

Culture, Faith and Spiritual Care

For children and young people
with learning disabilities



Introduction

Life threatening illness potentially plunges children and young people with learning disabilities into a confusing and previously unknown world, where people speak in medical jargon and they may be subjected to painful treatment and uncertainty. Normal routines are shattered and relationships are turned upside-down. However, under the watchfulness of people who care, it is possible for them to adjust to what is happening and to maintain a sense of hope, not only for themselves, but for those who love and care for them.

Ethnicity and Culture

Many people have multiple ethnic and cultural identities, possessing mixed heritage, with parents, grandparents and great grandparents from different groups or communities. Ethnicity and culture profoundly affect the way in which the life-limited child and their family adjust and cope. There are numerous definitions of culture. In general, they tend to place emphasis on culture as a shared system of meaning, which derives from 'common rituals, values, rules and laws'. A helpful working definition might be how people do and view things within the groups to which they belong.

Culture also includes shared values, expectations, perceptions and lifestyles based on common life experience and language, which enable people to function together.



For many children and young people, it is important for them that they are able to maintain their cultural values and practices, but cultures are not fixed and static. They change in response to new situations and pressures. Some aspects of culture are visible and obvious. These include dress, written and spoken language, rites of passage, architecture and art. The less obvious aspects of culture consist of the shared norms and values of a group, community or society.

Grief is experienced in similar ways across all cultures but, within cultures, there is a huge range of individual responses. Furthermore, micro-cultures exist within cultures, with individual differences.

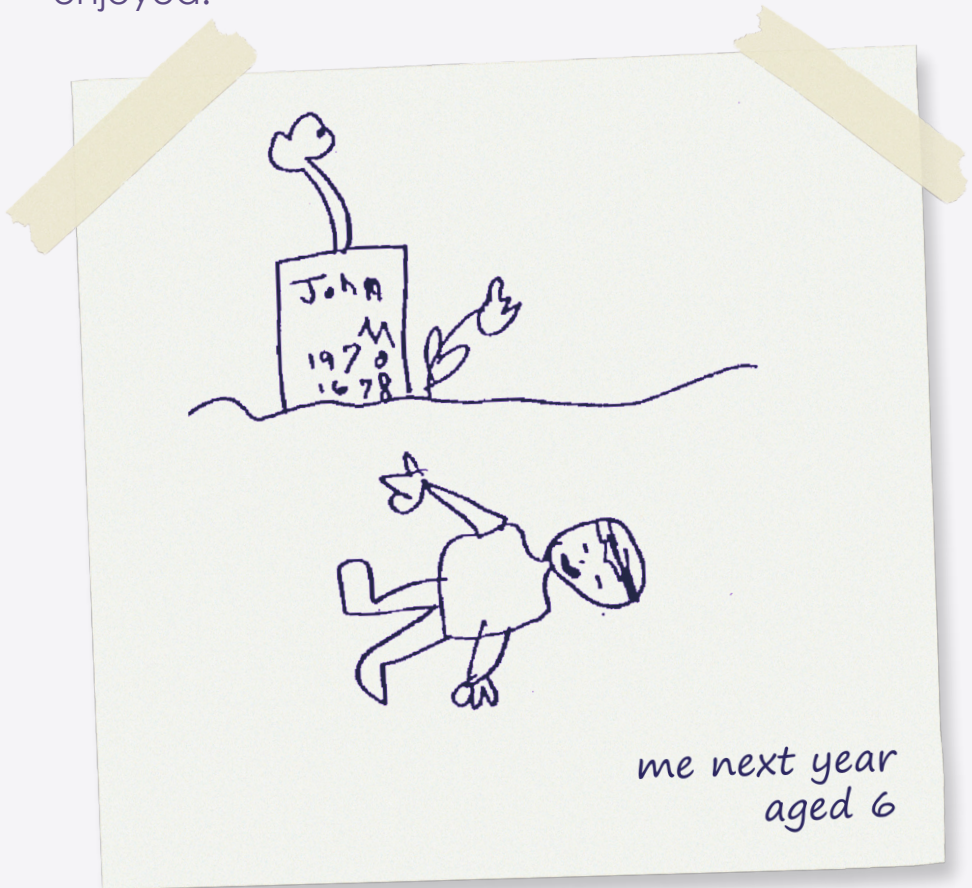
Religion

Sometimes people turn to religion for an explanation of personal tragedy. Most major faiths teach that physical death is not the end. However, the precise form that the continued existence takes, varies within different religions and, sometimes, within different denominations.

A child or young person's age, cognitive ability, anxiety level and home background, will all influence their understanding of what happens at the time of death and beyond. Each family is unique, and the culture or faith in which children are brought up, and the way in which they are taught at home and at school, will influence the way in which they perceive death. Therefore, it is vitally important that children and young people with life-limiting conditions are given age and developmentally appropriate opportunities to share and explore their fears and concerns. Professionals also need to be sensitive to the fact that talking about religion may be unhelpful because, for some people a secular lifestyle (one that does not accept the existence of god(s) or an afterlife), makes the most sense.

