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Neonatal Loss

Welcome to the eighth issue of the ChiPPS electronic newsletter. ChiPPS (the Children's Project on Palliative/Hospice Services) is a program of the National Hospice and Palliative Care Organization and, in particular, NHPCO's Education Work Group, co-chaired by Christy Torkildson and Mary Kay Tyler. Comments about the activities of ChiPPS, its Education Work Group, or this issue of the newsletter are welcomed. They should be addressed to Christy at ctorkildson@georgemark.org or Mary Kay at mktyler@hospicewr.org.

The subject of this issue of the newsletter is neonatal loss. Here is a brief Table of Contents highlighting the articles included in this issue and offering a brief description of each piece.

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Karen Paradise Baranowski, RN

Karen provides resources in our newsletter and maintains an up-to-date calendar on the NHPCO Web site that can be found at <http://www.nhpc.org/pediatrics>

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Passing the Torch: Hard-lessons Learned and Shared from One Family to Another

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Introduction

Two babies. Two weeks. Two best friends. This is a story of how one family's grief and heartache after the loss of their son was shared and made another family's loss of a baby more loving, more compassionate, more healing.

Dylan's Story

We had a routine ultrasound at 16 weeks into my pregnancy with our first child, Dylan, when we learned the news—our baby had a serious birth defect, a congenital diaphragmatic hernia (CDH) and was given a 50% chance to survive. As shocking and overwhelming as this news was, we were also given the gift of time. We had 24 more weeks before he was due to have the news sink in, learn what a CDH was, and appreciate what it meant for Dylan. As we struggled to learn the more technical aspects of our situation (e.g., pediatric anatomy, medicine, extracorporeal membrane oxygenation [ECMO]), we also wanted to bond with Dylan. We wanted him to know and feel that we loved him, we wanted him, and we would do everything we could to help him live. I read books on when babies could start hearing in the womb and knew they could recognize parents' voices, so we constantly talked to Dylan and read to him every night. The neonatal intensive care unit (NICU) doc we met with prenatally acknowledged the impact parents could have and he mentioned the "magical effects" from parents talking to their baby. I felt then we had not been crazy to have been talking so much to Dylan.

We asked if there was a family who would be willing to talk to us who had a baby with a CDH. We met with a local family whose baby survived and they were a great resource. They let us know it would be an emotional roller coaster—one small improvement/step forward would leave you feeling so high, but then you would have a set-back/take two steps back and come crashing down. We would soon know exactly what they meant. They gave us the best practical advice by suggesting we put a message on our answering machine so others could be updated with Dylan's status without bothering us (this was prior to care pages on the web that serve the same purpose). We received many positive comments from family/friends about the "Dylan Hotline." It allowed them to be connected (they could call 10 times a day if they wanted to) without being a burden. This family showed us the photo album of their daughter's month-long stay in the NICU. They encouraged us to take lots of photos in the hospital, "don't wait" they said, you never know.

This support and information directly from a family was invaluable. Nothing can quite prepare you for the experience of having your critically ill newborn baby in the NICU. But this hard-won



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wisdom helped us understand the family perspective—we would not learn this from the medical journals we were reading.

Once Dylan was born, we felt we had good access to him. We had to work around the wires, tubes, and machines, but we could be near to touch, talk, and read to him.

It felt great that NICU staff told us Dylan recognized our voices by observing monitors with vital signs, etc. They said it did not happen when our family was not there—it was only when my husband and I were with him. We were so happy that Dylan “knew” us and we seemed to have a positive effect on him.

My sister-in-law is the photographer in our family and we had two “photo sessions” with Dylan. The first one was when he was five days old and we were able to get great shots. We took them to the one-hour developing (this was pre-digital cameras) and it was good to have them immediately. We taped one of Dylan, Mom, and Dad up in his isolette, told him it was there and we were with him 24 hours a day. We put one on our night stand at home and sent others to family and friends. We did another session when we held Dylan at the end of his life. We are so happy we have these wonderful photos. They are priceless.

