

The Hospice Movement

the modern hospice movement began in 1967

The word 'hospice' is derived from 'the hospitium', that part of the monastery where traditionally help was given to travellers, the sick and the poor in the Middle Ages. The first reference to palliative care (which is similar to hospice care) dates back to Hippocrates and 460 BC. In 1996 palliative care was described as 'a concept where there is a shift of emphasis from conventional care that focuses on quantity of life, towards a commitment to care which enhances the quality of life.'

hospices provide 80% of the palliative care beds in the UK

The modern hospice movement began in 1967 with the opening of St Christopher's Hospice by Cicely Saunders. She was inspired by her work as a nurse and then social worker, to meet not only the physical needs of the dying, but also their emotional and spiritual needs. She then trained as a doctor. There are now 231 hospices, including 29 for children and 3 exclusively for people with HIV/AIDS. The first hospice for adolescents was opened by Acorns Children's Hospice Trust in 2000 in Birmingham. Independent hospices provide 80% of the palliative care beds in the UK, but most of their income derives from charitable donations and legacies. No charge is made for hospice care.

Around 96% of adults cared for by independent hospices have cancer. Children's hospices help young people with a much broader range of life-limiting illnesses.

Hospice care is based upon the belief that death and dying are a natural part of life, and important experiences in people's lives. Hospices believe that the quality of life for people with terminal illnesses should be made as positive as possible.

hospice care is holistic

What do Hospices Provide?

Hospice care is holistic and supports the whole person and family. Holistic care supports many needs:

- physical
- emotional
- social
- spiritual
- psychological

so that those facing death and their families can make the most of whatever time is left.

Hospices employ a range of specialist staff, but also rely heavily on the goodwill and hard work of volunteers. On average each hospice has three times the number of volunteers as employed personnel. The CD-rom provides information about the services offered by hospices and the work of paid staff and volunteers. Many hospices have education and training departments that keep staff and volunteers up to date with information and professional development. Some hospices also provide training and support for professionals in other care services.

Section 1

hospice care offers a range of services

Hospice care offers a range of services:

- pain control
- symptom control
- nursing care
- counselling
- complementary therapies eg aromatherapy
- spiritual care
- physiotherapy
- creative workshops, eg painting and making music
- beauty treatments
- pre- and post-bereavement support
- respite care (particularly for parents of children with life-threatening illnesses)
- therapy, eg art and drama

Hospices also provide information, for example about benefits and welfare entitlements, to patients and their families.

hospices are not just buildings with beds

Where is Care Provided?

This care may be provided in hospices, at home, in hospitals or in nursing homes. Wherever the location, ensuring patients retain the power of individual choice regarding the nature of the care, and preserving their dignity, are paramount. Hospices do not simply care for people in the last stages of terminal illnesses, they specialise in helping people live with and cope with illness and death – to the end, if that is the case (but it isn't always so).

Hospices are not just buildings with beds, but are about a way of caring.

Your local hospice may be able to help you with further information about what services it provides and even offer a speaker.

the modern hospice movement started in 1967 with the founding of St Christopher's Hospice

Cicely Saunders

The Irish Sisters of Charity established Our Lady's Hospice in Dublin in the late 19th century and later founded St Joseph's Hospice in London as places for the care of the dying. The modern hospice movement started in 1967 with the founding of St Christopher's Hospice in south east London by Dame Cicely Saunders. She is regarded as the person who really developed the modern hospice movement.

Cicely Saunders was born in 1918 and after leaving school, she trained as a nurse. However, a back problem meant she had to stop nursing. She then trained as a social worker and, in the course of doing this work in a hospital, she became aware of the psychological and spiritual needs of dying people who she sensed often felt very

isolated and alone. Cicely Saunders thought there were two particular reasons for this. Firstly, doctors and nurses were trained to cure people and many of them saw death as failure – so communicating with dying people was seen as difficult.

*help patients
to come to terms
with the life they
had lived*

Secondly, dying people who were close to death and who recognised this, often had a great need to look back on life and reflect on both their failures and successes. They wanted someone who would listen to their thoughts, encourage them to express them and help them to come to terms with the life they had lived. Cicely Saunders did just this. She also became interested in the medical treatment for cancer – in particular, pain control – and was told the best way to investigate this was to become a doctor herself. So, in her mid-thirties, she started medical training and qualified as a doctor in 1957.

