



Paediatric End of Life Care Network (PELiCaN)

Spiritual Care

NOTE

This guideline is not intended to be construed or to serve as a standard of care. Standards of care are determined based on all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at following discussion of the options with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be fully documented in the patient's case notes at the time the relevant decision is taken.

Spiritual care for children and families

Spiritual care is an important part of overall care for children, young people, and their families.

Chaplains are trained specialists in spiritual care. However, all staff aim to support your spiritual needs as part of your care.

What chaplains can offer

Chaplains work in NHS hospitals and in organisations such as CHAS. They can provide:

- A safe, confidential place to talk
- Someone who will listen without judgement
- Companionship during difficult times
- Prayer or reflection if this is important to you
- Support to contact faith or community groups
- Help with planning funerals
- Support with grief and bereavement

You can ask to see a chaplain at any time.

What is spirituality?

Spirituality means different things to different people.

For some people, it includes religion or faith. For others, it may be about:

- What gives life meaning
- What gives comfort or hope
- Relationships with family and friends
- A sense of peace or connection

Everyone has spiritual needs at different times in their life, whether they follow a religion or not.

Why spiritual care matters

When a child has a serious or life-limiting illness, families may start to think about:

- The meaning of life
- Loss and grief
- What matters most

Spiritual care in children's palliative care is about supporting you through this time. It includes:

- Taking time to listen
- Supporting what is important to you
- Helping you find hope in ways that feel right for you

You do not need to have all the answers. Support is available to help you explore your thoughts and feelings.

Changes in spiritual needs

As your child becomes more unwell, your beliefs, values or spiritual practices may change.

You may:

- Find religion or spiritual practices more important
- Want time to reflect on your life and your child's life
- Have new questions or concerns

This is normal, and you can talk about this with staff or a chaplain.

Spiritual wellbeing and distress

Spiritual wellbeing is often described as feeling at peace.

Sometimes people experience **spiritual distress**. This can happen if it is difficult to find meaning, hope, or comfort.

Spiritual distress can affect emotional and physical wellbeing.

Children, young people, and their families may all experience this.

Signs of spiritual distress

You or your child may be experiencing spiritual distress if you notice:

- Asking questions such as "Why is this happening?" or "Why me?"
- Feeling alone, withdrawn, or isolated
- Being afraid of being alone
- Feeling scared, anxious, or worried
- Not wanting help or care

If you notice any of these signs, please speak to a member of staff. They can arrange support for you.

Getting support

You do not need to cope alone.

- Speak to any member of your healthcare team
- Ask to see a chaplain
- Tell us what matters to you

We are here to support you and your family.

The following is the Hope Assessment Tool for Professionals.

Some professionals find it hard to discuss spirituality due to lack of training, not knowing what to say or being concerned about saying something inappropriate.

The HOPE assessment tool is a good conversation starter:

Hope

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

Organised religion

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

Personal spirituality and practices

- What do you do that gives you a sense of meaning and purpose in life?
- In what ways does this add to your sense of identity?

Effects on medical care and 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 for your care?

This document has been developed by Rev Amanda Reid, Chaplain, Children's Hospices Across Scotland (CHAS), using adaptations from The Hope Assessment Tool for Professionals, developed at Brown University, Rhode Island, USA. Thank you for your assistance in the development of this guidance.

The PELiCaN Service Development Group have endeavoured to create as complete a document as possible, however, if you have any constructive feedback or comments on this document this would be greatly appreciated. You can do this by emailing the team on nss.pelican@nhs.scot or by completing the following feedback form. NB- these documents will be subject to NSS document governance and will be subject to regular review.