

Spirituality in Advance Care Planning - Helpsheet

'Spirituality is the dynamic dimension of human life that encompasses how individuals and communities experience, express, or seek meaning, purpose, and transcendence, and how they connect to various aspects like the present moment, themselves, others, nature, and the significant or sacred!'

European Association for Palliative Care

1. What is spirituality?

Spirituality encompasses multiple areas:

- Beliefs about life and death
- A search for meaning and purpose
- Faith, hope, or dreams for the future
- Cultural or religious rituals

Spirituality does not equal religion, although the two are closely linked. Religion provides a structured system of beliefs, often involving a set of rules, rituals and scriptures. Spirituality is a more individual search for meaning and connection, and you can be spiritual without being religious. Both provide a context in which people can “make sense of their lives, cope with their experiences and maintain a sense of [...] peacefulness in the midst of existential challenges of life” (Carroll).

When facing a life-limiting condition, many young people and their families search for meaning and purpose. Their views on spirituality may change as they approach the end of life.

Spiritual suffering occurs when people question their beliefs which can cause significant distress to young people and their families. It can manifest as hopelessness, grief, anxiety, and concern for the loved ones they will leave behind. Conversely, spiritual wellbeing is often described as feeling at peace.

2. Key considerations

Spirituality is incredibly personal to an individual, their family, and their wider cultural community. Every family will have their own unique culture and, even within a specific religion, practices can vary. Care should be individualised, with no assumptions made.

Discussions should start early, and you should listen carefully and record what is most important to a young person and their family. Information should be gathered in the family’s own language wherever possible. Responding to spiritual needs is everyone’s responsibility.

You may have access to a chaplaincy team or a spiritual support worker. They will have a wealth of experience and can be contacted for advice.

3. Starting the conversation

Professionals often find spirituality hard to discuss, but it is a key component of providing high-quality palliative care. The "Hope Assessment Tool" can provide structure to your discussions and spark a conversation.

Hope

- What are your sources of hope, strength, comfort and peace?

Organised Religion

- Do you have a religion or faith?
- How important is your religion or faith to you?

Personal spirituality and practices

- What do you do that gives you meaning and purpose?
- In what ways does this add to your sense of identity?
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Effects on medical care and end of life issues

- Has being unwell stopped you doing things that give your life meaning and purpose?
- Are there any specific practices we should know about in providing your care?

Religion is one way of expressing our spirituality, here is further information regarding specific religions that you may encounter.

Buddhism

Buddhism is an Indian religion and philosophical tradition based on teachings attributed to the Buddha, a wandering teacher. Buddhists believe that after beings die, they are reincarnated into a new form.

Buddhists believe that it is important to die consciously with a clear mind. They may wish to avoid sedating medication and pain management should be approached sensitively.

Mantras are recited at the time of death. Meditation, breathing exercises and study of scripture may also be important.

The body is normally cremated following death. There are unlikely to be religious objections to post-mortem or organ donation.



Christianity

Christianity is focussed on the life and teachings of Jesus Christ, who Christians believe to be the son of God. There are many different denominations within the religion, with different traditions and methods of worship. Christians believe they will be given eternal life in Heaven.



Prayers may be said at the bedside of the dying. Certain denominations may request holy communion or baptism prior to death.

The body may be buried or cremated following death, and funeral practices vary between denominations. There are unlikely to be religious objections to post-mortem or organ donation.

Hinduism

Hinduism is made up of a variety of different religious beliefs and practices. Central to Hinduism is the belief in a supreme God Brahman. Hindus believe death is not only the end of the physical body, but the natural progression of the soul to the next state of existence.



Hindus believe in karma - the belief that good and bad occurrences in one's life are a result of past actions - and may feel that if you circumvent karma by taking action to stop suffering, you will pay for it later. This should be approached sensitively by professionals. Hindus also may not openly discuss issues regarding urinary or bowel needs.

