

FROM: **Parenting Your Premature Baby and Child: The Emotional Journey**,
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PROFESSIONALS

Appendix A

A Note to Caregivers

While you may find your job incredibly rewarding, it can also be incredibly distressing. Working with sick and struggling infants can be discouraging and emotionally depleting. Watching their suffering can be painful. Some babies die or have chronic problems, and you grieve for them and their families. You will witness many mothers and fathers with broken hearts. But you will also witness joy, triumph, and growth—emotional growth in the parents and physical/developmental progress for the babies. In recognition of the inspiring as well as challenging and draining aspects of your job, we offer the following tips for supporting parents and taking care of yourself, in ways that honor their needs as well as your own. Some of these points are more applicable to NICU settings while others are broader, encompassing maternity, NICU, and follow-up care. Take what seems useful and find the balance that works for you. Also check out Chapter 7 for more insight and suggestions for building collaborative relationships with parents.

Supporting Parents ...

Consider “family-centered care” to be so much more than just a protocol or set of techniques. It is a positive attitude that welcomes parents into the NICU as full partners in taking care of their baby. It is a philosophy that provides a respectful, collaborative environment where everyone recognizes that the baby is part of a family and that the family is part of the health care team. A fervent mission is to reinforce the relationship between parents and their babies by honoring their central roles in caregiving and decision making, and supporting them in nurturing their babies and making the most appropriate decisions. Consider developing and posting your “unit philosophy” so that parents will know from the start that you believe their presence in the NICU is important, you regard them as members of their baby’s health care team, and you respect their observations and contributions. Make sure that all of your NICU staff members are on board by providing them with the education that they need to understand and implement the unit’s philosophy, a forum to discuss their questions and concerns, and adequate staffing and encouragement to give them the support they need.

Recognize that you are the host and also the guest. Family-centered care recognizes the power that families possess in determining their own paths and eliminates the power differential that exists between them and medical staff. In order to truly collaborate with families, you must hold the attitude that you are the host *and* you are the guest. So for instance, when you go to the bedside of a baby, you are the host because the baby is in your unit; you are the one with the expert medical knowledge; you are the one who invites the parents to become members of the health care team; you are the one who guides them through their NICU course. But at the same time you are also the guest: You are in their “family space” in the unit; you are brought into their family crisis to be a trusted consultant; when you connect with the parents and their infant, you become a guest family member; you walk with them on their personal and family journeys. As the host, you have much to teach families; as the guest, you will learn so much from them as well. Feel the honor in both of these roles.

Provide developmentally supportive care for babies *and* parents. In the NICU, providing developmentally supportive care is central to implementing a family-centered care philosophy. Developmentally supportive care promotes health and development in babies because it is sensitive, responsive, appropriate, and individualized. When you provide developmentally supportive care to babies, in effect you are also providing one important component of developmentally supportive care to the parents, because it reflects, affirms, and accommodates parents’ natural urges to nurture and protect their babies from the harsh or overwhelming aspects of intensive care. This fosters their growing competence, confidence, and bond with their little one. Developmentally supportive care also mandates close physical contact between baby and parent, often through touch, kangaroo care, and feeding at the breast, with precious few circumstances getting in the way. Incidentally, when your unit provides the education, resources, staffing, and support you and your colleagues need to carry out family-centered care, that means that you’re getting developmentally supportive care for yourself, which promotes your health and growth as a professional. (For more on developmentally supportive care see “The Growth of Developmentally Supportive Care in Chapter 7; for information on developmentally supportive care for caregivers, see “...And Taking Care of Yourself” later in this appendix.)

Help parents gather together all the parts of their story. Because delivery, early days in the NICU, and medical crises are usually chaotic and traumatic times, most parents will have gaps in their memories and knowledge about what happened, both to the mother and the baby. Parents benefit from going over the details of the labor, delivery, and NICU care with the attending nurses, obstetricians, and neonatologists. Asking, “What happened?” and “Why?” is a way for parents to reclaim memories and satisfy their need to know. Remember that their questions are not meant to second-guess or attack, but to fill in the gaps. When a parent can create a coherent narrative, it is profoundly healing.

