

Exploring and Supporting Spirituality in a Child with a Serious Medical Condition: A Guide for Caregivers

Written in collaboration with chaplain and researcher Amanda Borchik, MDiv, BCC



Learning Objectives

After reviewing this Guide you will be able to:

- Appreciate the central themes of child spirituality
- Help your child cultivate their unique sense of their self and their world
- Identify and respond to signs of spiritual distress

Introduction

A child's serious illness stirs up many kinds of questions. Some parents find themselves in a crisis of faith, striving to understand why the illness has occurred and how to make things "right." Others find that their faith is strengthened; they may even feel that they are being tested and must respond in faith. Some who have never had a faith system seek one; others reject their faith out of fear, anger, despair.

But what about the child? Emerging clinical research reveals that even very young children can express their spirituality.^{1,2} Children who are exposed to religious concepts may use them in their appreciation of the world. But children carry a unique understanding of spirituality, with or without religious background or training, that may exist without or beyond words.³

For the purposes of this Guide, spirituality is defined not as religion or faith, but can be described as the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.⁴ Spirituality may include religion, but it can also be separate from religion. Experts suggest that there are ways to encourage children's ideas about how they connect with the world around them, and that exploring spirituality can help a sick child navigate the illness path.⁵

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Spirituality and Connection

We are all born with the capacity to see and experience the world in a spiritual way. Research with young children has shown their incredible ability to be aware of relationships and connect with people, places, and things that may feel even bigger than life. These connections happen with the child in four main areas³:

- Connection to self: Knowing what about them is unique and special
- Connection to others: Sense of being loved and loving others
- Connection to the world: Being in the natural world outdoors
- Connection to the Divine/Other/God: Awareness of a special, or sacred, quality in certain life experiences

Cultivating Your Child's Uniqueness

Understanding your child's sense of self can present opportunities for meaningful interactions. Many children are able to let us know how they feel and react to what they experience, even if they do not have language.⁶ For example, they may communicate through:

- Sounds, language (verbal, vocal)
- Movement, gestures (tactile, kinesthetic)
- Facial expression
- Drawing, storytelling, etc. (expressive)

How your child uniquely uses these forms of expression is their “spiritual signature,” a portrait of who they are in the world³:

- Preferences: What they like and do not like, how they express their reactions and choices
- Aspirations and dreams: Their world as they wish it to be, what they see as possible
- Curiosity and wonder: The questions they ask and what most catches their attention, what is full of mystery
- Sociability: How they relate to others as they meet, work and play with them
- Persistence: What they commit to and how they pursue it
- Ritual: Their participation in activities that bring joy, comfort, meaning, understanding

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You can nurture your child's spirituality in many ways. You might consider how to include your child (or children) in your own spiritual and/or religious practices. You can also:

- Encourage questions and allow your child to explore possible answers in their own unique and creative ways
- Listen for what is important to the child as they speak and react to different experiences, like a story or an event
- Teach values like kindness and empathy, with examples from your own life and your relationships
- Explore the natural world, where your child can feel a sense of belonging to something greater than self
- Respond to your child's interest in self-expression through movement, sound or other passions
- Use familiar rituals that bring a sense of togetherness and stability, and/or create new ones

Attending to Children's Spiritual Questions and Well-being

Your child may have questions about their illness and what (or who) has caused it. They may wonder about what is to come and may struggle with an uncertain future. Many children with a serious medical condition report feeling isolated by the nature of their illness and the lack of freedom to do as they would like.^{2,5} And most especially, these children (and adults) tend to feel alone with their feelings about their circumstances. Because they are very attuned to their caregivers' feelings, they frequently have an instinct to protect their parents and other loved ones from sadness. Not being able to share with their caregivers can isolate a child even more.⁵

Children with serious illness may be anxious, angry, lethargic, or withdrawn as they are navigating difficult questions and experiences in their healthcare journey. These concerns may affect a child's perceived pain level and contribute to difficulty sleeping. If you sense your child is struggling, it is important to give them opportunities and ways to explore their feelings and spirituality, such as play, creative expression like art, and time with people they love.⁷

