You're Getting Warmer

A Discussion Guide
for Parents, Hospital Staff, and Volunteers

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The Story Behind *You're Getting Warmer*

I wrote the play in the first four months of my work as an Art Program Specialist in the Child Life Program at the University of California Davis Medical Center (UCDMC), months in which I came to know and love many children, and to lose one of those children to leukemia. The play was born from my own grief and loss.

The setting was clear from its inception. An actual helicopter window exists at UCDMC, so named by the children. As you entered the pediatric ward on the seventh floor, a large window looked out on the life flight helicopter pad. I became aware what a special spot this window was for the children and their families, despite the fact that nothing in the space accommodated their needs: there was no place to sit, placing chairs there was frowned upon because it cluttered the hallway, and a dark, rather forbidding abstract mural hung on the adjoining wall. Nothing about this "entrance" said pediatrics or welcome.

And yet the children would sit there for hours waiting for the helicopter to take off or land. Parents sought out this area too. As I became aware of the area's appeal, I realized parents could be away from the hustle and bustle of the ward and yet be clearly visible from the nurse's station in case their child needed them. The quality of morning light was heartening, the sunsets lovely - and always you could see the comings and goings of the "outside world." Staff frequented this area as well, most often bringing a baby to hold while they gazed out the window, together.

At that time, I was also a member of the Sacramento Playwrights Workshop, and we had chosen the theme of "hot and cold" for an evening of one acts that were to be performed by the Sacramento Theatre Company. One night I came out of a child's room and saw a family standing in front of the helicopter window. Their three-year-old son had been diagnosed that day with leukemia. I heard the line "Sometimes I wish I could get in that helicopter and fly away and never come back"—and I knew I had the opening line of my play.

When it was completed, Connie Baker (Child Life Director) wanted it performed as part of our presentation at Pediatric Grand Rounds. The response of the medical staff touched me deeply. Many people urged me to have it taped. I was able to secure a grant from The Sierra Foundation and Channel 3 Studio videotaped it. The video won an Honorable Mention in the national competition sponsored by the Association for the Care of Children's Health in 1988 and led to a presentation by Connie and me at their national conference in Ohio. At the urging of Donna Wong, I wrote a discussion guide to accompany the video.

Over the course of that year, the helicopter window would be transformed by an area of warm, colorful carpet and window seats. The large mural was replaced by a painting with an aerial view of the Sacramento Valley, including animals in hot air balloons. Below the mural was an interactive play wall featuring a pilot's wheel and switches that looked like air strip landing lights. It was the first of our many programs to use the arts to create a more healing environment.

Suggestions for Guiding Discussion

This discussion guide is intended to be simply that - a guide. You, as the moderator or instructor, know best your focus and objectives and how this particular play can best serve your needs. For some groups all the points of the discussion guide may be important and applicable; for others, only certain portions will be useful.

I would recommend that you first view the DVD to allow your own response to the play. Next, review the discussion guide, selecting those areas you wish to focus on. Then, it might be helpful to view the play again to make notes on specific dialogue and dynamics between the two mothers.

Though giving people points to keep in mind as they view a DVD can be an effective teaching approach, I would not suggest such an approach with this piece. Instead, you should simply allow people to view the DVD without prior discussion to facilitate both an emotional and intellectual response in each viewer - thereby strengthening the depth and effectiveness of the group discussion.

Many people experience a strong emotional response to the play. They may cry or be very quiet, so you need to be prepared with tissues so that people are not embarrassed by their responses and acknowledge these responses in ways that make people comfortable exploring their feelings and sharing their own experiences.

Educational Objectives

This play was written out of my own experiences and emotional responses to working with critically ill children and their families at the University of California Davis Medical Center. The play attempts to engage both heart and mind regarding the complex issues of dying children and the impact these deaths have not only on their families, but on the medical and support staff.