Hindus believe that the state of mind at death significantly influences rebirth. Hindu scriptures describe hearing as the last sense to be active before death, and there may be recitation of the names of God or chanting of mantras. At the time of death, families may want an atmosphere to remind them of their relationship with God, this may include religious deities or prayer beads.

Following death, the body should have the eyes closed, limbs straightened, jewellery removed and be wrapped in a plain sheet. Cremations are the norm, but burials may be preferred for young children. This should happen as soon as possible, and professionals should consider this prior to an expected death. There are unlikely to be religious objections to post-mortem or organ donation.

Islam

Muslims believe there is one true God, Allah, and follow the revelations of God's last prophet, Muhammad. Death is the departure of the soul to enter a state of waiting, called Barzakh, until the Day of Resurrection.

In the last moments of life, the family will often recite verses from the Quran and pray for peaceful departure of the soul. Islamic teaching encourages Muslims to visit the sick and professionals should be as accommodating as possible to large groups of visitors.

Following death, the body should be positioned towards Mecca, with eyes and mouth closed and limbs straightened.

There is a religious requirement for a quick burial and professionals should consider this prior to an expected death. In Islam the body should be buried whole and unharmed, and post-mortems are acceptable only if the law requires it. Organ donation is permitted



Judaism

Jews believe that there is only one God and following a covenantal relationship between God and the Jewish people. There are several key denominations, including orthodox, conservative and reformed. Jews believe that the soul lives on following death and is a part of God's plan.

Judaism greatly values life and some orthodox Jews may feel the directive to preserve life outweighs the alleviation of suffering. In the days leading up to death, the young person should not be left alone. The family will often recite verses from Psalms.

Following death, the body should be washed, covered in a white sheet and the eyes closed. The Jewish Burial Society, the Chevre Kadish, can support in preparing the body.

Burial should happen as quickly as possible following death, ideally within 24 hours, and professionals should consider this prior to an expected death. Post-mortems are acceptable only if the law requires it. The religious principle of pikuach nefesh, saving life, means that Jewish people are permitted to donate their organs after death.



Sikhism

Sikhs believe in one God who guides and protects them. In Sikhism, everyone is equal before God and your actions are important. They believe that death is a natural part of life, and the soul is reborn into a new body.

Close to death, family will gather to recite Sri Guru Granth Sahib. This helps fix the mind on God and leave this world detached from worldly matters. Some may bring holy water (Amrit) and blessed food (Prashad) with them to comfort their loved one.

At the time of death, Sikhs may repeat the word "Waheguru" meaning "wonderful lord". Religious items, including the kanga (wooden comb), kaach (undershorts) and kara (iron bracelet) should be left on the body.

The body is normally cremated following death, as soon as possible, and professionals should consider this prior to an expected death. There are unlikely to be religious objections to post-mortem or organ donation.

One final thought

'As people we seek to find connection and discover meaning, purpose and hope in our life experience. We often search for our own truth about what gives our life most value and what matters to us. This is often referred to as spirituality. This search can inform the whole of our lives, influencing personal values and beliefs.'

(Golden Jubilee NHS Spiritual Care Strategy, 2023)



Useful resources

European Association of Palliative Care – Spiritual Care (Available:
<https://eapcnet.eu/eapc-groups/reference/spiritual-care/>)

NHS Golden Jubilee Spiritual Care Strategy 2023-2026

Paediatric End of Life Care Network (PELiCaN), NHS Scotland, Spiritual Care Leaflet, including HOPE assessment tool (Available:
<https://www.nn.nhs.scot/pelican/wp-content/uploads/sites/6/2021/05/NSD610-002.03-Spiritual-Care.pdf>)

Public Health England - Faith at the end of life, 2016 (Available:
https://assets.publishing.service.gov.uk/media/5a809fe1e5274a2e8ab5136c/Faith_at_end_of_life_-_a_resource.pdf)

Symptom Management of Spiritual Suffering in Paediatric Palliative Care, Foster et al, Journal of Hospice and Palliative Nursing, 14(2):p 109-115, March/April 2012

The SPARK Project – Supporting the complete care of children, young people and families

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