After surgery to repair his CDH and being on ECMO in the ICU for two weeks, we decided to remove Dylan from life support because his lungs could not function on their own. That last night we stayed up all night with him. In the middle of the night I asked the respiratory therapist to suction Dylan. She asked if I wanted to and I said yes. It felt really good to do that. Then she asked if we wanted to give him a sponge bath and we said yes. So Mark and I cleaned him up and then put lotion all over him. Doing all of these things for Dylan made me so happy but I had no idea why. What was the big deal, I was just giving him a bath? Later I figured it out. I got to be a Mom and take care of Dylan. I was able to do some of the things I had planned to do with him at home. What we had been doing for the last two weeks was *watch* the staff take care of him. We knew there were things we could not do, things that were medical/technical. But we never realized there were things we could have done. Later I thought, how many times had we watched Dylan being suctioned, have his diaper changed, getting cleaned up, exercising/ range of motion? These things should not have been “saved” for our last hours with Dylan, we should have been taking care of him all along.

When Dylan was getting prepped for us to hold, the nurse asked whether we had Dylan's foot/hand prints. I said I didn't think so, I had not seen them if they were done. So she did that and we cut some locks of his hair. I had not thought of these things at all. I am so glad she did.

There are no words to describe the feelings when we finally held Dylan—what would be our first, only, and last time. It was wonderful for our little family to be so close together. Since Dylan was on ECMO he had a nurse and respiratory therapist with him 24/7, so this was the first time the three of us were alone. It was very comforting Dylan could die in our arms.

Some friends left us a card and book on our doorstep the day after Dylan died. The book was *Empty Cradle, Broken Heart* (by Deborah Davis). I'm glad I read it immediately. I had no idea what this grief would be like and the book helped us tremendously. It did not make us feel



better, but it gave us perspective on what to expect. Grieving for an infant is different than grieving for an adult. It helped me realize I was not going crazy.

After Dylan died I was once again given the gift of time to write our story and reflect upon it—what had helped and hindered our experience. I sent "Dylan's Story" to our healthcare team and also gave it to family and friends. I wanted *and* needed to talk about Dylan, proudly display our photos, and share what we had learned. I heard that our healthcare team had welcomed my story and was acting upon some of my recommendations. Because I was open with our experience, I was getting calls from family/friends/colleagues who wanted to know how they could support a family during a difficult situation—miscarriage, premature birth, and after a child's death. I shared everything I learned from our experience with Dylan plus additional insights from talking with/reading about other bereaved parents. Knowing that Dylan's short time with us here on earth helps other children receive better end-of-life care and supports their families continues to be incredibly healing for me.

Riley's Story

It was mid-December...the season of holiday parties and family get-togethers. Bad things aren't supposed to happen around Christmas, but they do. It was on December 19, 1999, that my niece was born dying with a very aggressive teratoma that had developed in the previous four weeks since my sister's last ultrasound. Without warning in my sister's eighth month, it just grew and grew until there wasn't any viable brain tissue left. It was only a week from when the signs in utero were noticed until Riley Ann decided to enter our world. We were told later the doctors only gave her a day or two to live. She lived two magical weeks and died on January 2, 2000.

Unlike Beth with Dylan, there was no time to prepare for what we were about to go through with Riley. Our heads were spinning, yet the clock was ticking, and ticking loudly. One of my first calls when we knew Riley was in danger in utero was to call Beth. She would know what to do. She'd been through this with Dylan. And she did. Her wisdom, counsel, love, and practical "To Do" list became our roadmap from the second Riley was born and throughout the two weeks of Riley's life. We did some of what Beth got to do with Dylan, and lots of things she didn't, or didn't until the very end. Our experience was better because of what she learned from her loss of Dylan and we're forever grateful to her being there for us through this. Sharing Dylan's story and her struggles during Dylan's two weeks gave us the insight and courage to do what we did with Riley, and, after she was gone, to live with no "What If's."

We held Riley. We bathed her. We sat with her. We rocked her. We took footprints and handprints and cut a lock of her beautiful dark hair for her baby book. My sister pumped breast milk and fed her through a feeding tube. We dressed her in clothes we'd bought in preparation for her coming. We invited all of her family—grandparents, aunts, uncles, cousins, close friends—to see her (two at a time, of course, as she was in the NICU and we were respectful of the other babies and their families). We took pictures, pictures, and more pictures. It didn't matter that it was with a disposable camera. Everyone who came to see her got their picture taken with her. We stayed with her and never left her alone. We had a goal to not let her die without someone from her family being with her.

