

Spiritual, Religious and Cultural Wishes

Finding out that your child may not live the life you had planned for them, and especially that they may die before they reach adulthood, is devastating and life changing. It can make you question everything you thought you believed, and leave you wondering, “why me?”

This factsheet explains how spirituality, religion and cultural backgrounds can play a big part in shaping families’ wishes, and aims to help give you the confidence to ask professionals to care for your child in accordance with your values or beliefs, whatever they may be.

Is it possible to be spiritual without being religious?

Learning that your child is very ill is distressing, and it is often a deeply spiritual time, no matter whether or not you are a religious person.

Spirituality refers to what it is to be human – to the things that give life meaning and value, and as such is a deeply personal and subjective thing. It can involve questions and concerns about life, meaning, morals and values, and can encompass our relationship with ourselves, other people, the world around us, and sometimes but by no means always, a god or deity.

Spirituality is an integral part of any religion, but it can also be a meaningful part of a person’s life if they do not belong to a religion or have faith in a god.

Spirituality is a deeply personal part of a person’s life and is entirely unique to each individual.

How can I be sure my religious preferences will be respected?

If you are a member of a religious faith, there are often specific rituals surrounding end of life and what happens after a death.

Even if you are not a practicing or devout member of a faith, you still may feel these rituals are important for you and your family. People often draw much comfort from rituals, as well as readings from religious texts, or having various religious items such as holy books, prayer beads or icons with your child during their final days or hours.

If it is something you want, you should feel confident to ask a religious leader to come visit you in your home, or at the hospital or hospice where your child is being cared for, to talk to you about any questions you might have, to guide you in your decisions, or just to comfort you or lead you in prayer or meditation.

How can I be sure my cultural preferences will be respected?

Different cultures often have specific attitudes towards illness and death, and may have different practices according to the age or sex of the person being cared for. This cultural diversity leads to many varying beliefs about medical treatment, and the sort of care a child should receive.

Professionals will often be aware of different cultural attitudes, and should be able to help accommodate your wishes. Sometimes, however, professionals may not know about certain cultural practices, but they should be open to learning about your culture and how this has an impact on the way you would like your child to be cared for. Make sure you talk to someone in your child's care team to help them understand your culture, and exactly what you would like to happen.

If English is not your first language, and you need support to help you articulate your cultural values or to help clarify your wishes, an interpreter should be made available to you if you ask a member of your child's care team.

You could also ask a community leader to come talk to the professionals looking after your child, to help explain your cultural background and how this affects your wishes for your child's care.

Will my wishes for my child's care be fulfilled?

Every family is unique in their spirituality, religion, culture, beliefs and values. Whatever your wishes for your child's care, these should be respected by the team supporting you and your child, and they should all work to accommodate your wishes as closely as possible.

Professionals should not assume anything. Just because you belong to a particular religion or culture, they should understand that each individual will have different values and beliefs and will interpret their own spirituality differently.

If you are not a practicing member of a faith community, professionals should not assume that you do not want to perform any rituals, say any prayers, or speak to a religious leader.

Spirituality, religion and culture are very intertwined and very fluid in today's society. Many families are multi-cultural and/or multi-faith, and many families may have moved to the UK midway through life which means they hold or respect the values of two cultures and societies. Some, although they may belong to a non-Christian religion, may still see some value in 'British' rituals or practices which are based historically in Christian values – so may draw upon two religious backgrounds when deciding what they want to happen.

Whatever your wishes, whether they reflect the typical values of one faith, of two or more faiths or cultures, or of none at all – you are entitled to your beliefs, and should feel comfortable articulating those beliefs and values to anyone working with your child. All professionals should be

able to assist you in meeting your wishes as closely as possible.

What support is there for me?

Throughout your child's illness, end of life stage, and after their death, you will no doubt want to talk to someone about how you feel.

It's a good idea to talk to family members and friends about what you are going through, but sometimes you might feel like they just don't "get it", as they have not experienced the same as you. You may also want to talk to someone who is emotionally detached from the situation, and who you can be confident won't judge you.

A spiritual care team or chaplaincy service should be available at most hospitals and hospices, and should also be able to help you link with local services if you are caring for your child at home.

What is a spiritual care team or chaplaincy service?

These professionals are specially trained to talk to you about emotional and personal issues, and can help you to try and make sense of what is happening through a spiritual or religious context, regardless of your faith.

They will help you to explore your feelings, attitudes and beliefs and discuss with you any questions or concerns you might have. At all times, any conversation you have with a member of the spiritual care team or chaplaincy service will be completely confidential, and you should feel confident that they will not judge you.

The spiritual care team or chaplain can be called upon at any time throughout your

child's care. Depending on the hospital or hospice you are using, they may require you to make an appointment, but often, they are available 24/7 upon request. Many services have these professionals available on an on-call basis in case of emergencies.

As well as being there to talk, spiritual care and chaplaincy professionals can help organise religious services, especially in situations when there has been little to time to plan or contact your usual religious leader.

Hospitals and hospices usually have a quiet room or multi-faith prayer room where you can go at any time during the day or night to pray, meditate, or just have some quiet time to reflect.

Some hospitals and hospices keep religious artefacts, symbols or sacred books for families to use, so if you are not very religious or do not have the objects yourself, you can access them at times of need. This service is not available in all areas, and may not extend to all religions, especially those less common in the UK.

If a chaplain or member of the spiritual care team is associated with one faith, it doesn't mean they won't be able to help you if you belong to another religious community, or have no faith. Often they can help by talking with you more generally about how you are feeling and what it all means. In many cases, spiritual care professionals have a great deal of knowledge about many faiths, and contacts within the religious community as a whole, and can call upon members of other faiths when required.

Just because a chaplain or member of the spiritual care team is affiliated with or representative of a certain religion, this

does not mean they will not be able to meet your individual needs. They will be happy to talk to anyone, including those of no faith or spiritual inclination, and it is not their role to “convert” you to their religion. If you are non-religious, you can still talk to your chaplain about spiritual concerns, emotional well-being and the big questions without being concerned that they will want to discuss religion.

What if I don't understand something?

If English is not your first language, it might be hard to tell the care team about what you want for your child. You might find it difficult to understand what your doctor or nurse is telling you about your child's illness. It is your right to ask for an interpreter to help you.

Even if English is your first language, you may not always understand all the medical terms and jargon professionals use. It is important that you understand

everything they are saying, and the implications and risks associated with any treatment that is being planned for your child. If you are unsure about any terms, ask questions and make sure you ask your doctor to explain the terms in a way that you can understand. You can also ask them to write down what they have said, so you can reflect upon it later.

If you find it difficult to understand written or verbal information about your child's condition or their care, make sure you ask for this information in a way that is clear to you. If you have a visual or hearing impairment you can ask for a signer, or for information to be provided to you in Braille. The team will not want to administer any treatment to your child, unless they know you are absolutely clear about what will happen, and are happy to go ahead.

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Together for Families Helpline
7am-Midnight, 7 days a week

0808 8088 100

info@togetherforshortlives.org.uk

www.togetherforshortlives.org.uk

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