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# How to Find God in a Children's Hospital

by Rev. Dane R. Sommer

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*This article explores the spirituality of children who are facing sickness and death. Children often have a difficult time discerning God's presence in the midst of their suffering. Because children tend to derive their understanding of God from their parents, and because they may blame themselves for their illness, they frequently experience the problem of theodicy: If God is all-loving, all-knowing and all-powerful, why has God abandoned me? Activities that focus children's theological concerns help them to discover the nurture and love of an accepting God. Through storytelling, ritual and play, children can define God in their own ways and grow to an awareness of how God sustains them.*

To enter into the lives of sick and dying children is to participate in a depth of wisdom, hope, courage and clarity that can only be described as a revelation of God's living presence in the world. It is important to discuss the spirituality of children who are sick or dying. For although children suffer, and although they have the traditional questions and feelings that accompany suffering, their ability to demonstrate faith and hope, to claim a sense of God's presence in the midst of their suffering, is truly remarkable. If children are given both permission and prompting they can talk about God, heaven and eternal life in ways that bring vitality to the somewhat tired, narrow and unimaginative theological and biblical images that guide most adults. Children are uniquely able to experience direct and intimate relationships with God. Whereas adults might read about God, children can play with God. Whereas adults might meditate on God's presence, children can draw pictures of God. Whereas adults might rely upon unexamined phrases and cliches to remind themselves that God is present in their lives, children can actually see and believe in God.

There is great power in this belief. One ten-year-old cancer patient had struggled through two and one-half years of chemotherapy during which she went through several cycles of remission and relapse. It was finally determined that her cancer had metastasized to her brain. Because she had fought so long and so hard, and because she felt a strong sense of responsibility for the well-being of her parents, she kept on fighting even when her tumor left her unable to walk and nearly unable to talk. Approximately three days before she died she began to

talk about having a sense that Jesus was present. She said that she could actually see herself walking to Jesus and believed that when she died, if her legs would not work, Jesus would walk to her. She made repeated references to this image, gaining courage and peace as death approached. She died quietly.

It is important to understanding how spirituality affects children and their experience of sickness and suffering. Regardless of their religious heritage or the faith background of their parents, all children are spiritual. Like everyone, their spirituality is the natural, creative and adaptive force that both raises and resolves issues of life and death. Our spirituality asks life's difficult questions and seeks resources that establish a foundation of meaning and predictability for life. Our spirituality prompts us to ask "why" questions, pondering why things happen as they do, why our lives end up the way they do, and why we are ever born. We are led by these questions to resources such as community, family, tradition, religion, education and meditation. This process of asking questions and seeking helpful resources may seem buried in some children because of their parents' religious orthodoxy; it may also be denied by some children whose families claim to be atheistic. But when we define spirituality as that part of us which confronts life issues, we must affirm that all people, including children, are spiritual, all people ask questions about life, and all people develop resources that help them interpret what they experience.

## Difficulties in Children's Spirituality

The issues that surround our spirituality are not necessarily easy. Most people believe that our spirituality comes naturally. They believe, for example, that our understanding of God and our ability to

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relate to God are gifts from God that should not be questioned or explored. In reality, most of us have a cluttered understanding of God. This is especially true of children who face illness and death. Uncluttering their idea of God requires awareness of a number of problems typical for children who are hospitalized. Some of these problems are developmental, some are catechetical. Some arise when children are unable to define God.

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Children nearly always base their understanding of God on relationships with their parents (or other primary caregivers). If parents are present, open, honest, empathetic, accepting and loving, then children will automatically have an image of God that reflects these supportive and caring characteristics. If parents are blaming, judgmental, inconsistent, abusive, manipulative or narcissistic, children will conceive of God with these somewhat dysfunctional traits. If parents are passive, overly protective, hide their grief or are unable to show emotion in the midst of crisis, then children will develop an image of God as insulated from their suffering. Just as it is difficult for children to question their parents' attitudes and behaviors, and just as it is difficult for children to separate themselves emotionally from their parents, it is difficult for them to revise the primary images of God that originate in their relationships with their parents.