It was the holidays, so we brought her Christmas presents and Christmas cards, many of them homemade with love. We sang Christmas carols and read her the Christmas Bible story that



we'd never get to read to her next year. We read her some of our favorite kids' books. We told her about Santa. And we surrounded her with love of family and faith. Religious medals of meaning to the family were taped to her isolette and many, many prayers were said around her bedside and alone, in silence, in other places.

We also had great nurses who made reindeers using Riley's feet as the antlers and taped it to her isolette with a note to my sister's family that read, "Merry Christmas Mom, Dad, Nolan and Dylan. Love you, Riley." We still have that reindeer today. The staff became our extended family and held her if we needed a bathroom break. They created space for us in the hospital in a private room, to be with her and to let her 2- and 5-year-old brothers come visit her and spend time with her. The nurses encouraged us to take Riley home even with the accompanying medical equipment...first for 8 hours to see how it felt, and then overnight on New Year's Eve, so my sister and her family could create some memories of being with Riley at home. The nurses told us that Riley knew that we loved her. They couldn't possibly know this, but just hearing them say it, made us feel better. We needed to hope that Riley could feel our love and the nurses provided us with that validation we would never get from Riley.

Unlike Beth and her two weeks with Dylan, perhaps one of the most important things the nurses did was to let us care for Riley, but more importantly, we knew to ask if we could do this, and the pay-off was huge. It let my sister be Mom to her, and allowed the rest of us to play our respective familial roles of dad, brother, aunt, grandma, and grandpa. The staff was there if we needed, but they supported us without intrusion so we could create the memories we were going to need to last us a lifetime. They operationalized neonatal palliative and hospice care in a system where there wasn't such a service, and it made a difference as we let Riley go with no regrets.

Our Aha! Moment

Oprah loves to talk to guests about their "Aha" moments. We all have them, it's just that some are bigger than others. A few months after Riley died, Beth and I were comparing our experiences of the losses of these two beautiful babies and realized there was something powerful in the sharing of these stories, and the hard-lessons learned. We concluded that if we could have this impact one-to-one, imagine how many others we could help by passing the torch of what we'd learned to other families and the healthcare profession. It was out of this Aha! moment that our mission of advocating, educating, and conducting research to assist families, healthcare professionals, and the community in being supportive during and after the death of a child was spawned. We continue to try to be the illuminating "family voice" for pediatric end-of-life care because we know first-hand the lifelong impact that sharing families' stories can have on one baby, one child, one family at a time. Encourage the families and colleagues you work with to pass their torches to other families and staff so that a loving light will always guide their way.

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Palliative Care and the Special Care Newborn

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Introduction

For parents experiencing the special care nursery (SCN) the environment may be as intimidating and frightful as the news that their infant requires intensive care. Indeed, it is one of the most sophisticated and technical environments in any hospital. While intensive care is applied in measures aimed at stabilizing the infant's perturbed physiology during the transition from intrauterine to extrauterine life, it is at once necessarily intensive, often invasive, and at times aggressive. The intent of such care is without a doubt to save lives. But what happens when a newborn is not responsive to such life-saving interventions? When can, or should, curative treatments give way to comfort-oriented, supportive, or palliative, care? Is it an anomaly for palliative care measures to be considered amid the SCN? If not, when and for whom should palliative care be offered? In the following paragraphs, this article will endeavor to address the important concept of palliative care for newborn infants, some ethical principles underlying decisions for such care, and a brief "how to" section on the provision of family-centered, comprehensive palliative care in the SCN.

Background

In 1982, the application of palliative care [hospice] concepts to certain newborn infants was first described in the U.S. by Whitfield and colleagues [1]. For clinicians who practice in the SCN or neonatal intensive care unit (NICU) it might at first seem contrary to the goals of neonatal intensive care to meld palliative care principles, goals, and environments with those inherent to an intensive care unit. Nonetheless, they can endeavor to create a space where highly technical life-saving care and compassionate comfort-oriented palliative care can coexist in a patient and family-centered unit. It might even be stated that these facets of care can complement each other. By virtue of their histories, and the patient population that they serve, most SCN staff consider themselves competent to care for newborns that die. However, there is a wide, and often inconsistent, variety of supportive care measures that are actually provided for hopelessly ill newborns – and their families – that underscores the reasons for taking opportunities now to improve palliative care in the SCN. Comprehensive palliative care that is applied in a compassionate manner includes not only the care of the imminently dying newborn, but managing her pain and other symptoms, providing psychosocial and spiritual support for family members, and making efforts to address her quality of life and best discernable interests in a culturally sensitive, negotiated, and family-centered manner. When these measures become the focus of care, three specific stakeholders in the SCN will be in a position to benefit: the newborn patient, his/her family, and the SCN staff.