Audience
The play can be used effectively for a wide range of training and support programs:

*Physicians and nurses
*Social workers
*Child life interns and volunteers
*Clergy and lay ministers
*Professional and volunteer hospice staff
*In-service presentations on grief and dying for pediatric staff
*Parent support groups
*College classes in grief and dying

Educational Objectives For Medical and Support Staff:

*Discuss ways to help families and children adjust to the hospital environment

*Explore possible staff expectations of parents and how to improve support for parents

*Share personal and professional challenges in working with critically ill children and families

Educational Objectives for Parents and Parent Support Groups:

*Discuss the things that are difficult about the hospital environment and the supports you might find helpful

*Better understand your self expectations and share changes in your life that are stressful for you

*Share your feelings of grief and loss

The Hospital Is Another Culture

A Reminder for Hospital Staff and Volunteers:

Stating the obvious can be a useful reminder. An environment, however strange to you at first, becomes "normal" once you work in it, so you can become less sensitive to its impact on patients and their families.

I would like to share one way our Child Life Program helped our pediatric patients adjust to the hospital environment. We asked them to identify sounds that they noticed or were troubled by. Their responses were numerous and varied: "I hear the babies crying, especially at night." "All the footsteps—I can tell when someone from my family is coming." "The IV's and the beepers." "I know all the different carts by how they sound." Our ten minute recording then captured a wide range of sounds they identified—from keys jingling and elevators beeping to the sounds of complex medical equipment. When new patients were admitted, we used the tape like a game, hoping to make the sounds less overwhelming; the children were adept at identifying the sounds, and felt more in control of their new environment.

Some of the things children and parents struggle with in this new culture:

*New and often disquieting sights, sounds, and smells assault their senses
*New medical terms and abbreviations can be intimidating and confusing
*The sheer number of staff children and parents meet in the first couple days of a hospitalization
*New routines to understand and confusion as to what they can control about these routines
*A set of new tools to master—wheelchairs, IV poles, hospital beds
*For parents, a primary shift in identity—they become known as the Mom or Dad of a specific child. "You're Davey's Mom, aren't you?"
*For parents, struggles with feelings of inadequacy and a desire to protect their child

Discussion Questions:

*How can hospital staff and volunteers remain sensitive to the hospital environment from the perspective of the children and parents?

*What can hospital staff and volunteers do to help children and parents feel more comfortable in this often strange environment?

*What can be done to humanize the hospital environment itself?

Hospital Staff's Expectations of Parents

Comments:

Staff often have high expectations of parents. While it is natural and human of you to want the best possible care and support for a sick child, sometimes staff develop rigid ideas and strong judgments of what constitutes "the good parent" versus "the bad parent." Also, as you know, expectations of parents can vary between staff members on the same pediatric ward. This potential confusion is reflected in the "Should" and "Should Not" outline regarding some conflicting staff expectations of parents.

Parents' Perceptions of Staff Expectations: I Should…

*Accompany my child to all medical procedures

*Stay with my child throughout their hospital stay

*Be a strong advocate for my child

*Be the one to tell my child about his/her prognosis

*Help support other parents on the ward

Parent's Perceptions of Staff Expectations: I Should Not…

*Accompany my child to procedures but rather offer support after the medical staff has completed their work

*Stay throughout my child's hospitalization, but rather leave periodically for breaks and sleep

*Question staff regarding medical treatments and decisions

*Necessarily be the one to tell my child about his/her prognosis

*Support other parents but rather leave these needs in the hands of the staff

Discussion Questions for Hospital Staff:

*****What judgments and expectations lie behind the label of "a good parent" versus "a bad parent"?

*****What can you do to guide parents away from the self imposed expectation to be the "perfect parent?"

*Does your pediatric ward or hospital have clear and agreed upon policies regarding parental involvement in a child's care? What are the policies as you understand them?

*Does your pediatric ward or hospital have clear and agreed upon policies regarding parents sleeping by the bedside of their child, sibling visitations, etc.? In what way are these rules made clear to parents?

*When a parent feels unable to perform a certain action, like accompanying their child to a medical procedure, how can you support them in their decision? How can you find ways to accent what they are able to do, rather than what they can't do?

*What can you do to help parents feel free to express their fears and concerns or sense of inadequacy and frustration?