Address feelings first. Before you talk to parents about the medical issues, acknowledge the emotional issues. Sit down and ask parents, “How are you doing with all this? What does this feel like for you? What are your concerns?” Help them to verbalize their feelings and help to normalize them, for example, “I can see how disappointing this is for

you—many parents feel this way.” Stay with them and give them both the attention and space they need. By being emotionally available and inviting them to express and share their experiences with you, you’ve begun to develop a relationship. Building a rapport with you helps parents negotiate the emotional terrain, which in turn helps them listen and absorb information when you talk about the medical terrain. With emotions out on the table, when you start discussing the medical facts, issues, and options, you will probably find that parents are more able to fully participate in these difficult conversations. Any time you can really be with the parents, walk the emotional journey with them. Ultimately, it will make your job easier. You’ll be a more effective supporter and teacher, and parents will see you as their ally and teammate, which makes for a trusting, collaborative relationship. Your collaborative and emotionally supportive relationship with the parents is in the best interests of the baby who is in your care.

Expect a variety of emotional responses from parents, including detachment, anxiety, anger, sadness, vigilance, and depression. Adjusting to a baby’s premature birth, hospitalization, and outcome is a process, and parents can experience a wide range of intense and often contradictory feelings. Each parent brings with them a personality, temperament, and baggage that will affect how they cope. Respect differences, and remember that you only know a small bit of their larger emotional stories.

Show parents their baby. When you introduce new parents to the NICU, before you point out the equipment and technology and lay of the land, first take the time to introduce them to their baby. Ignore the tubes and wires and talk about the baby first, as a person instead of a medical case. Point out the “normal things”—the soft ears, downy hair, long torso, tiny fingers, and facial features. Address issues of the baby’s comfort such as warmth, positioning, pain control, and shielding from harsh lights and noise. Tell them about the importance of parental touch. Talk about the ways that tiny babies show how they know their parents, such as changes in heart and respiratory rates and turning toward voice, touch, and smell. Make sure that you know about developmentally supportive care and reading babies’ signs of distress and relaxation, and start teaching the parents about how they too can learn to read these cues and respond to their baby’s need for comfort.

Show parents you care about them. Parents won’t care what you know until they know you care. Tell them that you are glad to be attending to their baby and, while you know it’s not the same as being the parent, you’ll do your best. This reassures them that you aren’t trying to commandeer their parenting role, but you are invested in their child, and will take good care of their little one.

Encourage parents to enjoy their baby, but elaborate on what you mean by that. Many parents are in agony, and the suggestion that they enjoy this baby can infuriate them. First tell them that you know this is a difficult time for them, full of uncertainties, fears, and other painful feelings. Reassure them that you are here to support them through this turmoil. Then gently express your hope that they can remember that in spite of the difficulties, their baby is a precious little one, growing and changing before their very eyes, and there is so much for them to witness and marvel at. Encourage them to enjoy

what they can about the baby, because this will give them respite from the harder parts of the NICU journey.

Consider writing notes to the parents in the form of a “diary from their baby.” The idea of baby diaries was developed at Simpson Maternity Hospital in Edinburgh, Scotland, when the nurses began leaving messages and notes for the next nurse coming on shift. They began sharing these “diary entries” with parents who were delighted and comforted by these little notes “from” their babies. As one mother in this book says, “It made me giggle and made me cry. ... It really helped with the bonding process and helped us accept this wee scrap of fighting life as our son.” Of course, some nurses will feel more comfortable and confident doing this than others will. And not all parents will be open to this lighthearted touch. But for many others, it will give a much-needed break from the grind of having a sick preemie, and they will treasure their diaries. Diaries are also powerful, cherished mementos for parents of babies who die. (See Chapter 8 for more on baby diaries.)