The need for palliative care in the SCN is underscored by the large numbers of neonatal deaths when compared to older infants and children. According to the 2003 Institute of Medicine report *When Children Die*, 34% of childhood deaths occur in the neonatal period [the first 28 days of postnatal life]. And, when examined by disease-specific cause, 28% of all childhood deaths



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have some neonatal-perinatal origin: "More children die in the first year of life than in all other years of childhood combined," the preponderance occurring in the neonatal period [2].

Potential candidates for palliative care are not difficult for experienced SCN staff to identify, and generally fall into 3 categories: extremely premature/extremely low-birth-weight (ELBW) newborns at the limit of viability (typically ≤ 24 weeks' gestation and < 500 grams); newborns with a lethal congenital anomaly or birth-defect syndrome (at times diagnosed prenatally); and newborns that no longer continue to benefit from appropriately applied life-extending, cure-oriented, intensive care that are now considered to be suffering from its undue burdens.

When palliative care is the prevailing care paradigm, it may follow delivery room resuscitation that is either unsuccessful, wherein supportive care to the mother and infant is focused on comfort, support of spiritual rituals, creating positive memories, and initiating grief and bereavement work. Palliative care may also follow a successful delivery room resuscitation and aid in getting the newborn into the SCN where a confirmatory evaluation of a known or suspected anomaly can be initiated, or an initial trial of intensive care be offered and the newborn evaluated for response over some limited time period. If intensive care measures are applied while awaiting a confirmation of a lethal anomaly/syndrome, this does not preclude the concomitant provision of supportive, palliative measures, nor does it preclude the subsequent withdrawal of life supporting medical technology. Communication and supportive care are essential in these situations.

The uncertainty of outcomes in the SCN may make it seem difficult for staff to prognosticate and readily identify patients for whom palliative care is best suited. But clinicians who are honest about known generalizable outcome data for the three broad categories of patients noted above will know when to engage families in conversation about the limits of benefits for continued SCN care and when such benefits may be eclipsed by burdens. Open communication, transparency in clinical thinking and decision-making with families, and knowing local or regional outcome data are essential in discussing and implementing palliative care. In the face of uncertainty, decisions are colored by more subjective and value-laden considerations than objective certainties. Families, provided that they are present and informed, should retain the primary role in voicing those values that guide their newborn's care. This rule should generally apply unless parents appear to be acting out of self-interest, or interests that conflict with their newborn's well-being. At times, a negotiated determination of the newborn patient's 'best interest' by family, staff, and supportive persons, may need to be pursued. This certainly should be more meaningful and meet with greater accord than a course of care prescribed solely by clinicians and their notion of 'best interests.'

As discussed in a previous newsletter, parents whose newborn requires admission to the SCN experience loss that is multifaceted – including the loss of the idealized healthy-term baby, the loss (or ending) of the pregnancy, the loss of self-esteem as a healthy parent, or perhaps even a loss of the social status normally conferred on parents. If a parent has prior experience with perinatal loss, this may shape current feelings and responses to events as they unfold in the delivery room or SCN. Realistically, families often anticipate the potential death of their sick or premature newborn. These families all stand to benefit from those aspects of palliative care that generally can be integrated into the SCN: emotional, psychosocial, and spiritual support – all of



which are part of an overarching palliative care paradigm but may not be applied consistently in all settings.

Some Case Examples

The following cases are intended to illustrate potential recipients for palliative care.