Patients with cancer often suffered pain and they were given strong drugs, called opiates, which can easily cause addiction in healthy people. Medical personnel were afraid to give too many of these drugs to patients because of the fear of addiction, and people had to ‘prove’ they were in severe pain before they were given the drugs. However, Cicely Saunders did research which showed that addiction was not a risk when opiates were being used to lessen pain. She demonstrated that they could be given on a regular basis to patients, provided they were used only for the purpose of pain control. This was a revolutionary change in the way these drugs were given to patients, who could then live more fully because the pain was not constantly at the forefront of their minds.

*St Christopher’s
Hospice was
founded as a charity
in 1961*

During her time as a social worker, Cicely Saunders had a patient called David Tasma, and she told him about her dream of having a special place where she would be able to care for dying people. He left her £500 in his will – the first donation towards St Christopher’s Hospice. The window in the reception area of the hospice is dedicated to David Tasma. He had felt that life had little meaning, but the window is a testament to a life which, through a generous donation, has contributed to a worldwide movement dedicated to helping people nearing the end of their lives.

*the first patient was
admitted in 1967*

Armed with the first £500 and her conviction that a hospice needed to be built, Cicely Saunders drew around her a group of like-minded friends and colleagues who had similar views on helping people with advanced illness. These people also did a huge amount of fundraising. St Christopher’s Hospice was founded as a charity in 1961. Building started a short time later and the first patient was admitted in 1967.

*St Christopher’s
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research*

From the beginning, St Christopher’s was like a magnet to those who wanted to provide high quality care for people with advanced disease. In particular, many nurses and doctors wanted to improve their care of patients who were dying and who had disabling conditions resulting from their life-threatening illnesses. Many people involved in health-care work, such as chaplains, occupational therapists, social workers and physiotherapists sought to apply the lessons learnt at St Christopher’s

Section 1

Hospice to their own situations. Almost immediately St Christopher's role, apart from caring for patients, was one of education and research.

a hospice is really the organisation rather than the building

Within two years of the first patient being admitted to St Christopher's, a home-care service was set up. This was just one of a number of different types of hospice care that has gradually developed over the years. Hospice care is provided in many places other than in purpose-built, hospice units. People from the hospice provide specialist care for patients who are in hospital and in their own homes, so a hospice is really the organisation rather than the building in which the organisation is housed.

the hospice movement has had a profound effect on the care given to dying people and their relatives

The hospice movement has had a profound effect on the care given to dying people and their relatives. Its influence has spread across the world with hospice care facilities in many countries throughout the world. The World Health Organisation has encouraged the development of hospice care in developing countries, although there is still much more development possible, even in terms of getting the strong opiate drugs accepted as a medical treatment. They are not approved as a method of pain control in some countries that have strict drug laws.

RECOMMENDED FURTHER READING

Cicely Saunders by S Du Boulay – a revised edition, Hodder and Stoughton, 1994
Available from St Christopher's Hospice. It is the story of the life of Dame Cicely Saunders which is inextricably linked both with the growth of St Christopher's and the modern hospice movement. It has a final chapter by Dame Cicely Saunders on euthanasia.

Changing the face of death – 2nd edition, RMEP, 2001

This book is an updated version of a previous book by S Du Boulay about the life of Dame Cicely Saunders. It is particularly useful for children in secondary school doing projects on famous people and on euthanasia.

Children's Understanding and Experience of Loss and Grief

*every year thousands
of children face
bereavement*

Children do not live long before they encounter loss and change in their everyday experience. Every year thousands of children face bereavement through the death of a grandparent, parent, sibling or friend. When someone dies, adults are understandably so engrossed in their own grief that children's grief may be unnoticed. However, the way in which children are helped when sad things happen may have a profound effect on how they are able to adapt to loss and change throughout their lives.

Children's Understanding of Death

EARLY YEARS

Because children mature at different rates, their understanding of death may vary. It is also helpful to remember that knowledge comes through experience. Therefore what a child understands may depend as much on past experience as it does on his/her chronological age. From as early as six-months old a baby may respond to the absence of someone who has been a primary carer by showing irritability and changes in their feeding, sleeping or crying patterns. This is sometimes called separation anxiety.

*few young children
will understand the
permanence of death*

In their early years children begin to develop strategies to help them deal with the world around them. They may attempt to make dangerous or threatening situations seem safer, so in games about monsters or 'scary' people the 'bad' character is dealt with by removing them, eg shouting 'bang, bang, you're dead.' Few young children will understand the permanence of death and they may believe that being dead means being asleep. They think in literal terms and therefore euphemisms or metaphors such as 'lost' or 'gone away' may be confusing. If children ask questions, they are usually asking in order to gain more facts. It is unusual for a child to ask more than one question at a time. However children may need to ask the same questions over and over again in order to make sense of the situation in different ways.