Children will adhere to religious teachings that reinforce these primary images of God. Children are literalists; they believe word-for-word what they are taught about God and do not understand metaphorical language. Children use what we teach them about God to interpret their life experiences. Difficulty arises when children adhere tightly to notions that suggest God is all-loving, all-powerful, all-knowing and will protect those who have faith from all harm. The content of this catechism leads to great expectations. Expectations lead to disappointment. Disappointment leads to increased unnecessary suffering. The inability of most adults—especially parents—to find creative ways of interpreting or challenging these literal teachings leaves children puzzled and fearful. Unfortunately, only after considerable spiritual growth can parents creatively interpret these teachings for their children. Because parents are unable to offer any bet-

ter explanations than what traditional theology says, children are stuck, wondering where God is.

Children learn how to respond to life's challenges by following the examples set by parents and other important adults in their lives. Children watch and learn. In the hospital, this is revealed by the way children accept the informal rules created by family members and staff that prohibit the expression of emotions and questions about illness and death. Children will often follow these rules to protect their parents from painful emotions. This separates children from the people who nurture them and provide support. Children may also feel it is inappropriate to express feelings and questions to God. The same learning process that creates distance between children and their support systems creates distance between them and God. Instead of being able to approach God in conversation or prayer, and instead of being able to sense a natural freedom to bring all concerns and questions to God, children become frozen, unable to direct any thoughts or emotions to God out of fear that import-

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ant rules will be broken or that God, like mom or dad, will be saddened, angered or frustrated by what is communicated. Children translate this protective "conspiracy of silence" to their relationship with God. This is a disconcerting role reversal, for rather than being able to seek comfort and acceptance from God, children live and sometimes die with the awesome burden of comforting the God who should be their comforter.

Another difficulty arises out of the tremendous sense of responsibility children feel about the cause of their illness. Children, like most adults, are naturally inclined to believe that they are sick for some reason, even if it cannot be easily discerned. None of us deals well with questions that have no answers or with events that have no apparent cause; all of us try to order the chaos of an unpredictable world by seeking answers to life's puzzlements. When we cannot find an exact answer to our questions we invent reasons for why things have happened. Sometimes we blame God. More often we blame ourselves. For older people, self-blame may take the form of remorse for past wrongdoings or lifestyle indiscretions. Because children lack this historical context about what they might have done

to deserve their suffering, they simply conclude that they are sick because they are bad. This badness often has its origin and finds reinforcement in the negative messages and abuse characteristic of dysfunctional families; or it may result from strong, orthodox religious teachings that suggest that all people sin and life's difficulties are God's punishments. Most people somewhere deep inside believe that God has willed their suffering. It is sad to see, with near perfect predictability, that if children have no

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clear explanation of the etiology of their illness, and if they have poor self-esteem or come from a non-nurturing family, they will blame themselves for their illness and conclude that God made them sick because they were bad. This creates great difficulty, because God, who should be a source of love, nurture and acceptance, becomes the cause of suffering. In weak resignation children sigh and say that their sickness is part of God's plan or that they are getting what God believes they deserve.

A final problem follows this logic. As children spend more and more time in the hospital, as they face recurrent infections or more aggressive medical interventions, they become more and more isolated. They see their friends less often. They are removed from the familiar environments of home and school for longer periods of time. Parents and siblings visit less frequently or stop the natural flow of communication because they are unable to face the unrelenting pressures of hospitalization or the inevitable reality that a cure is not possible. Children also feel increasingly isolated from God. They expect that God will never let them die because this is what parents and clergy have unwittingly told them; thus each relapse creates more distance between them and God. Most children have been taught that if God were present in their lives God would miraculously cure them. Since everyone else has abandoned them, since there is no miracle, they naturally conclude that God has also abandoned them. As if this terrible loneliness were not enough, these thoughts only reinforce the need to endure their suffering quietly and heighten their sense of badness: God has abandoned them simply because God does not want anything to do with them.

To enter into the lives of sick and dying children is to realize the problem of theodicy. If children believe that they have to take care of God, yet feel isolated from God because God will not do a miracle; and if children view suffering as a result of their own badness, then we confront the question of why people suffer in the presence of God. Children, in their innocence, often can articulate these problems far better than those of us who make our faith claims as the result of biblical, theological and philosophical studies. Children can sense, without any need for abstraction, whether God is present in their lives, whether God loves them, and whether God has any power to alleviate their suffering.

