

8 THINGS TO UNDERSTAND WHEN IT COMES TO SPIRITUALITY AND CAREGIVING IN PEDIATRIC ILLNESS

- 1** Diagnosis of a serious illness—especially in a child—challenges our sense of the natural order of things. A devastating diagnosis also raises awareness that some things cannot be explained or controlled and that the future is uncertain.
- 2** This awareness relates to spirituality, which can be understood as our individual sense of what is meaningful: connectedness to self, to family, to community, to work, to something beyond – the “Divine,” a power beyond oneself or an energy that does not end.
- 3** Spirituality is our inner life, part of all of us and also different for each of us. There is no one way to experience it.
- 4** How we express our spirituality is unique to each of us. You may express yours in a place of worship, through rituals, prayer, meditation, connecting to nature, artistic activities, or in another way with a sense of something beyond our day-to-day reach.
- 5** Religion and spirituality may overlap, but they are not the same.
- 6** Spiritual distress is commonly experienced as a struggle between what we believe or wish, and what is occurring in our life. During times of crisis, it is natural to want to make some sense or meaning out of our situation.
- 7** If your spiritual life is important to you but you are not asked about it, be sure to bring it up with your child’s team. This is especially important if you feel that your spirituality is connected to how you make decisions. You do not need permission to talk about what matters to you and your family.
- 8** Keep in mind that everyone is entitled to their beliefs, and you are not obligated to hold or follow others’ beliefs for yourself or for your child.