THE PRIMARY YEARS

*understanding of
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By the time most children are seven years old they begin to understand death as having a cause, as being permanent and as being something that can happen to anyone, including themselves. Therefore they may show signs of fear, although some children as young as seven may demonstrate a denial of their feelings and appear to be unaffected by a sad event. Generally, children will expect adults to show sadness at what has happened. Where families are members of faith communities, children's understanding of what happens after death will reflect the teachings and beliefs of the community. For example, Nicola aged nine belonged to a Christian family. When her brother died she told her granny, 'Don't be sad granny, Sam has gone to heaven. It's a lovely place.'

*it is not unusual
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MIDDLE YEARS

Gradually a young person's understanding of the finality of death becomes more mature, although in the early stages abstract concepts may still not be fully grasped. Young adolescents are more likely to ask questions about funeral arrangements or cremation or burial practices, and they have often formed their own opinions about what happens at death and beyond. It is not unusual for children to 'idealise' the person who has died.

YOUNG ADULTHOOD

Young adulthood involves independence and psychological, physical and social changes. Often the death of a family member may result in feelings of guilt or self-reproach, or the death may even be perceived as a stigma or something to be ashamed of. Many young men have learned that feelings should not be openly expressed and suppression of reactions and denial of death are common. Some will seek out dangerous experiences in order to gain control over death.

*children will
experience grief
reactions*

Grief Responses

One dictionary definition of grief is a 'deep and violent sorrow'. Like adults, children react to the news that someone has died in a variety of ways, but it is important to understand that emotional bereavement in a child is just as painful as it is for an adult. The results may be devastating and last for years because children are less in control of their circumstances.

While it is important to realise that not all children will experience the following grief reactions, the most usual responses are:

- 'searching' for the person who has died;
- crying, yearning or anxiety at being separated from primary carers;
- refusing to go to school;
- role-playing the dead person;
- denial of grief in an attempt to protect adults;
- anger, self-reproach or guilt;
- sadness, anger, withdrawal or depression;
- overeating or loss of appetite;
- psychosomatic symptoms such as tummy ache or headache;
- phobias about hospitals or doctors;
- sleep disorders;
- questioning their own identity;
- inability to concentrate or to study;
- regression in academic performance.

If any of these responses persist over a significant period of time there may be cause for concern and an indication of the need for specialist support. Most children will reach an acceptance of the death of a person and learn to live with the loss providing

they are given:

- information
- reassurance
- opportunities to express their feelings.

*often children
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In order for older children to understand the significance and permanence of death they will need information and opportunities to respond to what they have been told. So often children become 'the forgotten mourners'.

*adults may need to
explain the finality
of death*

If the death has been sudden, children may have limited access to accurate information. They may even have to live apart from their family for a while. Most young people find it helpful when they are given facts in an open and accurate way. In the case of young children, adults may need to explain the finality of death. If insufficient information is given it is likely they may make up their own explanations in an attempt to make sense of what has happened.

Children are very perceptive to the emotional responses of adults. No amount of silence or secrecy can hide the fact that something is wrong. Overheard conversations, glimpses of adults in tears and changed routines can make children fearful. By giving children concrete information, fantasies and confusion can be avoided. Often adults refrain from telling children the truth because the task is such a difficult one.

YOUNG PEOPLE AND BEREAVEMENT

*staff need to be
aware of the impact
on a young person
of the
death of a family
member or friend*

For a child or young person, a bereavement can be an acutely sad and difficult time, to the point of being overwhelming. Young people differ in exactly how and when they respond, and what they need of others as they live through the experience. A school might become the one place in their lives they feel is untouched by the death and they might appear to be 'coping' remarkably well. You might not notice very much difference in performance, attitude or behaviour. For some, the effects may clearly manifest in behavioural and attitudinal changes.

Because each young person will react differently, he or she will need support to be provided in different ways. It is important that school staff are sensitive to the individual needs of children. All staff need to be aware of the impact on a young person of the death of a family member or friend, and confident enough to ensure that the youngster's needs are being met at school. At this time, young people are especially vulnerable and staff may need to contact external organisations for advice and support (such as those given on page 11) or local health, counselling and support services.