Accommodate parents’ needs to be involved with their baby. Instead of expecting parents to adjust to the constraints of the NICU, try to make your NICU accommodate parents. Tell parents that their presence, touch, observations, advocacy for, and parenting of their babies are valued. Encourage their participation in the baby’s care, making room for them to do as much as possible, and involve them as members of the health care team. This partnership with you helps them exercise their parenting abilities and promotes feelings of competence and confidence. Obtain their consent for *everything* but emergency procedures and treatments. This reminds them that you know that this is *their* baby and demonstrates your respect for their role as primary nurturers and decision makers, which supports them as they come into their own as confident parents of this child. More importantly, when their consent is required, they become their child’s primary advocate and protector, which facilitates bonding with their infant. Recognize the importance of “firsts” and the parents’ desires to be there whenever possible to witness and participate in milestones. Reassure them that you share a common goal: to get their baby healthy enough so she or he can go home.

Keep parents informed during their baby’s roller-coaster course. Parents benefit from knowing the whole story—the good, the bad, and the uncertain. If their infant’s prognosis is poor or uncertain, they have a right to know that not every baby comes out of the NICU unscathed. You can tell them this without extinguishing their hopes. Still, when a baby has a major complication or setback, telling parents can be very difficult. Bad news is hard for them to hear and some parents may not seem to absorb it. And sometimes, what you consider a minor setback in their baby’s course can feel monumental and devastating to the parents. You may feel like you want to spare them by not fully disclosing the details. Unfortunately, keeping parents in the dark robs them of their ability to master reality and reinforces unreasonable expectations. Keeping information from parents also creates barriers between them and their baby, and spawns anger and mistrust toward their baby’s caregivers. The parents may even question your motives and assume you are trying to protect yourself, not them. In any case, withholding information from them does *not* protect them. Instead of worrying about how

parents will react when they hear bad news, plan on helping them face the situation *and* their emotions. It's your job to support them, *not* hide the truth from them.

Instead of walking away from parents, walk with them. You serve parents best, and your job is made easier in the long run, if you can speak honestly and openly *and then support them as they face painful feelings head on*. This is how you can *walk with them*. It may also help to remember that because knowledge is empowering, it is far easier for parents to cope with the grief they feel when facing bad news or uncertainties from the outset than to cope with the confusion, disappointment, and disempowerment bred by half-truths and cover-ups. Most importantly, when parents are fully informed, they can be fully present and involved with what's going on, which in turn enables them to integrate what is happening to them and to their baby. Parents may encounter some painful situations, and you may be tempted to protect them from being overwhelmed or scared. But sometimes the truth *is* overwhelming and scary. If you're having concerns, remind yourself that by sharing information about their baby you are drawing parents into the circle of caregivers, which in and of itself provides comfort and instills confidence and courage.

Accommodate parents' unique and changing needs for information—and help them stay focused on their baby. Although your goal is to keep parents fully informed, you must be responsive to what “fully informed” means to each parent. Some parents just want to know what is going on with their baby right now, while others also want to know every etiological detail you know and every future possibility you might surmise. Some parents want to be spared all the “gory details” and just given the big picture, while others want a crash course in neonatology. Some parents just want the most basic information at first, adding layers of knowledge over time, while others want it all right away. So rather than loading up parents with standard information, take into account what the parents really want to know, their biggest concerns, and their readiness to absorb facts and advice. Say to parents, “Let's talk about what's going on so you can figure out what you want to know,” and then follow their lead. Parents will be grateful for your responsiveness to their style of information gathering and mastery. And when parents are overwhelmed with information, you can help them narrow their focus. For instance, you can disclose all the risks of a treatment *and* be more specific about what that may realistically mean for *their* child. You can refer parents to the research *and* help them interpret the implications for *their* infant. You can help them cope with “bad news” by acknowledging their feelings and answering their questions. Also, always keep in mind that when you are sharing information, you're not giving a report, *you are building rapport*.