Case 1: *Baby A was born prematurely at 23 and 1/7 weeks' gestation, weighing 540 grams. Apgar scores were 1 and 3, depressed due to mother's severe pre-eclampsia. Following initial resuscitation, life support was initiated and she was managed in the SCN for respiratory failure, metabolic acidosis and hypotension. She failed to improve on maximal life-support and over the next 36 hours developed pulmonary complications and a large intracranial hemorrhage. After discussing with her mother the unlikely survival of her daughter to discharge from the SCN, and the grave concerns for her health in the remote circumstance that she did survive, she was removed from life support and died shortly thereafter.*

Case 2: *Baby B was born following a complete placental abruption at a community hospital without a SCN. He was resuscitated and air-lifted to the regional SCN. He was profoundly depressed, had multiple acute problems, and developed seizures shortly after arriving. The non-English speaking parents made the trip to the regional SCN 24 hours after their son's delivery, seeing him managed on assisted ventilation and receiving medically-induced hypothermia and anticonvulsants for his severe encephalopathy. Following 72 hours of hypothermia and an EEG that demonstrated persistently severe encephalopathy, they discussed with the SCN staff all options for continued care and potential outcomes for their son. They determined that they did not see continued mechanical ventilation or artificial nutrition and hydration to be in their son's best interests and asked that they be withdrawn. An ethics consultation was pursued by the staff and ultimately the family's wishes were supported. Baby B received comfort-oriented palliative care in the SCN, receiving small volumes of oral or nasogastric tube feedings – due to significant gastroesophageal reflux – that were administered by his mother. A feeding gastrostomy and fundoplication was not desired. He went home under a hospice care program receiving small volume nasogastric tube feedings and his anticonvulsant medication. At nine months of age he remains hypotonic, has occasional seizures, and has been seen by his neurologist. He continues to receive home-hospice care.*

Case 3: *Baby C was born with trisomy 18 and a complex congenital heart lesion diagnosed in utero as likely hypoplastic left heart syndrome (HLHS). Having decided against pregnancy termination, her neonatal management was addressed by the pediatric cardiologist, neonatologist, and geneticist who met with the family when they made serial visits to their maternal-fetal medicine specialist. The family felt 'prepared and educated,' as they spent numerous hours reading about the trisomy 18, as well as congenital heart disease, on the Internet. At birth the cardiac lesion was not HLHS but was a double-outlet right ventricle and was not creating any critical instability. Her family asked to take her home after mother recovered from delivery and the neonatologist and cardiologist counseled her and her husband about the likely signs and symptoms that might herald impending death at home. Her pediatrician came in to the hospital for the discharge planning meeting and met the SCN*



staff as well as the home hospice coordinator. A mutually derived care plan was developed and implemented.

Decisions for palliative care may best be framed around consideration of the infant's well-being, perceived interests (generally related by parents), and a balance of the burdens and benefits of continued life-prolonging interventions ("treatment" may be a misinterpreted or misunderstood term by some parents - implying healing and resolution of a disease process which may not, in fact, be realistic).

"All treatments are interventions,
but not all interventions are treatments."

When clinicians want to promote collaboration and accomplish shared decision-making, the use of transparency in thinking and deciding together may be helpful. Palliative care and life-extending intensive care are not mutually exclusive, but each aspect of care may wax and wane over any given patient's course of illness in the SCN. When death becomes foreseeable, or imminent, clinicians should consider removing or withholding those interventions that may only prolong patient suffering and stand in the way of a transition to palliative care. In such settings, either in the SCN or in a private room off the unit, patient comfort, human contact, and family support that allows creating positive memories may comprise the main goals of care.

Professional care-givers in the SCN often must consider certain facts in decision-making about whether or not to apply palliative care. These facts generally fall into two categories. First, are the medical facts about the newborn and his/her diagnosis, responsiveness to treatments or care, potential responsiveness to treatments or interventions being considered, and the prognosis. The second category of facts to weigh is that of pertinent human value considerations. Questions here may need to address what the parental expectations are, the values, principles, and psychological underpinnings that inform parental risk consideration and assessment as it pertains to their newborn, and how they weigh options in decision-making (of course, the health care team may also need to ask these questions of themselves). These kinds of facts are not explicitly discussed on SCN rounds each day. But, they may be elucidated in such settings as care conferences, ethics consultation, or other planned conversations in which parental values and perspectives are determined in efforts to best inform and shape choices about the newborn's care. The American Academy of Pediatrics has published guidance about decision-making for critically ill newborns that acknowledge the need for these human value facts to be clearly elaborated – just as medical facts are – in order to allow for an informed and shared decision-making process.