The Initial Impact of a Child's Illness on Parents

Initial Responses of Parents

*Denial
*A sense of aloneness and isolation
*No one can understand but another parent going through it
*General feelings of inadequacy
*Feeling uncomfortable in the hospital environment
*Overwhelmed by all the new information they must process
*Agony of waiting for the test results to come back

Potential Long Term Impact on Parent's Lives

*Life lived at the hospital
*Disruption of daily routines
*Loss of control and privacy
*Arranging care for other children
*Feeling torn between the needs of the sick child and other healthy children
*Balancing other roles (mother, wife, daughter, friend)
*Comparing themselves to other parents or staff and family member's expectations
*Feeling judged and observed by everyone in the environment
*Potential loss of job
*Financial burdens
*Marital conflict/tensions, sometimes ending in divorce
*Sense of failure at inability to protect one's child from pain and unhappiness

Discussion Questions:

*From the DVD, can you identify some of the initial responses a parent might have to their child's diagnosis?

*What impact has her child's illness had on Davey's mother? On Tiffany's mother?

*In the play, the mothers clearly enjoy talking about their children. Are there ways for staff to encourage this expression of love by helping their child personalize their hospital room, by creating photo albums of their children or by providing opportunities for them to talk about their children—and perhaps most important, by you valuing their knowledge of their children?

Introduction to the Code of Protection

Comments:

When a person becomes a parent, an unspoken promise and desire exists to nurture and protect their child. While there is a great deal we can do as parents to nurture and protect our children, we are not able to shield them from every harm and disappointment - nor would the child grow into maturity if we were perfectly successful at this feat. Ordinarily, parents come to accept their limitations and the natural maturation process of their child by stages. When a child becomes critically ill, however, the illusion of control swiftly shatters. Suddenly a parent is not in control of what happens to his/her child - from the simplest matters of their daily routine to anxiety-producing and often painful procedures.

In the face of this crisis, what was once a parent's natural desire to nurture and protect their child can become an unhealthy code of protection, involving both parent and child. The play centers on this code of protection in its most dramatic form - the inability of Tiffany's Mother to tell her child she is going to die. However, this code of protection begins early in hospitalization and in less dramatic ways. It is important for staff and support people to recognize this cycle early to help parents and children be honest and supportive of each other throughout the process of illness and hospitalization.

One example occurs again and again during medical procedures when the child asks "will it hurt" and the parent must find a balance between honesty and reassurance. Another example revolves around the need for a parent to take breaks or leave the hospital. Most pediatric patients, particularly young children, do not want their parents to leave and will often cry. To "avoid upsetting their child," parents will often leave when the child is asleep or directly lie and say that they will be right back. When staff explain to the parents that this response makes the situation worse, parents generally respond to future situations with honesty. What parents need to understand is though their child may cry, staff are there to reassure and comfort the child. It is important for staff to reassure parents that taking breaks and adequate sleep are important both for themselves and their child, without pressuring a parent to leave if staying is the better choice for them.

Illness has a way of undercutting parent's faith in their own knowledge of their child; staff and support people need to affirm that parent's knowledge and their unique relationship with their child. It is that parent's love and knowledge, coupled with the child's own cues to the parent, that will provide the parent with the way to talk to their child about death. It also helps a great deal if staff listen to a parent's fears and concerns, give them an opportunity to role play, if desired, and provide the support that may be needed before, during, and after telling the child.

In my work I never ceased to be in awe of how children would often know of their impending death before they were told (or before medical staff knew), and I continue to be inspired by how honest and courageous they were in finding ways to express what needed to be said and acknowledged. Children will protect their parents, but they are often the ones to break that unhealthy cycle as well. In the play, Tiffany breaks the code of protection through one of children's greatest skills and strengths - through play. But it is a burden to place on a child. Equally important,

the code of protection prevents honest and loving exchange at a time when both parent and child need it most.

Since no one play or piece can begin to deal with the complexities of dying, I was not able to portray children's concerns in the dying process. I have, therefore, included a few points in the outline to the "Code of Protection" in the hopes it might be useful to discussion.