Be honest about uncertain or grim prognoses. One of the hardest answers to give a parent is “I don't know.” However, parents would rather hear that than your guesses and opinions presented as facts or guarantees. You can acknowledge the uncertainties of the future, but be honest in saying that this child has a lot to overcome. There is a huge difference between saying, “Your child will never be able to ... ” and “I've never seen a child with these sorts of complications be able to ... ” Parents will appreciate this show of sensitivity and integrity. While it can be painful for parents to discover that medical

technology cannot always predict or cure, your honesty creates a bond that will benefit all of you. Perhaps harder than “I don’t know” is “There’s nothing more to do but comfort care.” If it looks like the baby is turning away from the path that leads toward home, keep parents abreast. Parents benefit from being included when goals change. Knowing that their baby is dying allows parents to make the most of the time that’s left and to make plans that are meaningful to them. Likewise, if the baby has catastrophic problems that require long-term hospitalization or that may become permanent or chronic, parents need to be informed as soon as possible so they can adjust their expectations. When you are honest with parents their hopes don’t disappear, they gradually change direction.

Be a decision collaborator and sometimes a decision leader. When a baby’s prognosis is certain and the treatment plan is clear, be a decision leader. For instance, when the baby’s survival is virtually certain and the standard interventions are in order, you can bring the parents on board by informing them about what is happening and why these treatments are in the best interests of their child. Likewise, when the baby’s death is virtually certain and comfort care is the best option, you can bring the parents on board by informing them about what is happening and why these treatments are in the best interests of their child. But when the prognosis is uncertain or if experimental treatments are an option, be a decision collaborator. Bring the parents on board by explaining the options, risks, benefits, and outcomes, and inviting them to be central partners in the decision-making process to determine what is in the best interests of their child.

Slow down and listen to parents. Most of us need to become better at slowing down and listening. This means giving parents information and then being able to sit quietly and patiently with them. Encourage questions and then stick around to give parents time to formulate those questions, express what’s on their minds, and note anything that is still unclear to them. Open the door to questions that the parents may be having trouble formulating and normalize this process by saying something like, “It takes time for parents to form questions. Do you have things on your mind that you want to talk about, even if you’re not sure if it’ll make sense?” Be comfortable with silence, as parents need time to think, ask, and respond. Validate how difficult their baby’s hospitalization must be for them and ask them, “How are you doing with all this?” Consider tape-recording these meetings (see below), so parents can have the opportunity to listen again when they feel less overwhelmed or shocked by the information. Also be present and available for follow-up chats in person, by phone, or by e-mail. By being accessible, going at the parents’ pace, and providing audiotapes, you increase the likelihood of them absorbing information from you.

Audiotape your conversations and give parents a copy. Although there is a new movement to audiotape care conferences and give tapes to the parents, many caregivers are wary. But there are many benefits. If parents can listen to a tape repeatedly, they are more likely to absorb what you say. By sharing the tape with relatives, they can be spared daily grilling by concerned family members and friends. If you agree that parents don’t always remember what they are told, audiotapes can be a remedy. If you are worried that audiotapes will only encourage parents to obsess, remember that they can and will obsess even without a tape. The audiotape can ground them in reality, and in fact, you might

encourage them to listen to the information as many times as they need. When parents have access to audiotapes, they can be more informed, be more satisfied with professional-parent communication, and have a better working relationship with you—which as you know, reduces the chance of lawsuits being filed against you. If you behave in a responsible, professional, ethical manner, you have nothing to hide, and a tape cannot be effectively used against you.

Accept the parents' right to cry at their baby's bedside. Tears don't hurt babies, and parents often benefit from shedding tears in their baby's presence. Give parents their space and privacy when they cry, because your presence, touch, or words may convey the message to "calm down and dry your tears." If one parent's tears lead to another's, accept that floodgates will open sometimes in the NICU. If your unit culture respects a range of expression by parents, this is a sign that you are providing an emotionally healthy and supportive place. Another healthy sign is that limits are set. If a parent is losing control and behaving in ways that intimidate or endanger anyone or anything, they will benefit from your gentle intervention to help them calm down or to lead them to a place where they can vent without restraint. When your instinct tells you that things are getting out of hand, trust it and act quickly and decisively.

