

'The way in which children and young people are treated when someone important in their life dies has a profound effect on their future ability to manage their own lives. School has a very important role to play in this.' This quote from the Child Bereavement Charity will strike a chord with anyone who has had to help children and young people come to terms with the loss of someone close to them. But how can we support children and young people who may have a condition where their own life expectancy is threatened or where they have a life-limiting condition? How should schools respond when a pupil is close to death and eventually dies?

These and other issues were explored at a major conference in Birmingham organised by the Child Bereavement Charity (formerly known as the Child Bereavement Trust). Young people involved in the conference chose the conference title, 'Live and Let Die' and gave live presentations or shared their views and experiences through videos and film.

What emerged from the conference, and from literature available from the Child Bereavement Trust (CBC) and other groups such as the Muscular Dystrophy Campaign, is that the most important factors in working with young people in schools with life limiting and life-threatening conditions are communication, honesty and respect. At the centre of a school's response should be an effective whole school plan for dealing with bereavement.

Life- limiting and life- threatening conditions

There are many life- limiting conditions, where it is known, often from an early age, that a child will either not reach adulthood or will have a limited life expectancy. These include neuromuscular conditions such as Duchenne muscular dystrophy and spinal muscular atrophy, neuro degenerative disorders like Batters disease and adrenoleucodystrophy, as well as cystic fibrosis. In some of these conditions, such as Duchenne muscular dystrophy, there will be physical degeneration and loss of independence, often over a long period of time. Typical life- threatening conditions, where a child or young person may suddenly develop an illness that may be terminal, include leukaemia and other forms of cancer. Complications can also arise when children have certain types of congenital heart disease.

Good communication, training and information

Jill Adams, CBC's Schools' Training and Support Coordinator for the UK, believes that good communication and accurate information are at the heart of any school's response to terminal illness and bereavement. Jill is responsible for organising and running a wide variety of training programmes to meet schools' needs. She stresses that all information provided to pupils and the wider school community about a pupil's illness should be *timely*. By this she means that decisions need to be made about how much information should be shared, when and with whom. These decisions will be affected by the wishes of the family, the stage of the child's condition, and what is judged to be appropriate at any given time. Children's understanding of death changes as they get older, and the way that we explain death and illness needs to reflect the age of the children we are talking to: often responding to questions that they ask.

A school's senior management may choose, for example, for one person to be responsible for receiving key information about the pupil and liaising with the parents. If the school has a school nurse, they may be tempted to entrust that person with this role. Though naturally school nursing staff's support and knowledge is important, Jill sees this as not necessarily the best decision. This can unwittingly make staff focus on the medical aspects of the child's condition, rather than looking at the child as an individual, or as Jill put it, "Better to concentrate on the child being alive rather than having a medical problem."

Jill can help schools to find organisations that are available locally and is happy to talk to anyone over the phone. The CBC offers a 'signposting' service using their online database to allow parents and schools to search for local and national organisations that may meet individual needs. Parents and carers can also download information sheets that from the CBC website, including topics such as 'understanding bereavement', 'how men and women grieve', and 'how to support a grieving child'. Information sheets for children and young people are also available, including 'understanding your feelings', 'funerals', 'going back to school or college' and 'seeing the body or not'. Many adults and young people have found participating in CBC's online Family Forum and Professionals forum very helpful and informative.

Honesty

School staff, including head teachers, may need support to address their own feelings and reactions. Some adults may have had difficult experiences with bereavement, or for other reasons find it difficult to acknowledge that a pupil has a life limiting condition. This can manifest itself in them taking controversial actions or making unhelpful decisions, which are often based on denial that the pupil has a problem. One class teacher, for example, was unable to accept that a child in her class required physiotherapy during lesson time, and made the child catch up on lost time while other children were out at playtime. A head teacher refused to sanction a year six class being relocated to a ground floor to accommodate a boy with Duchenne muscular dystrophy 'because Year 6 has always been upstairs.' This was despite the fact that the school had a summer holiday to plan such a move. The LEA was therefore forced to buy an expensive and time-consuming stair-climbing wheelchair. An HMI Inspector criticised a primary school for providing extra swimming lessons for children with physical disabilities because they were 'losing their entitlement to the National Curriculum'.