The Code of Protection

Important Aspects of the Code of Protection for Parents

*The parental role as protector of their child - a role or pact that seems shattered by the intrusion of illness, procedures, and hospitalization itself.

*The daily dilemma of how to reassure and yet be honest

*The continual and understandable need for hope

*An attempt to protect the child's innocence; in essence, their childhood

*Struggling to understand when the child is ready, rather than imposing one's own needs

*The feeling that there must be one right way to tell a child that he/she is going to die - and you simply don't possess the wisdom to know what that is, causing a deep sense of inadequacy

Important Aspects of the Code of Protection for Children

*Sometimes, especially in younger children, there is a feeling of betrayal - "how could you let them do this to me? You are supposed to protect me."

*Sensitivity and concern for the parent will involve the child in protecting the parent from the truth

*Child will seek out people, other than the parent, to discuss their fears and concerns

*Often, despite the code of protection, it will be the child who will find a way to break the cycle

*Often the child knows of the impending death before he/she is told - sometimes even before the staff knows

Some Concerns of Dying Children

*A fear that they are being punished for some real or imagined misdeed

*A strong concern as to whether their parents and siblings will be all right when they're gone. This concern can be so strong that children will need permission to die from the parent before they can let go.

*A fear of being forgotten

*Shattered future dreams

*A need to complete things in their own way, whether it is farewells to friends, making a will, etc.

*Curiosity about life after death - how one gets to heaven, what is it like, if they can send messages to their family, is there a God?

Discussion Questions

*Tiffany's Mother clearly feels a failure in her inability to tell her daughter she is going to die. Yet, Tiffany's actions reveal a confidence that she can reach out to her mother, that her mother will listen. How can staff and support people offset parent's feelings of failure?

*Why couldn't Tiffany's Mother tell the staff she needed help? What might have interfered with the staff perceiving the mother's inability or readiness to tell her child?

*The role of religion/beliefs plays an important role in a parent's approach or ease with telling his/her child about death. How can staff and support people become aware and sensitive to the belief system of a family, particularly when it differs from their own?

*Sometimes art forms are an easier way for a child to express their feelings about dying or heaven—making art supplies available to children, supporting them in writing stories or writing about their favorite things can create an opening for the child and parent.

*If there are people in the discussion group who have worked with dying children, could they share what they know of children's concerns about dying? Have they had experiences in which a child broke "the code of protection" surrounding his/her own death?

Parent Support Groups

Comments:

In the play, it is implied that a rather informal one-on-one parent-to-parent support system exists in that particular hospital. But when a parent loses their child, they also lose the hospital support system that, in many cases, has come to mean a great deal to them. The support may have come from a network of staff (nurses, a social worker, child life specialist, a doctor) or even with one particular person. Sometimes a parent will write to staff or return to visit, but very often this form of support is abruptly terminated, another form of grieving for the parent (as well as for the staff who have loved the child and family). Some hospitals have developed sensitive and effective support systems for parents, siblings, and staff; other hospitals have not yet committed their resources to this vital need. In this case, is there a consistent effort to inform parents of ongoing support groups that exist within their own community and if so, who is responsible for conveying that information?

Benefits of a Parent-to-Parent Support System

*Acknowledges parent's shared feeling that "only another parent could understand what I feel."

*Flexible scheduling - only two schedules need to be coordinated

*One-to-one sharing can be less intimidating than group sessions

*Potential for ongoing support and friendship outside the hospital environment

Potential Problems of a Parent-to-Parent Support System

*A parent may be burned out or overwhelmed by his/her own situation and be unable to help another parent - but it may be difficult to say no

*Parents may not be well matched

*No real system may exist for making the matches or there may be a lack of staff follow up as to whether the match helped

*Staff may lack awareness of when a parent is being asked too often to give their support to another parent

Support for Caregivers

Comments:

For those people who have committed themselves to caregiving professions, whether as paid staff or volunteers, it is crucial to honestly explore and express our own feelings of stress and grief over the loss of someone we love. Ironically and sadly, codes of "professionalism" often preclude open sharing in the very institutions charged with training people for service professions. I will never forget the words of a first year resident to me, after watching the performance of *You're Getting Warmer* at Pediatric Ground Rounds: "All of us are struggling with our feelings, working with dying children, but we never talk to each other about it. Many of us have children the same age as the children we are working with. I feel so inadequate—other people do too—but we all pretend we are on top of it. Today, for the first time, we talked to each other about how difficult it is to tell a parent about a cancer diagnosis or to lose a child you have worked with."