Ethical Considerations

Ethical considerations in neonatal palliative care can be organized into a few broad categories. Patient selection for palliative care has a potential for abuse, and the use of principles such as of justice, equity, and nonmaleficence may all prove helpful. In its definition of palliative care, the World Health Organization (WHO) states it is intended for those patients for whom "cure" is not a reasonable expectation – or perhaps is not even possible. The WHO also advocates for an active and comprehensive management of the whole patient receiving palliative care – not



merely an abandonment of care when cure-oriented treatments are no longer being offered. Frequently, the clinicians and families in the SCN must wrangle with when to withhold or withdraw certain of life-sustaining measures, “Do Not Resuscitate” orders, and both substantive and procedural matters that are applicable to a given patient and family that may be influenced by institutional or other (e.g., state) jurisdictions. Clinicians must be familiar local and state laws that affect care within their institutional and given jurisdiction. Ethical considerations may also be operative in how staff and family communicate, undergo disclosure (truth-telling), and how they honestly appraise the need for and allowance of neonatal palliative care, as well as matters of professionalism.

An article on this subject would be remiss if it did not note concerns for malpractice liability, as well as the Baby Doe regulations, that have influenced physician’s attitudes and actions in withholding or withdrawing life-sustaining interventions from time to time – even when many would declare such actions as just, humane, and clinically appropriate. The so called Baby Doe regulations provide for three indications in which life-sustaining measures may be withheld or withdrawn:

- irreversible coma,
- treatment that prolongs dying, is not effective, or otherwise is futile in terms of survival, and
- treatment that is considered inhumane.

Practical Considerations...a brief “How To” section

When considering palliative care in the SCN, all professional care-givers should consider the following:

- Determining which infants should receive palliative care.
- Identifying any barriers (physical or philosophical) that exist and limit the provision of palliative care.
- Discerning from staff and families both what they consider to constitute an optimal care environment for palliative/end-of-life care.
- Discussing with staff and families the timing of when clinicians should approach families about decision-making, advance care planning, and the goals, values, and preferences that factor into optimizing palliative care in the SCN. These discussions should also be documented and accessible to other professional care-givers for times when primary staff are not available.
- Determining if a “Do Not Resuscitate” order is appropriate in advance care planning.
- Assessing and managing pain and other symptoms optimally.
- Clearly defining the roles that social workers, educators, child-life specialists, pastoral care providers, behavioral health specialists, and bereavement specialists will have in the SCN.
- Considering the role and value of a parent support group or network.
- Recognizing that professional health care staff need to be supported, too; and developing a staff support model accordingly.
- Considering linkages, affiliations and collaboration educationally, programmatically, and in clinical service that might be developed with an area hospice.



- Looking into community resources that might be accessible to families as they transition out of the acute care facility.

Pieces of Palliative Care for the Newborn

Addressing end-of-life care and minimizing suffering includes attention to the physical environment of the SCN, and ensuring an actualized philosophy of family-centered care. Such measures will facilitate shared decision-making, advance care planning, and the incorporation of psychosocial and spiritual support, too.

If a newborn is likely to die in the SCN, she may be relocated to a nearby family care room. At times this will precede the withdrawal of life-support (e.g., ventilator and endotracheal tube), but it may follow certain cessation of other technologies (e.g., intravenous drips, ECMO, chest tubes). The idea is to facilitate a family space that allows proximity and does not impede human touch, holding, or shared time by parents and extended family. In hospitals with a private SCN room, the same room may be re-arranged to accommodate more support people, become quieter, and intentionally have staff interruptions diminish to allow for greater privacy. Alternatively, relocating to a room outside of the SCN or on a general inpatient pediatric unit may be best.