Parents and staff will naturally want to protect children from the reality of death, and may choose to tell their children nothing about their condition. Youngsters in this situation often want to protect their parents by pretending that they don't know anything either, or by not complaining. Other parents may tell their children everything about their illness, while others will share exactly what they want or need to know. Most parents will have very strong views on this subject, and schools will need to find a way of respecting parents' wishes. However, as the MDC point out, "Schools who feel that children's needs are not being met should seek professional advice." This

may be from the Educational Psychology Service or LEA support teams working with pupils with physical disabilities. Above all young people, including brothers and sisters, need to have people around them who they can talk to and to share their feelings in private and in a non-judgemental way. There was agreement among conference speakers that children generally want to know the truth.

Respect

Chris Hassell, Head Teacher of Reepham High School in Norfolk, shared with the conference his school's experiences of two tragic losses within one year. His guiding principle was to respect the wishes of the youngsters and their families undergoing the trauma of coping with life-threatening illness. One family, whose 11 year old son was diagnosed with a brain tumour that, it sadly transpired, made him terminally ill, did not want this information to be shared with the wider school community.

Another youngster who developed leukaemia when aged 15, was keen for everyone to know about his condition, and appeared in the local media. Unfortunately, after hopeful signs of recovery, he too was diagnosed as having a terminal illness. Chris was able to respect both families' wishes about sharing information, though this was not always easy.

A whole school plan

The Muscular Dystrophy Campaign (MDC) strongly recommends that schools develop an effective whole school plan for bereavement, before a child dies, rather than in response to such an event. This could cover other types of loss, including staff members, death of parents, or children dying suddenly through accident or illness. Areas to be considered can include contact with the family; informing staff, children, and other parents; providing support for staff and pupils; identifying a key person to coordinate the school's response; and marking the death with a memorial or thanksgiving service. The plan needs to be broad enough to cover other circumstances when the school may have to deal with a loss or bereavement.

Key strategies when a pupil dies

How should a school mark the death of a pupil? Perhaps the account of Kerry Tuck, Reepham High's Head of Year and Active Listening Forum Coordinator might help teachers decide the most appropriate way to help fellow pupils express their feelings in "calm and dignified grief".

"We set aside my classroom as a space where the pupils could come and remember. We lit candles and played quiet background music. We laid out large sheets of paper with crayons and pencils so youngsters could record their feelings or make posters with memories and anecdotes. We also provided memory boxes that the students could fill with items that were meaningful to them. Teachers were involved, but were able to stand back once the students had been given a space for quiet gentle grieving. It was amazing how the young people had the strength to cope with this in such a dignified manner."

Chris Hassell added that the school were grateful for the support of Norfolk LEA's Critical Incident team, who provided counselling, and for the work of the local vicar. Pupils and staff attended both boys' funerals, and the school are now considering the best way to mark the boys' memories, one year after these tragic events. There has been rigorous fundraising by pupils, and many older pupils and their parents find this a valuable way of keeping memories alive, as well as helping them come to terms with terrible loss.

The MDC has some practical suggestions for school staff to help mark the death of a pupil, but this could equally be applied to any member for the school community. Similar advice is available in the CBC's literature. They recommend that staff acknowledge the child's death, even though the child may have been off school for some time. Tell small groups, such as tutor or class groups, before telling the whole school. Be aware of 'best friends' who may need extra support and may wish to mark the loss in a particular way. Bear in mind that this is a loss for the whole class or form, and work out with pupils what they would like to do. Don't change the layout of the classroom immediately, but acknowledge that the young person isn't there. Let teachers and other staff show their emotions and allow them to acknowledge that they are finding it hard. Give everyone 'permission' to feel sad or cry in front of the class.

Providing ongoing support

Staff need to cope with the immediate crisis following the death of a pupil, but they also need to plan to provide ongoing support for pupils, staff and the family during the long process of grieving. Thought will need to be given to helping brothers and sisters in the school, particularly when they return to school after the funeral, and in the future. Expressions of grief do not always show just as sadness, and school staff may benefit from the CBC's training opportunities or reading their literature, to find ways of supporting siblings. Many children will have received support from a local hospice, and this may continue for families and siblings. Fundraising for such organisations often provides a positive focus for the school community's energies in the months and years after someone's passing.

References and useful contacts

The Child Bereavement Charity www.childbereavement.org.uk

Muscular Dystrophy Campaign www.muscular-dystrophy.org

Talk About Change (A film made by young people with life threatening conditions) www.talkaboutchange.co.uk

Grief Encounter, by Shelley Gilbert. (A workbook to encourage conversations about loss between children and adults)

Grief Encounter Project, PO Box 49701, London N20 BXJ