Seeing your child in distress is upsetting, and it can be helpful for you to seek professional guidance and support. A spiritual care clinician, often called a pediatric chaplain, or other trusted member of the medical team who understands children can assist you in determining how to help your child express their concerns.^{[AB1.1][CT1.2]}

The Courageous Parents Network guide "[Spirituality and Caregiving in Pediatric Illness](#)" is devoted specifically to caregiver spirituality. Please find it in the [Navigating Medical Complexity](#) section of [CourageousParentsNetwork.org](#).

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When Your Child Asks the Hard Questions

As children grow older, or as their illness experience deepens, they may have questions that you will not know how to answer. As the parent, it is natural to want to protect your child from worries and uncertainty. You will also want to honor their questions. A child may ask why this happened to them, whether they did something to cause it, what will happen to their body, or what happens after someone dies. These are not questions with ready answers—they are invitations to be present.

Questions about cause and blame

Many children, especially younger ones, carry private theories about why they became sick—including the fear that it happened because of something they did, thought, or said. This kind of magical thinking is a normal part of how children make sense of the world, but left unspoken it can become a private burden of guilt or shame. Gently inviting your child to share what they think caused their illness—rather than waiting for them to bring it up unprompted—can surface and ease worries they may not know how to voice.

Questions about the future, illness progression, and death

Older children, and teens in particular, often have a clearer and more concrete grasp of their prognosis than parents expect, even if no one has directly discussed the prognosis with them. They may ask directly “Am I going to die?” “What happens after?” “Will it hurt?” These questions can surface suddenly—in the car, at bedtime, in the middle of an unrelated conversation—and rarely on a schedule that feels convenient.

You do not need a perfect answer. What matters most is your willingness to engage in the question with your child rather than deflect it. Some ways to respond:

- Reflect the question back to your child. Ask “What made you start thinking about that?” or “What do you think happens?” Children often already have an answer in mind and are testing whether it’s safe to say it out loud.
- Resist the urge to immediately reassure or redirect. A quick “Don’t say that” or “You’re going to be fine” can close the door on a conversation your child needs to have.
- Acknowledge the significance of the question. A response like “That’s a big question. Can we think about it together?” can be reassuring to a child.
- Answer at the level of the question asked. Children, especially younger ones, often want less than parents fear—a short, honest answer is usually enough. Follow their lead on how much detail to offer. (See Developmental context below)
- Let your own beliefs—religious, spiritual, secular—inform your answer, but stay open to the fact your child may be developing an understanding that differs from yours.

Developmental context

How a child understands illness, dying, and death shifts with age and experience:

- Young children (roughly under 6–7) tend to think concretely and may see illness or death as reversible, temporary, or caused by something they did.
- School-age children increasingly understand death as permanent and universal, and may ask very direct, factual questions as they try to make sense of what is “real.”
- Adolescents often grasp mortality abstractly and personally, and their questions may be less about facts and more about identity, meaning, legacy, and what their illness means for who they are and who they’re becoming.

A child’s cognitive age and their emotional/experiential age (shaped by the illness itself) do not always match; many seriously ill children mature more quickly in this area than their peers.

Finding Support

These conversations can bring up your own fear, grief or uncertainty. That’s expected. A pediatric chaplain or other spiritual care clinician on your child’s care team is specifically trained to help children (and parents) explore these questions, and can also help you find language that fits your family’s values and beliefs. Consider bringing them into the conversation not only after a crisis, but as a standing part of your child’s care. Many families find it easier to have these conversations with support already in place, rather than searching for it in the moment.



Conclusion

Every human being is unique and has their own special understanding of the world. When you help your child to celebrate their sense of self and connectedness, you are building their resilience and strength to navigate the illness path and live a life that is as rich in meaning and love as possible. Seeing the world through their eyes may also open your own to new curiosities, to wonder about life in new ways, and to see unexpected beauty in the unique personhood of your child.

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