If a parent is venting anger toward you, don't take it personally. Even if the parent personalizes the attack, remember that it's *the situation* that deserves those charges. If you can listen and *acknowledge their anger*, this can help diffuse it. Validate their attendant feelings of powerlessness, confusion, shock, and fear. Agree with them that this situation holds many disappointments and uncertainties, and that it can be really hard to deal with. Acknowledging and validating their painful feelings shows them that you are an ally, not the enemy. It also shows them that they can feel angry and not lose your support.

Avoid judging parents. It is tempting to make snap judgements when parents behave in ways you consider inappropriate, especially toward their babies. But you don't know their whole story, their background, or the hurdles they experience. For parents who live far from the hospital or who are without transportation, funds, babysitters for older children, strong social support, or emotional resources, spending a lot of time with their baby can be more than they can manage. Negotiating the maze of continued medical and developmental follow-up may be unduly burdensome. Even if you don't respect lifestyle choices such as drug abuse, know that their lives are way more chaotic than you'll ever know and having a sick baby might be just a drop in the bucket, rather than the center of their existence. Parents do the best they can, and while that may not seem adequate, it's still their best. Judgement is a poison; empathy is a salve—for them as well as for you.

Deal with difficult parents. Every parent comes to the unit with a unique personal history of stress or loss or difficulty adjusting. First assume that any interpersonal challenges you're seeing are a result of the trauma of having a premature infant. If everything you've tried to do to support a parent seems ineffective, call for a psychiatric consultation and collaborate with your affiliated mental health care providers who are knowledgeable about both perinatal stress and psychological dynamics. When a parent

needs support above and beyond what your best efforts can supply, recognize their limitations, don't take their criticisms to heart, and rely on the staff who can work best with these folks.

Give parents the benefit of the doubt. Recognize that even though many parents become overwhelmed at some point or may seem bumbling or incompetent, they do have a life outside the NICU or preemie parenthood where most likely they can function very well. Try to see them as competent people who need time to find emotional equilibrium and learn the ropes in this unfamiliar, often scary situation.

Make referrals. Parents can benefit from support or assistance beyond what you offer, so refer them to resources and get other agencies involved. Most parents would benefit from a support group or psychological counseling. Getting additional assistance outside the NICU will help them get back on their feet, as well as give you peace of mind and the ability to let go, especially with particularly needy parents. If services are lacking in your area, church groups, Internet groups, and national organizations can be important resources. Let parents know that there is a network out there of other parents of preemies. They deserve the benefits to be gained by plugging into it.

Show cultural sensitivity. Nowadays, diversity is the norm. Whether you work in a large metropolitan area or a small village, remain open-minded and become culturally aware.

- Even if the parents look, act, or talk like you, do not assume that they feel like you or think like you.
- Remember that some people have a basic fear or distrust of authority figures. Whether they hail from foreign countries ruled by corrupt or brutal regimes or from the oppressive inner cities of your region, some parents will not automatically look to you for help and support. You can earn their respect and trust, but it may take extra time and effort.
- Always ask parents about their religious and spiritual beliefs. Ask about their rituals for celebrating life, dealing with crisis, and if the baby dies, for honoring the dead. Seek clarification from other family members or cultural and religious agencies.
- Encourage the supportive presence of many family members. Remember that loud displays of weeping are considered normal and appropriate in many cultures.
- Look beyond language barriers and relate to the person. When using a translator, maintain the most common usage and keep your words to a minimum. This reduces the chances of filtering, mistranslation, or confusion. Be aware of the importance of nonverbal communication. Touch and eye contact are more appropriate in some cultures than others.
- Even when English is the common language, choose your words sensitively. For example, you might want to stay away from the phrase "quality of life" because a family may feel as though you're judging them and their baby, implying that they are incapable of providing a quality life for this child. Instead, talk about "suffering." And rather than wondering if parents distrust you because you are from different cultures, ask, "Are you worried that there are medical treatments we aren't offering you?" This gives families a chance to air their concerns and get reassurance.
- Your best credentials are your warmth and sincerity.

