

Pupils with a life threatening illness

Children who are not expected to live, whilst they are still able, may benefit enormously from normal routines such as attending school. This can present challenges for the school community. Sensitive but honest communication between the family and professionals involved, will overcome most of these, hopefully enriching the lives of all those who come into contact with the child or young person. Suggestions on how to manage such situations are given below.

Children who are constantly in and out of hospital, welcome attending school as an opportunity to have some normality in their lives. Continuing to take part in school routines as much as possible can give a feeling of achievement, with the emphasis on living rather than dying. It can also give back a sense of identity as a person rather than a patient.

Classmates who have had the situation explained to them are usually supportive. It often helps to involve them by giving jobs such as wheelchair pushing. Try to ensure these tasks are shared and do not become the responsibility of just one child.

The school and family, including the sick child, need to decide together how to share the news that a pupil is terminally ill. It is not easy, but an open and honest approach is usually the best way. However, as much as adults try to hide what is happening, children instinctively know something is wrong and will often have worked out that a class member is dying before being officially told. Telling only the immediate peer group may seem like a good idea but the grapevine will take over resulting in gossip and half-truths throughout the rest of the school.

If the child is receiving treatment from a local hospice or hospital, there is often a nurse or social worker whose job includes visiting schools to explain to pupils about a friend's illness and treatments involved. This should help alleviate any worries that fellow pupils may have. It is helpful for the school to at least identify the key professional responsible for the ill child and how to contact them for advice and support.

Children deal with difficult situations much better when truthful explanations are given regarding absences, changing appearance, lack of energy, treatments and exclusion from activities such as sport. Being naturally curious, classmates will ask questions, and these should be answered sensitively but factually. Seriously ill children are often extremely knowledgeable about their illness and may well be happy to provide the answers themselves.

A sense of normality is further maintained by continuing to expect usual standards of behaviour within the child's limitations. This helps to reduce feelings of favouritism amongst other children. Other parents and carers at the school may have concerns surrounding their own children being upset or made anxious by a classmate who is seriously ill. Reassurance that children and young people will have fewer anxieties if presented with the truth, rather than having to make up what is happening, may help. With consent from the family of the sick child, information on the illness and treatments will help other parents and carers to understand and feel informed. The realisation that their children are contributing to an increased quality of life for the sick child may create a more

positive approach. Offer information on what to say to children when someone is dying. (see resources below)

Resources

My Book About Me by Sally Harrison and Lynda Weiss

A workbook for children age 4-11 with a life threatening condition to help them make sense of their illness. Could be used as a resource to help classmates understand treatments and symptoms.

Only available from [Child Bereavement UK](http://www.childbereavement.org.uk)

Cost £5.00

My Brother and Me by Sarah Courtauld

Good for primary age siblings of a seriously ill child, this book will help them to understand how facing illness and change in a family is difficult for everyone. From [Child Bereavement UK](http://www.childbereavement.org.uk).

Cost £5.00

When Someone Has A Very Serious Illness by Marge Heegard

A workbook for helping children learn the basic language associated with a serious illness and age appropriate ways of coping with someone else's illness. Available from Amazon.

Cost £7.00

As Big As It Gets by Julie Stokes and Diana Crossley

Aims to help families cope with the serious illness of a parent or child. It provides a range of ideas for parents and carers including suggestions for what to say and how to offer support. Available from Winstons Wish Tel: 01242 515157.

Cost £6.95

Children at school with a life limiting illness-guidance for health care professionals

CBUK information sheet www.childbereavement.org.uk/publications

www.cancertalk.org.uk

Excellent website from Macmillan Cancer Care, a resource guide for teachers and youth workers. Download classroom teaching packs on cancer for primary and secondary schools. It also has a link to Why Bother, their youth website.

CLIC Sargent www.clicsargent.org.uk Free helpline: 0800 197 0068

The UK's leading children's cancer charity which provides support to children suffering from cancer and leukaemia and their families. Download a useful guide from the CLIC Sargent website "Pupils with cancer: a guide for teachers" Home/About childhood cancer/for teachers.