Pupils who are already experiencing difficulties, either socially or in learning, are especially vulnerable following bereavement. Teachers should be aware that if the bereavement is through suicide, this presents a particular risk to children. Behaviours which should alert teachers to seek advice are:

- psychosomatic problems
- additional difficulties with schoolwork
- nightmares/sleep problems
- changes in eating patterns
- regression
- suicidal thoughts.

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The Caring Role of the School

Caring for others is emotionally demanding, especially in the emotive environment of loss and grief. We all bring our past experiences (including loss and grief) to the present. They are an intrinsic part of what shapes our humanity. Teachers and other professionals who are not trained counsellors can use counselling skills, and respond to children's needs and concerns as they arise. Fundamental to the relationship is the ability of the adult to use inter-personal skills such as listening, exploring, clarifying and responding. In many ways supporting children involves becoming more aware of the communication skills we use every day in the classroom. This includes not only our verbal language but also our body language. Communication includes understanding children's emotional responses and endeavouring to interpret whatever they are trying to tell us. Good communication involves total involvement with children so that they are in no doubt that we are doing our very best to understand how it might be to be in their shoes.

There are situations where adults will require specialist skills if they are to work effectively with children who are experiencing grief. These skills are not learnt overnight, but are professional capacities gained as the result of lengthy training.

Confidentiality and the Supportive–Carer Relationship

In the supportive–carer relationship between a child and an adult, the adult strives to create a safe environment where the child feels sufficiently comfortable and valued to share his/her experiences and concerns. For this to happen it is essential there is trust and confidentiality, but inevitably there will be times when the capacity of the adult to support the child fully will entail sharing information with other people. Therefore it is very important to agree with the child, at the beginning of the relationship, that some information may be passed on to other people and why this may happen. All schools will have policies that relate to Child Protection and teachers should know how to respond if a child shares personal information or something comes to their attention that may affect the child's short-term or long-term welfare.

What reassurance can we give children?

What reassurance can we give children?

- Tell them you will not reveal information carelessly or unnecessarily.
- Tell children that any information they share will only be discussed with people who need to know and that other people will treat it confidentially.
- Reassure children that their welfare is of prime importance.
- Tell the child that if it is necessary to share information with other people you will ask the child's permission to do this.

Children and their families will need different support during the phases of their grief. There are two main phases:

- phase 1, or the impact phase;
- phase 2, the adjustment phase.

phase 1, the impact phase

The first phase lasts from the death, through the funeral and for a time afterwards. It is important that children and their families are familiar with people who will support them at this time of crisis. In many cases this will include extended family members and people such as GPs. The events surrounding the death will still be very new and everyone will be struggling to come to terms with what has happened. The overriding concern will be to prevent further distress.

phase 2, the adjustment phase

Phase 2, the period of adjustment, comes after the shock of the death, after the funeral is over and the pace of life has returned to 'normal'. This is the moment that many adults and children will begin to experience grief. The role of the supportive-carer at this time will be to:

- establish a relationship with the child;
- support the child through the pain of loss, change and grief and to convey sensitive understanding of the child's needs;
- help the child to identify and express feelings and to be in touch with his or her own emotions;
- provide continuing and reliable support.

having feelings understood can be very affirming

Having feelings understood can be very affirming. In order to be fully in touch with how children express emotions we need to listen very carefully to what they say and how their levels of emotional response are articulated through different words. There will be times when children who are usually verbally articulate will be at a loss for words. This is especially so when they are struggling with painful feelings. Silence may seem prolonged and uncomfortable for the adult, but generally it is not like this for the child. Space for thought may give children an opportunity to reflect on what is happening to them and to communicate this in a different way, for example through their body language.

teachers who are providing support to pupils need to be cared for themselves

Caring for Each Other

Many teachers and professionals suffer from personal stress as a result of a commitment to caring from somebody else. Often this affects the carer's personal life. Support is essential if teachers are to cope with difficulties and minimise professional stress. Indeed, without support their capacities as carers will be diminished and their confidence undermined. Teachers who are providing support to pupils need to be cared for themselves. Such care will involve:

- being aware of how colleagues may respond to stress;
- being willing to offer personal and professional support;
- acknowledging the stress colleagues are under;
- encouraging colleagues to seek specialist professional support if necessary.

in good schools, people have time for each other

In good schools, people have time for each other amidst the hustle and bustle of activity. Teachers are used to creating support networks for their pupils. Nevertheless some people are more comfortable supporting colleagues than others. Sharing responsibilities with colleagues provides an opportunity for continuity of care as well as protection from stress and burn out. Team relationships are important. In many ways they involve the same principles as working with children and their families. However it can be difficult to determine the needs of individuals.

willingness to support families should not undermine our own needs

CARING FOR OURSELVES

The relationship which exists between ourselves and a child or his or her family is often an unbalanced one, where we do most of the giving and the child and the family do a large proportion of the receiving. It is important that we are able to recognise our own emotional depletion. This will include:

- feeling overworked and unable to delegate;
- feeling physically exhausted and ineffective;
- feeling hopeless and helpless;
- low motivation;
- physical illness and vulnerability to infection;
- negative attitudes towards other people;
- gaining little job satisfaction.