Honor the journey that parents are on. Instead of trying to get parents to make the “right” decisions or helping them cope “the right way,” remember that your job is to *walk with them on their journey*. Recognize that while you have much to teach parents, they have much to teach you as well. And how well you listen is more important than what you say. You can shine a light on the options and be a sounding board, but ultimately, you must let them go down the path they feel drawn to.

When a Baby Is Dying or After a Baby Dies

Most hospitals have protocols in place for dealing with families whose baby is dying or has died. However, don't rely on the protocol to be “the absolute right way” to manage every situation. Don't assume that the protocol will suit the needs of every parent. Don't assume that what's right for one family (or for you) is right for another. Don't consider marching through a protocol as the key to providing support to grieving parents. The key to providing support is *forming a warm connection with parents*, including

- Being present with the parents
- Listening and accepting their expression of feelings without trying to fix them
- Being sensitive and responsive to their emotional, physical, and spiritual needs
- Informing them of their options and recognizing that their first decisions may change
- Letting parents know that you will be checking in with them every couple of hours to assess their changing needs and desires
- Giving them the time they need to make the most of their opportunities to have contact with their dying baby or their baby's body
- Encouraging and answering their questions
- Showing tenderness and respect for their baby and later, their baby's body
- Taking into account that this is an exhausting and traumatic time for parents. For example, some parents may find it most helpful to be given time to absorb the shock of their baby's death and warm up to the idea of having contact with their infant's body, instead of having the baby thrust upon them

Perhaps most important of all, instead of persuading parents to buy into a certain protocol, *encourage them to do what is best for themselves*. The goal of encouraging parents to be with their dying baby or their baby's body should be that parents have as little regret as possible about how they handled the opportunity to spend time with their little one. No parent should have to regret a lack of contact; likewise, no parent should have to regret the contact imposed on them. The parents who are reluctant to have contact with their baby can be encouraged but not coerced.

To walk this fine line between encouragement and coercion with reluctant parents, it is imperative that you yourself not be overly invested in a particular outcome. Keep in mind that every parent in this situation is on his or her own journey. Your job is

to walk with parents on their journeys and not to try to force them to take one path or another. Encourage parents to follow their intuitions and their hearts. Some parents will intuitively know without much encouragement from you that contact with their baby is something they need and want. Others need a chance to talk about their reservations, ask questions, and get reassurance. For example, is it scary to be with a dying baby? How will death come? What will death look like? Is it morbid to spend time with the body after death? Others will know that contact is something they do not want. Others need to hear that some parents decline, but that many others find it comforting and helpful to see how normal their baby looks without tubes and wires, and to do nurturing things such as cuddling and dressing their baby, and after death, bathing their baby's body. Some will have lots of ideas and engage freely in nurturing behaviors. Others will be grateful for your culturally sensitive suggestions. You can help parents think about being with their dying baby or their baby's body by describing to them specifically what other parents have found meaningful to do during this time. This gives parents a framework and permission to think broadly about what they might find meaningful and to confront the reality of their baby's dying and death in the context of their bond with their little one. Some will want you to be present when they are with their baby. Others will want privacy. Your relationship and connection with parents will enable you to tune into their needs. Ask them to tell you what are the best ways to support them as they meet death. The benefits of any supportive protocol come out of the heartfelt connection between you and the parent. Build a warm and responsive rapport with parents. Practice good communication skills and informed consent, giving parents options and time to keep their options open and make these important decisions. Encourage them to follow their hearts. *Walk with them on their unique journeys.*

Parents won't remember what you said.
Parents won't remember what you did.

They'll remember how they were affected by your presence.

They'll remember *how* you said what you said.
They'll remember *how* you did what you did.
They'll remember how well you listened
and how they felt supported, understood, and accepted by you.

... and Taking Care of Yourself

One of the most important parts of being an effective caregiver is giving care to yourself. By nurturing yourself first and foremost, you can approach your patients or clients from a place that is centered and healthy. This in turn will better enable you to encourage them on their own journeys toward balance and health.