Within the context of these difficulties there is much we can do to help children unclutter their spirituality, build their self-esteem and claim a new relationship with a God who is a vital force in their lives even as they suffer. Building a program that addresses theodicy in a systematic and comprehensive way takes a great commitment. Energy alone will not suffice to help children discover their own strengths and the presence of God. Neither can one rely on the com-

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passionate and incarnate presence of God that may develop through the natural confluence of two people entering into a covenant of friendship. We need to construct a focused, pragmatic set of directives that embodies the theological concerns of children and their families. Many things can be said and done to help children and families reflect on their spiritual needs, but for now it is helpful to pinpoint three categories that guide both plans and actions: storytelling, ritual and play.

### **Storytelling**

This essay has maintained that children's responses to their sickness and suffering are learned by following cues from their parents and caregivers. But children also develop responses from listening to and integrating the principles that are embodied in the stories they hear; thus it is important for children to hear and tell stories that express their feelings about suffering and death. These stories come from a variety of sources: the Bible, nursery rhymes, fables and popular children's literature. While it is important to provide children with the opportunity to hear their favorite stories without regard for their specific content, additional stories must be introduced

which place protagonists in the same situations that the children themselves face or offer some explanation for why things are the way they are. It is not easy to find these resources, because most people never face the reality of suffering children and are therefore not prepared to search for what they need. Likewise, most adults feel stymied when asked to share stories that creatively express the problems of suffering or theodicy. Yet this can be so helpful. Perhaps this is why there is so much power in the Jewish tradition of *midrash* and Jesus' use of parable. In both cases, stories captured exactly what the listeners were thinking and feeling; this enabled them to comprehend the message and apply it almost immediately to their own lives. Storytelling can help children voice their questions and emotions, reflect upon complicated issues, connect with others who have experienced the same situation, and rediscover God.

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*The Goop-Ooze Story of Creation* demonstrates how the creative use of storytelling can help children understand the concept of chaos. The authors of the story were concerned that children tend to blame themselves for the unpredictable and random events that take place in their lives. They were also concerned that most children are taught that God could somehow subdue this chaos and its attendant suffering if God wanted. Rather than trying to explain this to children, the authors wrote a story that helps children understand that chaos is part of life, and that God creates life, order and community out of this chaos. Children were then encouraged to act out this story by placing their hands in a cold, wet, runny clay-like substance called goop-ooze, a tangible metaphor for chaos. The children discovered that the goop-ooze could be shaped into mountains, rivers, plants and animals, but the material always retained some of its cold, clay-like features. In this way they learned that chaos is part of life, that God and human beings can work together to shape the world, but nonetheless, chaos is still part of existence. By doing this the children began to understand that their sickness and suffering was not their responsibility, nor was it God's.

## Rituals

Rituals, much like sacraments, are outward and visible actions taken to demonstrate the qualities of God's presence that are invisible or difficult to articulate. Rituals can bring an awareness of hope and faith into situations that seem to be technologically overwhelming. For example, when newborn children are brought into the neonatal intensive care unit, their parents are frequently bewildered by all the sights and sounds that create a foreign environment. Surrounded by so many monitors and tubes, and forced to take in so much new information and make difficult decisions, rituals can help them find familiar words and images that may help them understand what is happening to them and their child. Within this setting rituals not only bring familiarity, but also reinforce a sense of identity. When children are baptized or named or blessed they become more than "just" tiny human-like things connected to breathing machines that evoke fear and sadness from their parents. Their value as human beings can be seen and pronounced out loud. Rituals establish a covenant between parents and children in which every person is an irreplaceable member of the family. This allows parents to express their feelings, especially their fear and sadness, more openly, and gives them permission to love and hold their children even though the odds are against a long life. This is also a means by which parents can see that God stands with them in the midst of their confusion and pain. Later, when the crisis is resolved, rituals can enable people to tell their stories. As they sort through their experiences to try to determine why things ended as they did, they will include images of God that, while not taking away all their anger at God, may help them to see they are still in a relationship with God.

