A Bereavement Pack For People With Learning Disabilities, Their Carers And Families**

By Joan Cooley & Frankie McGauran (Speechmark Publishing Ltd, 2000)

ISBN 086388265X

(£53.00)

A bereavement pack containing five sets of illustrated cards and a user's guide. Designed for both families and carers to share the experience of death and bereavement with people with learning disabilities.

### **Interventions With Bereaved Children**

Edited by Susan C. Smith & Sister Margaret Pennells (Jessica Kingsley, 1995)

ISBN: 1-85302-285-3

(£16.95)

A useful resource with lots of practical ideas. Twenty contributors share effective ways of supporting and helping bereaved children. Chapter 13 is entitled "Helping Families and Professionals to Work with Children who have Learning Difficulties."

### **Training Pack**

#### **Understanding Grief: Working With Grief And People Who Have Learning Disabilities**

By Sheila Hollins & Lester Sireling

The Pack may be used in formal staff training or as an educational tool for families and carers of a bereaved person with a learning disability. The Pack includes a video entitled **When People Die** and a copy of the book **When Dad Died**.

The Pack may be purchased from the Department of Mental Health - Learning Disability, St. George's Hospital Medical School (Tel: 020 8725 5496) (£70.00 inc p&p)

### **Accessible Information For People With Down's Syndrome**

#### **When Someone Dies - An Accessible Guide To Bereavement For People With Learning Disabilities And Their Carers**

By Michelle Mansfield, Peter Aukland & Anita Evans (Speaking Up, 2006)

(£5.00)

Speaking Up have designed an accessible booklet to enable people with learning disabilities bereaved by death to understand their grief and cope with their loss and to give them greater confidence to access support and to help each other.

Over 40 people with learning disabilities were consulted to write this booklet and a steering group of three people developed this great new resource.

This booklet is a must have resource for all those working with people with learning disabilities, it is designed to be used either with a carer or worked through individually. It contains a pull out 'Mood Chart' so that individuals can explain how they are feeling through their grieving process.

Tel: 01223 566258  
Website: [www.speakingup.org](http://www.speakingup.org)  
Email: [sales@speakingup.org](mailto:sales@speakingup.org)

**Let's Talk About Death - A Booklet About Deaths And Funerals For Adults Who Have A Learning Disability**

(Down's Syndrome Scotland, Tel: 0131 313 4225)  
(£1.50)

The booklet may be purchased from DS Scotland or downloaded from the Internet free of charge at: [www.dsscotland.org.uk](http://www.dsscotland.org.uk)

**Understanding Death And Dying - Your Feelings**

By Fiona Cathcart (British Institute Of Learning Disabilities (BILD), Third Print 2001)  
ISBN: 1-873791-11-9  
(£3.50)

BILD also produce two other booklets in the 'Understanding Death And Dying Series' aimed at families, friends, professionals and carers.

These booklets are a valuable resource for general education and social development and can be used in a preparatory way if a relative or friend is diagnosed as having a terminal illness; and to help someone with a learning disability come to terms with bereavement. Designed for children and adults.

**The Journey Of Life - How People Change From Babies To Older People**

By Karen Dodd, Vicky Turk & Michelle Christmas (British Institute Of Learning Disabilities (BILD), 2005)  
ISBN 1-904082-91-2  
(£10.00)

The '**Journey Of Life**' will be useful for helping people with learning disabilities understand the human life cycle. The booklet includes pictures of a man with Down's syndrome showing how he changes over time.

The booklets may be purchased from BILD either from the Internet at [www.bild.org.uk](http://www.bild.org.uk) or by calling 'BookSource' on Tel: 08702 402 182.

**All About Feeling Down - A Booklet For People With Learning Disabilities**

ISBN 1-903645-395

Foundation for People With Learning Disabilities (FPLD), 2003

This booklet is for young people with learning disabilities aged 14 to 25 and contains information about what you can do if you feel down.

Single copies are usually free to individuals. Either call FPLD on Tel: 020 7802 0300 or download the booklet at FPLD's website: [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

**Books Beyond Words Series**

**When Mum Died**

By Sheila Hollins & Lester Sireling (Gaskell & St George's Hospital Medical School, Third Print 2004)

ISBN 1-904671-03-9

(£10.00)

**When Dad Died**

By Sheila Hollins & Lester Sireling (Gaskell & St George's Hospital Medical School, Third Print 2004)

ISBN 1-904671-04-7

(£10.00)

Many people understand pictures better than words. This series of picture books is for use by people with learning disabilities. They help people to understand and deal with difficult situations and emotions.