When people are ill or vulnerable, they need care that is focused on their needs and what is important to them. Professionals require skills, information and confidence to find out what each

family wants, and organisational structures that are sufficiently flexible to enable them to provide it. Practices, beliefs and attitudes are continually emerging. Professional awareness of the range of such patterns can be a vital starting point in addressing the needs of families from ethnic minorities. Families will seldom mind if carers ask about their customs and beliefs, as long as the subject is approached in a respectful and polite way. Indeed, interest may well be welcomed and enjoyed.



Spirituality

The terms spirituality and religion are often used interchangeably, but they have different meanings. Religion is generally interpreted as a set of beliefs and practices whereas spirituality is more to do with a person's sense of self, purpose, connection with others and quality of life.

Sometimes spirituality is expressed through religion but this is not always the case. Some people may describe themselves as both spiritual and religious. Others may consider themselves spiritual but not religious and others religious but not spiritual. Just as the circles on a tree trunk make up the story of the tree's life, so all that has happened in a child's/young person's life is never discarded – it is incorporated into the 'wholeness' of the child or young person.

Spiritual care has come to be regarded as an essential part of palliative care. Spiritual dimensions of care are notoriously difficult to define. One interpretation is that the spiritual dimension is located within the non-physical aspects of a person's body or a life-force. For other people spiritual meaning is located within loving relationships.

In palliative care settings spiritual care includes holistic care or 'whole person care' and addresses the quality of care given whilst engaging with some of the big questions such as 'Why is this happening to me?'

Spiritual care includes: helping families and their life-limited child/young person to trust and to maintain hope, supporting the child/young person and their family and 'journeying' with them, building and sustaining good memories, taking time to listen and show an interest, attending to physical needs and understanding that for those people who have faith that this may provide a source of hope.

It includes addressing the child or young person's quest for **meaning, purpose** and **relationships**.

Exploring meaning and purpose:

- Knowing what gives a child/young person meaning in their daily routine.
- What gives the child/young person a sense of well-being.
- Knowing what helps the child/young person adjust to uncertainty and physical discomfort.
- Knowing what helps the child/young person to re-build their resilience.

Relationships:

- Knowing what a child/young person values most about their family.
- Knowing who supports the child/young person outside their immediate family.
- Knowing whether the child/young person has a religious belief and if so, how the belief is expressed through rituals such as prayer or meditation.
- Knowing if the child/young person considers anyone to be their religious leader.

Each person will have spiritual needs which include:

- being respected for who we are
- receiving solace and comfort
- experiencing fun and laughter
- experiencing well-being
- friendships
- belonging
- choices
- being accepted
- time to be ourselves



Spiritual distress may be experienced by a child or young person or their family in their attempt to make sense of what is happening to them.



There may be fear of:

- loneliness
- misunderstanding
- things that don't make sense
- not mattering because you are you
- being marginalised and left out
- being different
- experiencing illness and pain
- uncertainty

For spiritual care to be effective carers need to identify a child or young person's needs so that support is guided by the recipient and not defined by the carer.

Defining a person's spiritual needs is challenging, and matching care to the unique needs of a life-limited child or young person can seem a daunting task. Many children and young people with learning disabilities are at the early stages of cognitive development.

It is important to provide age-appropriate and developmentally-appropriate care.

Providing age-appropriate and developmentally-appropriate care

Infant and early cognitive development needs:

- help coping with pain
- frequent physical contact (or touching) from primary carers
- frequent contact with the voices of primary carers
- normal routines as far as possible
- opportunities to play and to interact with family members

Developmental age 3-5 years:

- reassurance that any separation from primary carers is unavoidable
- reassurance that the illness is not a form of punishment
- open communication in easily understood language

- explanations about medical procedures
- constant reassurance about love and care from their family
- access to communication which will help indicate levels of pain or distress
- routines which are as normal as possible
- opportunities to interact with peers and family members where possible
- opportunities to communicate fears and concerns

Developmental age 5 - 7 years:

- open and honest communication about the nature of the illness
- opportunities to communicate preferences, needs, fears and concerns
- maintenance of familiar routines as far as possible
- constant reassurance of the love and care of family members, peers and friends
- access to communication which will help them articulate levels of pain or anxiety
- access to educational activities and hobbies
- liaison with school

Developmental age 7 - 9 years:

- open and honest communication about the nature and inevitable outcome of their illness
- opportunities to express their own opinions, wishes, anxieties

- constant reassurance of the love and care of key people in their lives
- freedom to make decisions about their own pain control and care
- opportunities to express their awareness of how family members are responding
- maintenance of familiar cultural or religious traditions

Adolescence/young adulthood:

- opportunities to express fears and concerns for self and family members
- privacy, especially when undergoing personal care
- opportunities to maintain autonomy and independence for as long as possible
- support from peer groups as well as family members
- involvement in decisions regarding their care
- maintenance of familiar cultural and religious traditions

An understanding of the cultural, faith and spiritual dimensions of care for children and young people with a learning disability will help professionals to provide meaningful holistic palliative and end of life care.

Artwork kindly provided by Erica Brown, Acorn's Children's Hospice and Donna Louise Children's Hospice Trust, Trentham.

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