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Rituals can also provide a means of discovering grace and forgiveness, and this is important for children as they prepare themselves for death. This may be especially true for older children who feel that the mistakes they made in life will result in eternal condemnation. This was particularly poignant in the case of an older adolescent who was facing his death. A seventeen-year-old hemophiliac boy was dying of AIDS contracted from a blood transfusion. He was withdrawn, in pain all over his

body and unable to discuss anything with his parents. His minister had visited him several times; the boy confessed that he could not relate to what the minister said and did. He felt that the minister's visits were for the sole purpose of helping him "get right with God" before he died. He was encouraged to repent of all his sins so he would be acceptable to God and avoid the furnaces of hell. The young man was in great emotional pain, terrified by death's mysteries. The chaplain visited him daily, and the young man was beginning to communicate his feelings. One day he told the chaplain that he had been raised in the church and that some of what it had taught him had meaning. He asked to be baptized because he felt it was important, but he did not know why or what it meant. He commented, "It is just something I need to do." The chaplain realized that the young man was

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feeling guilty and believed he was a bad person. He assumed he would never be acceptable to God, that he was being punished in this life, and that punishment would continue in the next life as well. His physical suffering was unbearable, yet for him to let go and die was terrifying. The chaplain told him a story about Jesus as a young man standing in the river with his cousin, John. John was baptizing people in the river, and when Jesus was baptized God said, "This is my beloved son with whom I am well pleased," after which Jesus had a clearer awareness that God loved him. The young man and the chaplain talked about the water washing away all the confusion and fear Jesus felt about who he was and what his calling meant. The young man could relate to this and wanted to be baptized in his hospital room. He had regrets; he thought of them and named them to himself. The water was placed on his head, symbolizing a cleansing and a letting go of regrets, confusion and fear. The young man was baptized with the proclamation that he was wholly loved by God, that nothing about him was unacceptable, that God knew his heart and his hurt and that God was pleased with him. The young man was moved, and tears streamed down his cheeks. Still very ill, he soon went home to die. In the weeks that followed he was able to plan his funeral, make a will and tell the people he loved "good-bye."

## Play

The final important focus is play. When Jesus said, "Let the children come to me," he was inviting them to play. He invited them to sit on his lap and tell him secrets, show him special rocks and stones and even tug at his beard. Children discover grace not through work but through play. It is in their play that they engage in honest conversation, open negotiation, creative contemplation and free expression of their emotions. Children find acceptance through play, whether that comes from their peers, their parents or hospital staff. Children can be themselves when they play, with no need for pretense or hiding. They can sit on the floor or at a small table on their own level. When they play, they are free . . . free from adult interventions and expectations, free to explore new and splendid territory, free from their worries and concerns. They are empowered to do what they want when they want to do it. When they play, they discover their value as human beings and may discover the loving presence of God.

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As children play, a magical transformation takes place. One somewhat querulous eight-year-old boy with leukemia was having a bad day: too many doctors probing, too many new medicines, too many demands on his weakened body. Yet, when he strapped on his two gallon super-squirt and engaged in a water fight that left this writer drenched, he stepped out of his difficulties, if only for a few moments, to become a warrior. His attitude lightened, he felt stronger, he felt free. He laughed. Even though this encounter only lasted about fifteen minutes, it was something he took with him through the rest of his battle for health, as he would frequently laugh and tell about his water gun conquest; and each time he told the story his power would come back.

By understanding the importance of play, programs can be developed that help children discover a God who loves and accepts them. By encouraging play, children can participate in grace. For example, if the story of Christmas is read to children it might seem like a nice fairy tale that has little bearing on their lives. If, however, children put on angel or shepherd or magi costumes and go to a nativity

with live animals, they will participate in the story in such a way that they feel accepted by God. If they are encouraged to sing Jewish songs and Christmas carols, rather than having others sing to them, they can feel courage and joy that is the product of their dwelling with God. If children are asked to share in storytelling or rituals rather than simply being "prayed over" by adults, they will explore and describe their own God rather than passively accepting adult ideas. As they are given permission to find out for themselves who God is, God becomes more real. As God becomes more real, children can experience more fully God's acceptance and grace.

### Conclusion

Realizing that children's spirituality is complex and subtle, we adults should not confuse their natural experience. If adults understand how children learn about God, and if we grasp how our interaction affects them, perhaps we can become guides rather than teachers and preachers, partners in discovery rather than revealers of truth; we can become co-creators of mercy and grace with them and with God. For God does participate in the lives of sick and dying children. If we look and listen, the children will show us how.

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