The other irony I have discovered, both in my personal and professional life, is that those people drawn to service professions are most frequently the least good at nurturing themselves. I believe such an awareness is essential, not only to avoid "burnout, but to be able to give to others in the very ways we are seeking.

Myths of the Caregiver

*My needs don't matter or I'm selfish if I think of my own needs

*If I were truly a good _____(nurse, doctor, social worker etc.), I would not feel drained in my work

*Other people cope better than I do

*I can be an effective caregiver to grieving adults and children without addressing my own responses to grief and loss

Discussion Questions: How do you define the role of a caregiver?

*How do you define the role of a caregiver?

*How do you cope with stress and grief? What nurtures or rebalances you?

*Does your work environment provide any support to its caregiving staff? Has any attention been given to a healing garden, the use of the arts not only for patients but for caregivers?

Coping with Grief and Death

Our culture is not comfortable with grief and death which only further impacts the difficulties for an individual struggling to cope with loss. Because we do not often talk about our experiences with death, each person has to learn at a time of grief about such simple things as death certificates—how do you obtain them and how many do you need? Individuals often feel isolated at a time they need comfort because people are uncomfortable when they talk about their feelings of loss or simply cry. People often mistakenly think a grieving person expects them to "fix things," but what they need most is compassionate listening. Our culture also often expects grief to follow a timetable. I will never forget when a woman told me about her return to work a month after her husband died. She began quietly crying at her desk and a co-worker said, impatiently "Are you crying? It's been a whole month now." Here are some ideas about how to cope with grief and death, drawn from my experiences and others who have shared with me.

Ways to Cope with Grief and Death

Reflect on your own beliefs about life and death.

Reflect on what nurtures you and give it a place of importance in your daily life.

*Going for long walks
*Engaging in vigorous exercise and/or sports
*Being in natural beauty
*Gardening
*Listening to or playing music
*Singing - in the car, the shower, or join a choir
*Reading
*Praying or meditating
*Cooking (particularly baking)
*Talking long hot baths
*Keeping a journal
*Talking to someone who understands or will simply listen
*Asking for hugs
*Savoring quiet time alone
*Leaving work behind

Share with the person you are losing your feelings for them, memories you cherish, things you'll remember about them or what they have taught you.

Find your own way to say goodbye.

Remember those you have loved in your own way.

Acknowledgements

The one act play, *You're Getting Warmer*, was first performed as part of Pediatric Grand Rounds at the University of California Davis Medical Center. Later the play was videotaped through a grant from The Sierra Foundation and was filmed at Channel 3 Studio in Sacramento, California. In 1988, The Association for the Care of Children's Health awarded the videotape Honorable Mention in its national media festival. At the urging of the late Donna Wong, co-author of *Nursing Care of Infants and Children*, I wrote a discussion guide for it.

More recently, the play was updated to DVD format through the generosity of the Wong-Baker FACES Foundation. The DVD, discussion guide, and script of the play are now available for free use on my website, victorialdavis.com

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Donna L. Wong, RN, MN, Researcher and Consultant

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Recommended Reading

I highly recommend these three books for their profound insights, honesty, and humanity.

Rachel Naomi Remen, MD
Kitchen Table Wisdom (1997) and her website (rachelremen.com). Krista Tippett's interview with Rachel is also wonderful, "How We Live with Loss."

Dr. Atal Gawande
Being Mortal: Medicine and What Matters in the End (2017)

Vivek H. Murthy, twice Surgeon General for the United States
Together: The Healing Power of Human Connection in a Sometimes Lonely World (2020)