When Mum Died and When Dad Died take a gentle, honest and straightforward approach to death and grief in the family. The pictures tell the story of the death of a parent in a simple but moving way. The approach is non-denominational. When Dad Died illustrates a burial, while When Mum Died shows a cremation.

The greatly expanded text in these third editions includes information on how people are likely to react when someone is very ill and to their death. It explores difficult emotions, possible physical feelings and behaviour changes. Guidance is given on how to relate to a bereaved person and how to answer the questions 'How do we feel when someone dies?', 'What happens after someone dies?' and 'How long does it take to get back to normal?'. There is advice for support staff and carers of those with learning disabilities (including how to formulate guidelines and a sample bereavement questionnaire), plus information on useful written resources and bereavement organisations that can offer further help.



These books will be helpful to adolescents and adults with learning disabilities as well as for their carers and supporters. In addition, children without learning disabilities will appreciate these books as they adopt a more direct approach to death than is usual.

### **When Somebody Dies**

By Sheila Hollins, Sandra Dowling & Noelle Blackman (Gaskell & St George's Hospital Medical School, 2003)

ISBN 1-901242-90-0

(£10.00)

Everyone feels sad when someone dies. People with learning disabilities have the same feelings of grief as anyone else, but they are seldom offered the help and support that other people are given.

This book tells the story of Mary who is very upset when someone she loves dies. She is encouraged by a friend to go to regular bereavement counselling sessions, which help her to feel less sad. Later on in the book, John also loses someone he is close to. He is given comfort and companionship by his friends, and is shown learning to cope with life better and better as time passes.

This book shows people with learning disabilities that they need not be alone when they feel sad about someone's death, and that talking about it to a friend or to a counsellor can help them get through this difficult time.

Books from the 'Books Beyond Words' series may be ordered from the Royal College Of Psychiatrists either by calling Tel: 020 7235 2351 (extension 146) or via the Internet ([www.rcpsych.ac.uk](http://www.rcpsych.ac.uk)).

### **Video**

#### **Coping With Death**

Explains what happens when somebody dies and shows adults with learning disabilities coping with death.

The video may be purchased from 'Speak Up Self Advocacy', Tel: 01709 7100199 (£28.00 inc. p&p).

## **Books For Children**

### **When Someone Very Special Dies**

By Marge Heegaard (Woodland Press, 1991)

ISBN: 0-9620502-0-2

(£8.99)

A simple workbook that can be adapted for children and young people with Down's syndrome. With adult help, users are invited to illustrate and personalise their loss. It also encourages the identification of support systems and personal strengths.

*The Down's Syndrome Association does not sell these resources. However, all these titles can be ordered through any large book retailer, via the Internet (e.g. [www.amazon.co.uk](http://www.amazon.co.uk)) or direct from the relevant learning disabilities organisation. Prices may vary according to retailer and availability.*

## **Useful Organisations**

### **CRUSE Bereavement Care**

CRUSE House  
126 Sheen Road  
Richmond  
Surrey  
TW9 1UR

Tel. 0870 167 1677

e-mail: [info@crusebereavementcare.org.uk](mailto:info@crusebereavementcare.org.uk)

Web Site: [www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)

A national organisation offering help to all bereaved people.

### **National Association Of Bereavement Services**

20 Norton Folgate  
London  
E1 6DB

Tel. 020 77099090

Puts callers in touch with their nearest service. Co-ordinates and supports bereavement services.

### **The Compassionate Friends**

53 North Street  
Bristol  
BS3 1EN

Tel: 0117 953 9639

e-mail: [info@tcf.org.uk](mailto:info@tcf.org.uk)

Web Site: [www.tcf.org.uk](http://www.tcf.org.uk)

An organisation of bereaved parents and their families offering support to others after the death of a child or children. The organisation also offers support, advice and information to other relatives, friends and professionals who are helping the family.

### **British Association For Counselling**

1 Regent Place  
Rugby  
Warwickshire  
CV21 2PJ

Tel. 0870 443 5252

e-mail: [bac@bac.co.uk](mailto:bac@bac.co.uk)

Web Site: [www.bac.co.uk](http://www.bac.co.uk)

**Mind**

Tel: 0845 766 0163

Web Site: [www.mind.org.uk](http://www.mind.org.uk)

**Stuart Mills, Information Office, DSA (updated Dec 2006)**