Our willingness to support families should not undermine our own needs.

Sources of Support for Bereaved Children

ORGANISATIONS

Cruse Bereavement Care offer free information and advice to anyone affected by death. They have a list of publications for various age groups.

www.crusebereavementcare.org.uk

If I Should Die is a website dedicated to providing as much practical information and support as possible, in one easy place. It is aimed at everyone, whether they are considering their own death, coping with the death of a loved one, thinking about making a will or just needing some comforting words to help write a letter to a bereaved friend or family member.

www.ifishouldie.co.uk

St Christopher's Hospice cares for people with cancer and other serious illnesses. Its catchment area is south east London but its influence, as the founder of the modern hospice movement, circles the globe. It produces some useful resources including *Someone has died suddenly*; *Your parent has died* and *Someone Special has died*. Also runs the **Candle Project**, which not only offers family-based counselling to any bereaved child within the catchment area of St Christopher's, but also offers telephone advice and support to parents and professionals on a national basis.

Contact – Librarian, Halley Stewart Library, St Christopher's Hospice, 51–59 Lawrie Park Road, Sydenham, London SE26 6DZ. Tel: 020 8768 4660

The Child Bereavement Trust provides support, information and training.

www.childbereavment.org.uk

The Child Bereavement Network is a national resource for bereaved children and young people, their families and other care givers.

Tel: 0115 911 8070 or e-mail cbn@ncb.org.uk

Winston's Wish is a charity supporting bereaved children and young people. There is a family line that provides guidance and information for families of bereaved children.

Tel: 0845 20 30 40 5 and www.winstonswish.org.uk

TEACHERS' RESOURCES

Bereaved Children and Teens: A support guide for parents and professionals
A Grollman (Ed.) 1995, Beacon Press

Fourteen different authors contribute their own expertise to this book. The style is straightforward. It is a very useful resource for any parent or teacher at a loss as to how to help a grieving child or teenager. A wide spectrum of issues are covered, including how grief affects young people. Activities are suggested that may help young people gain insight into different faiths, customs and beliefs about death. Very readable.

Caring for Bereaved Children Mary Bending 1993, Cruse Bereavement Care
A short, practical booklet in which ways of explaining death to children of different ages is discussed together with a section on how children think and feel about death. There is a short chapter on violent or unexpected death. The book is an excellent starting point for any parent or teacher. Very easy to read.
Available from: Cruse Bereavement Care, 126 Sheen Road, Richmond, TW9 1UR

Coping with bereavement: A Handbook for Teachers J Holland 1996, Cardiff Academic Press
Covers children's perceptions of death, opportunities for exploring death through the curriculum and how to react to a death within the school community.

Grief in Children: A Handbook for Adults Atle Dyregrov 1990, Jessica Kingsley
A short book which looks at children's understanding of death, and outlines practical ways in which adults can respond. Physical and psychological responses are discussed.

Grief in the Family A cartoon video pack from the Leeds Animation Workshop is available to buy (£40 in 2002) or hire. Tel: 0113 248 4997

It Hurts: A Resource Bank on Loss and Grief 1999, Youth Clubs UK
Includes guidelines on facilitating activities about loss and grief and how bereavement impacts on young people. Brief information about the nature of loss and grief and 11 photocopiable learning activities are included.
Available from: Youth Clubs UK Tel: 020 7242 4045
e-mail: youthclubs.uk@ukonline.co.uk

Loss, Change and Grief: An Educational Perspective Erica Brown 1999, David Fulton Publishers
The author explores many experiences of loss and grief. Different beliefs and practices are discussed so that the reader can gain a better understanding of how children grieve. Suggestions are given for ways in which this topic can be taught within the school curriculum.

Loss, Death and Grief Child Bereavement Trust

An interactive educational pack on loss, death and grief for use at home or in school. Designed to accompany the video *Someone Died – It Happened to Me*. Suitable for primary schools, it contains activities designed to enable children to explore and express their feelings.