Acknowledge your own feelings of sorrow. If you form meaningful relationships with the babies and families you care for, then when tragedy strikes or difficulties arise, it can be sad for you too. Even their discharge home can bring mixed feelings of happiness and

sorrow. If you try to deaden your grief, you'll also dampen your ability to feel joy, satisfaction, and accomplishment. Additionally, you'll find it more difficult to tolerate painful feelings in the parents you deal with. It may help you to keep a journal where you can process some of your feelings by writing. Psychosocial rounds are another way for staff to get together to discuss challenging parents, babies, or situations; to talk about emotional coping; and to provide support to each other. Find outlets away from the NICU whereby you can process your own emotions and tensions.

Face your own past losses. Since your work encompasses loss and sorrow, it may dredge up unresolved grief from your past. It is important for you to acknowledge all of your past losses, big and small, and give yourself permission to experience all your emotions and thoughts about them in a safe and private place. Some of your emotions may seem unacceptable to you, but if you have them, you are entitled to them. Find ways to work through your feelings by talking to others, writing, exercise, meditation, creating art, joining support groups, or getting professional counseling. If you can free yourself from the past, you can deal more effectively with the present. (See Chapters 3 and 4 for more on grief and recovery.)

Get your emotional needs met outside the NICU, so that you can become close to parents because they need it, not because *you* need it. This also frees you to be able to truly support and encourage parents. If your emotional bank account is full, you can make meaningful withdrawals without draining yourself or your family.

Find ways to add energy and health to your life. Good nutrition and exercise feed your body and spirit, and can help you weather the demands of your job. Lighten your life by finding the humor or absurdity in things, especially those things that annoy you. Leave your job at work. Trust that the families and babies are in the kind and capable hands of your peers. You do important work, but to do your best, you must make time for play. You need time away to recharge your batteries.

Allow yourself to cry. For many people, crying can be a valuable coping tool. If this is true for you, once you accept its value, it will feel less embarrassing. Still, if your culture or the unit culture frowns upon emotional displays, you will feel pressure to stifle your tears. The trick is to try to find a balance that works for you and the families you work with. For instance, be careful not to express your emotions in ways that put parents in a position where they feel *they* have to take care of *you*. Shedding some soft tears in front of parents may be appropriate and appreciated whereas sobbing usually is not. If you feel you are losing control, excuse yourself, with reassurances that you'll return soon. Find ways to calm down or a place away from the NICU (such as the chapel, where no one would think twice if they saw or heard you) where you can shed your tears.

Start an open relationship with each parent, as if the slate is wiped clean. Do what you need for yourself so that you don't shut down because the last parent was difficult or even if your first impression is poor. Give them the benefit of the doubt and let yourself be emotionally available.

Find a healthy balance in your relationships with parents. Get close to families, but also set limits and boundaries. Don't take on all their problems. You can care about them without taking care of things for them. Find a balance between involvement and detachment. Involvement can allow you to be empathetic and supportive; detachment can protect you from others' emotional intensity. Remember that both extremes—caring too deeply or not caring much at all—when chronic, are ineffective and unprofessional. Caring too deeply and becoming enmeshed can lead to burnout and clinical depression. Not caring and remaining aloof leads to numbness and detachment. A supportive and professional relationship with families includes a balance between and within the two extremes. Balance also includes showing your humanness and honoring your unique, heartfelt style of supporting parents.

Maintain your own emotional balance. If you are sensitive and empathetic, it is normal for you to be affected by the profound emotions expressed by parents. However, you need to be able to empathize without taking on the intensity of others' feelings. When parents are having a hard time and you're starting to feel overwhelmed or over-involved, affirm your boundaries by reminding yourself that you are most helpful when you remember that the pain is natural and belongs to them. Repeat this mantra to yourself: "This is their baby and their journey. I help them by walking with them, not for them." Refer parents to specific support people or organizations; trust them to find their own solutions in their own time. Talk with coworkers and others about your feelings—you are likely to discover that you are not alone, and that others have found ways to keep from becoming emotionally submerged.