Lost for words

A self-contained training programme designed to help professionals and others encountering children who have experienced loss and bereavement.

Available from: Mrs A Moore, City Psychological Services, 2nd floor, Essex House, Manor St, Kingston Upon Hull, HU1 1YD Tel 01482 613390

Someone Died – It Happened to Me Child Bereavement Trust

A video. Children and young people aged 7–18 years talk about their feelings when someone important in their lives dies. This moving video would make a good basis for a class discussion. It is essential that it is viewed by the teacher first.

The Death of a Child, Care for the Child, Support for the Family Erica Brown

This booklet gives ideas and support for training events tailor-made to your school or workplace.

Available from the author Tel: 0121 248 4850 and at erica.brown@acorns.org.uk

The Grieving Teen: A guide for teenagers and their friends Helen Fitzgerald 2000, Simon & Schuster

Using a clear and accessible format, this book guides teenagers through many aspects associated with a death. Although written about and for teenagers, teachers will find it gives them an insight into how young people may react to a family death or the death of a friend. Different types of death, including terminal illness and suicide are covered. The book could be used as a basis for PSHE/PSD lessons.

The Social Curriculum: Death and Bereavement Essex County Council Learning Services

A very readable and informative book, designed to guide schools through the management of bereavement. The book covers how to support a bereaved pupil and how to cope with the death of someone in the school community. Practical help is given and examples of case studies are included. There is also an imaginative section on ideas for exploring death through the curriculum.

Available from: PO Box 47, Chelmsford CM2 6WN Published 1998

When a child in your school is bereaved The Compassionate Friends

A very worthwhile organisation that lends a whole range of books on death and bereavement.

Available by post Tel: 0117 966 5202

Cruse offers various resources including books and publications.

Publication list from Tel: 020 8939 9530

Hitchin Boys School has developed a useful 'contact' system for the support of bereaved pupils, their friends and the adults working with them. They have produced a brief on how this works.

Contact Hitchin Boys' School, Grammar School Walk, Hitchin, Herts SG5 1JB

Tel: 01462 432 181 or Fax 01462 440 172

The National Council for Hospice and Specialist Palliative Care has recently published a document on early bereavement and a teachers' advice pack about supporting bereaved students in primary and secondary schools.

Available from: the National Council on Tel: 020 7520 8299

USEFUL WEBSITES FOR SCHOOLS

Acorns Children's Hospice Trust www.acorns.org.uk

An interactive website providing information about the work of Acorns Children's Hospice. Details of professional development courses for teachers based in schools, tailor-made to match the needs of individual organisations and staff groups.

National Youth Agency www.nya.org.uk

This website has information about 25,000 resources. The site is easy to access and resources may be borrowed from their library. The agency will carry out a topic search for teachers and send a list of the available resources, some of which are appropriate for professionals working with bereaved young people.

Youth Clubs UK www.ukyouth.org

A catalogue of resources written by professionals working with young people. Some of the materials are useful for PSHE/PSD or to introduce a topic on loss, change and grief.

The Child Bereavement Trust www.childbereavement.org.uk

Information with reference to the death of a baby or a family member. Resources and information for bereaved families, children, professionals and volunteers. Information about a small number of professional-development courses for teachers.

Childline www.childline.org.uk

Information on childhood responses to bereavement. Offers the chance for young people to talk about their feelings and emotions to trained bereavement counsellors.

Cruse Bereavement Care Youth Line

www.Cruselochaber.freeuk.com/youth.html

A website for children and bereaved young people. Provides a confidential number for contacting a bereavement counsellor.

Winston's Wish www.winstonswish.org.uk

Offers a grief-support programme for children who have experienced the death of a parent or sibling. Publishes a useful catalogue of resources.

BOOKS FOR 11-14 YEAR OLDS

Ashton, J (1995) *Killing the Demons*, London: Puffin

Samantha survives a road traffic accident in which her brother dies, but she has sustained bad injuries and will be confined to a wheelchair. She does not believe that life will be worth living again, but after she moves to Wales and makes new friends, her quality of life begins to improve.

Duder, T (1990) *Alex*, London: Penguin

Like most teenagers, Alex is sometimes rebellious and difficult to understand. When her boyfriend sustains fatal injuries after being hit by a car which fails to stop, she discovers that managing her own emotions and taking responsibility for them is a very grown up thing to do.

Henkes, K (1995) *Words of Stone*, London: Red Fox

Blaze cannot remember his mother because she died when he was a baby. He grows up with his father and his grandmother and has always been frightened of confronting or expressing his feelings. Joselle is a special friend who helps him to reflect on who he really is and to accept his emotions.

Hill, D (1995) *See ya Simon*, London: Puffin

Simon is life-limited because he is coping with the advanced stages of muscular dystrophy. His friend, Nathan, is determined he will make the very best of the life which he has left. The two lads come to value the meaning of loyalty and friendship.

Hughes, B (1992) *Then and Now*, Birmingham: Women's Press.

Soon after Felicity's father dies in the Falklands war, her mother remarries. The story tells of the love of a young daughter for her dead father and the conflicting emotions, which she feels when her mother becomes pregnant. An excellent, moving story.

Mahy, M (1995) *Memory*, London: Puffin

A powerful tale about Jonny whose sister dies and how he sets out to find her best friend.

Nystrom, C (1996) *Emma says Goodbye*, Oxford: Lion

Gill's family are Christian. When her aunt who has terminal cancer comes to live in her home, Gill finds she is angry with God and confused about things like death and suffering. An excellent story with a real-life storyline.

Section 2

Strachan, I (1994) *The Boy in the Bubble*, London: Mammoth

Adam has severe combined immuno deficiency and because he is at risk of infection he lives his life in a sterile bubble. A powerful novel with a sensitive but realistic message about the person he misses so much.

Faith and Cultural Aspects of Bereavement

a need to make sense of life by plotting our mark on a spiritual and cultural map

Part of what makes us human is a need to make sense of life by plotting our mark on a spiritual and cultural map. Indeed our hopes and dreams may be shaped by where we perceive ourselves to be on such a map. The way in which society responds to individual people reflects not only its qualities of compassion and caring but also its sense of justice and its commitment to enhancing the quality of human experience.

Until children have their fears and hopes affirmed, their holistic needs are not met. To be cut off from hope is to feel abandoned. Although a child's trust in the predictability and certainty of life may have been shattered most children seek for purpose and value in the midst of uncertainty.

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For children from minority ethnic families, it is tremendously important to match the care given by the teacher/school to individual needs because being 'different' has often been associated with being deficient. Often children grapple with their anxiety alone because they are fearful the trauma they are feeling will be brushed aside.

In order to support a planned and coherent approach to children's holistic care, all members of a school need to have a shared understanding of the values that the school is promoting. The process by which this understanding develops will be informed by statutory requirements and documentary guidance. However the concerns and interests of children and their families also need to be taken into account.

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Individual families will have needs that are specific to them. Some will have never experienced the distress of bereavement before. Most will have some hopes and expectations of the people who care for them. Although these expectations vary for each family, they may include hoping that:

- carers will be available and accessible;
- support will be matched to each individual family member;
- professionals will support and empower them in the face of adversity, rather than diminishing their confidence;
- care will be reliable, consistent and honest;
- professionals will give them sufficient time to absorb what has happened to them;
- professionals will support their needs to do things their way;
- professionals will help them to fulfil their own expectations of recovery from the bereavement.

Ethnicity, Culture and Religion

The Commission for Racial Equality uses the term 'ethnic minorities', believing that cultural and religious differences are important. Thus there is a tendency to use the notion of 'ethnicity' rather than race, so implying shared or common features such as language, religion and origin. Ethnicity includes culture.

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Where carers know very little about other people's sensitivities and values, the quality of experience offered may be impoverished and lead to individuals feeling marginalised and insignificant. There are important and distinct differences in culture between people from different communities. There are also many religious groups that will have their own philosophical and social systems. Each situation is unique and will require creative and flexible responses. When people are members of faith communities there may be some specific requirements carers need to know about and some of the key issues are given below.

for many people, religious observance is expressed through everyday practices

There is great diversity of religious belief and cultural practice amongst different communities. Some people are extremely devout and find a focus of their lives in religion; others have discarded most external signs of religious practice but still have a strong faith; some have no faith but keep the values of religious traditions in which they were brought up. For many people, religious observance is expressed through everyday practices such as ablutions, style of dress or dietary adherence. There are many examples that illustrate how faith can offer children solace and hope in the future.

Death and Dying in World Religions

Death arouses great curiosity. Questions about the meaning and purpose of life are accompanied by questions of what happens next. Religions seek to give answers. All major world religions teach there is some kind of continuity or survival after death. They also reassure mourners by helping to make sense of death and provide shape and meaning to the process of grieving. Children reflect their cultural and ethnic backgrounds in their understanding of death, their age is not necessarily an accurate predictor of how much they know or believe.