Have realistic expectations for your work with families. Do not expect yourself to make a significantly positive impact on every family you work with. Some families will be easier, more rewarding, or a better personality fit for you to work with than others, and that's okay. Also, remember the ripple effect—that by helping just one family, you've made a difference that stretches to many other lives, the way a drop of water makes ripples that fan out.

Have realistic expectations for your work with babies. Remember that you do not have the power to know all the answers. No one is perfect, and everyone makes some errors in judgment and mistakes in care. If you had a crystal ball that told you the information you needed and every correct move to make, you'd use it, because you want the best for your patients. But since you don't have a crystal ball, you cannot expect yourself to always have the answers or to never err. Some babies' conditions are so complicated or bewildering, and some babies are born only to die or to be significantly impaired, in spite of your best efforts. While letting yourself off the hook can be difficult, if you learn from your experiences, then your trials and errors are not in vain. Also learn from the babies and families you work with. While you have much to teach them, recognize that they have much to teach you too.

Understand the emotional aspects of parenting a preemie in the NICU. Part of taking care of yourself is making sure you have the knowledge and skills to do what you need to do every day in your dealings with struggling and distraught parents. If you don't

understand the dynamics or don't have the skills to interact effectively and supportively with parents, you'll continually feel inadequate, drained, and demoralized—the recipe for burn out. Having resources you can rely on—including informational materials, supportive consultants, and colleagues—can boost your competence and replenish your emotional reserve. Push for developmentally supportive care for babies and their parents in your NICU, as this integral part of family-centered care and philosophy will make your job easier and more rewarding.

Push for developmentally supportive care for caregivers in your NICU. Ask your hospital to improve your unit by funding efforts to support staff by providing the time and resources to attend in-services, seminars, and conferences that deal with family-centered care and the emotional aspects of parenting in the NICU. Advocate for the establishment of NICU psychosocial rounds and perinatal mortality rounds, which should be facilitated by an outside professional who is knowledgeable about the emotional aspects of perinatal crisis and adjustment and tuned into the needs of families and staff. (The Schwartz Center specializes in helping hospitals set up rounds like these—for more information on their model, go to www.theschwartzcenter.org/rounds.asp) These rounds can be a place where you and your colleagues can share your experiences, gather insight and ideas for ways of working with parents, talk openly, and alleviate some of the stress of being with sick babies and their grieving families. Also recognize that some staff members have a natural gift for working with dying babies and their families, and they should be considered important resources to all of us.

Know when it's time to move on. If you are feeling burned out, exhausted, depressed, depleted, overwhelmed, or waning interest in the welfare of others, take heed. You may be ready for a significant leave of absence or moving on to new challenges. It can be hard to quit. You may resist this need because of finances, guilt, or feelings of inadequacy. But there is no shame in acknowledging that this job is no longer right for you. You have changed and grown, given and given. Perhaps it's time to seek another path, one that doesn't involve the aspects of your job that you can no longer tolerate. Listen to your needs. Find ways to continue to use your signature strengths. Do what makes you happy, not what makes you miserable.

Being an effective caregiver doesn't involve changing the world. Just plant seeds of hope and encouragement. In other words, don't try to "fix" or erase others' difficulties or emotional pain. You may have the answers for your own life, but don't assume or insist that those will work well for others. People need to feel, recover, learn, move on, and live at their own pace, in their own way. In your role as caregiver, planting seeds means being a good listener and encouraging each person to find their own path. For instance, by giving a teen mother extra nurturing, you have planted seeds of encouragement that can germinate when the time is right in that girl's life. By showing faith in a mother who has little confidence, listening to a dad talk about his childhood, or encouraging befuddled parents to read their babies' cues, you have planted seeds of comfort and assurance that they can draw strength from. If you need closure, it may help you to follow up with families. NICU reunions; follow-up clinics; communication with social workers, pediatricians, and occupational, speech, and physical therapists can

provide this opportunity. Whether you seek follow-up or not, trust that you do make a difference simply by planting seeds of hope and encouragement.

www.ParentingYourPrematureBaby.com