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No tradition should be reduced to a few sentences and essentially it is impossible for non-believers to fully understand another person's faith. Professionals must be prepared to live with the discomfort of feeling de-skilled and inadequate and to learn to let families show them the way that is best for them. There is value however in having an insight into some of the beliefs and rituals associated with death and dying.

THE BUDDHIST COMMUNITY

There are three main schools of Buddhism, each strand demonstrating diversity of practice. Followers strive to walk in the path of the Buddha, following his example. Through Buddhism people attempt to achieve liberation from the cycle of re-birth in which all living things are caught.

Buddhism teaches that nothing is permanent and that suffering and unhappiness are to be expected in earthly life. Buddhists would hope to face adversity with an attitude of quiet and calm acceptance. Therefore anything that encourages them towards this is likely to be appreciated.

THE CHRISTIAN COMMUNITY

Three main movements are embraced by the Christian tradition, namely the Orthodox Church; the Catholic Church and the Protestant Church. There is enormous diversity of practice within these churches but at the heart of Christianity is the figure of Jesus as a model for human living.

Faced with adversity Christians often find compelling support in the hope of salvation and of life to come. In many Christian communities ordained persons minister to faith members, and at times of tragedy and grief they would strive to support families in the context of the fellowship of the church, providing comfort and solace.

THE HINDU COMMUNITY

Hinduism demonstrates diversity in devotion, sacred writing and practice. Deities that are manifestations of one reality, Brahman, the Supreme Being whose existence is innate in all living things, permeate the faith. Life is a continuing flux of birth and re-birth bound by belief that conduct in this life determines the condition of the next life. Liberation from the cycle of birth and re-birth can only be achieved through endeavour.

Belief in re-birth is based upon the conviction that the soul is immortal and indestructible. In the days following a death the whole family will mourn for a period of between 11 and 13 days and they will rely on support from their religious community.

THE JEWISH COMMUNITY

Judaism in the United Kingdom is divided mainly into Orthodox, Progressive, Reform and Liberal. There are also many Jews who are not affiliated to any of these traditions.

Hope of life after death has been a conviction of Jewish people since biblical days. Indeed the concept of after-life is fundamental to Judaism. Rabbi Maurice Lamm writes: 'There is little meaning to life, to God, to man's constant strivings, to all of his achievements, unless there is a world beyond the grave.'

Judaism teaches that although a person may have died, because they are created in the image of God, their body is respected. This respect is shown in death rituals and the way in which Jewish communities provide comfort and practical support to bereaved families.

THE MUSLIM COMMUNITY

Islam was revealed to the prophet Muhammad. There are many cultural variations within Islam. However in general terms, Islam is a way of life and a person who submits to Allah the Creator, can achieve peace of body and of mind. Islam teaches that Allah created life and that humankind is the highest form of creation.

Although people have free will, when they die, their earthly deeds are accountable before Allah on the Day of Judgement. On this day a person is either rewarded and enters a stage of blessing or heaven, or they are punished by a stage of punishment or hell. Faced with adversity many Muslims express solidarity within the community, and friends and relations play an important part in supporting families.

THE SIKH COMMUNITY

In Sikhism, references to death are often associated with birth and the words Janam (birth) and Moran (death) generally occur together. According to Sikh belief humankind is not born sinful but in the grace of God, which gives the soul the opportunity to become 'God in Flesh'. A person is not born free. They become free through breaking the cycle of life in order for their soul to rise to communion with God. Thus, life is mortal, but the spirit is immortal. Sikhism teaches that the Day of Judgement will come to everyone immediately after death. It also teaches that heaven and hell are not locations but are symbolically represented by joy or sorrow, bliss and agony, light and darkness. Hell is seen as a corrective experience in which people suffer in continuous cycles of birth and death.

The burden may only be thrown off by living a perfect life. In Sikhism there are two distinct doctrines about re-birth. Firstly, when the soul passes from one life to another in spiritual progress, Nirvana (or perfection). This is eventually achieved through reincarnation. Secondly, re-birth in animal life is punishment. In striving for Nirvana it is believed that the soul of the Sikh passes through a number of stages and moral conditions. For about ten days after a funeral, relatives will gather, either at home or at the Gurdwara or temple, for the completion of the reading of the holy book, the Guru Granth Sahib.

CHINESE RELIGIONS

Chinese religions embrace Buddhism, Confucianism and Taoism and so it is difficult to be definitive about Chinese belief and practice. However, many of the practices associated with death and mourning rites are not dissimilar for those within mainstream Buddhism.