Symptom Management

In the most critically ill newborns, death occurs soon after assisted ventilation is removed. In others, survival after life-sustaining measures such as the ventilator may be expected. These might be newborns with metabolic, genetic, or neurodegenerative disorders. A home-health or home-hospice service that is provided in the family's home may best serve these children. A primary care provider (pediatrician/neonatologist/family physician) who can serve as a coordinator and director of the numerous aspects of home-care in a palliative/hospice paradigm is essential for successfully managing the patient, his family, and the home-health/hospice staff. Skilled symptom management for pain, skin care, oral hygiene, dyspnea, nausea, or seizures can be expected and should lead to prompt attention. Medically assisted means of feeding may be preferred by parents, and services should be available; they are not, however, always required or recommended. The goals of medically assisted nutrition or hydration are different in focus for these children – patient comfort is of primary concern for the infant, not growth and development when such is unlikely to be possible. Opportunities to provide nurturing parental care should also be supported, but the differences in feeding approaches, volumes, and outcomes (including risks of harm) must be clearly addressed.

Making Good Memories

Memories matter most when there is no infant coming home or surviving, and parents cling to them as they might to their child if only they had the opportunity. In tandem with parents' memories are key care-givers and their words, personalities, space shared, and support in times of crisis. In this realm parents also may seek and find meaning for their newborn's life and, perhaps, for their experience of loss. An existential, or spiritual, dimension to care for families amid these difficult times requires attention by appropriate community clergy, pastoral care professionals, other support persons, and all inpatient or homecare professionals. Simple measures of support can be offered by clinicians when they simply ask what the family desires, how they usually manage difficult situations and problem solving, or if there are any people that



they would like the staff to call. At times, religious rituals (e.g., baptism, prayer, other) or other traditions may be provided that are memorable. Certainly, material objects that will contribute to long-lasting memories (e.g., a lock of hair, infant name-bands, crib card, hand or foot molds) also have meaning and should be provided to parents. Photographs may likewise be important. Sensitivity to cultural norms for holding, or touching, the dying or deceased baby must also prevail – requiring some earlier inquiry about these matters. Efforts to allay maternal guilt may be made in sessions both pre-death and in after-death care where the prenatal history is reviewed, and preventable or potentially recurrent conditions are noted. To this end, the consideration for the value of a post-mortem examination or referral to a genetics counselor is entirely appropriate. Finally, in addition to collecting mementoes, bereavement services information (local contacts and information for community-based support groups) may facilitate family healing after perinatal loss.

Staff Support

As intensive as any other aspect of neonatal intensive care, the provision of comprehensive palliative care is physically, intellectually, and emotionally demanding. Staff providing patient care and family support in the SCN from all disciplines may need support after caring for a dying newborn. Clinicians may naturally form attachments to patients and families that have the potential for subjective and emotional ramifications during or after a patient's course of care. In the SCN, attachments end through health and discharge of the newborn home, or through the newborn's death. Many SCN staff feel great loss when a newborn dies. And, like the parents who may go home without a baby, this loss may be unrecognized, invalidated, or disenfranchised. The potential sense for clinicians to feel they have 'failed,' or have been frustrated in accomplishing a desired good, or simply are sad when a newborn dies must be realized and dealt with. An interdisciplinary team approach in decision-making may help diffuse some of these feelings. Behavioral health or spiritual support may also be appreciated by some SCN staff. There may also be a helpful place for small group discussions, formal critical incident debriefing, or interdisciplinary morbidity and mortality reviews. When palliative care in the SCN results in a peaceful death for the newborn and family, staff should feel a sense of professional and personal fulfillment.

Conclusion

The application of palliative care principles in the SCN is absolutely necessary. All clinicians and staff can work together to provide an environment in the delivery room or the SCN where palliative care can be integrated into patient and family care plans. Such plans need not conflict with treatment goals such as obtaining a cure or prolonging life, and always have a place for comfort until an expected death. The best interests of the newborn patient remain the focus of such care. And the care should be consistent with the goals, values, and preferences of the family that are elicited in a manner respectful of their culture and faith tradition. An active palliative care plan – not just "being there" – is required to address both the physical comfort of the infant and the emotional, psychosocial, and spiritual well-being of the family. Peri-death care that includes anticipatory grief and bereavement support should be provided to help families integrate their experience of loss into their lives. Finally, professional care-givers should acknowledge the need for self-care in order to sustain their ongoing capacity to provide compassionate palliative care for SCN patients and families.

* * *



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Experience with Implementation of a Palliative Care Team in the NICU

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In the United States, the majority of infant deaths occurring during the first 27 days of life will take place in the Newborn Intensive Care Unit (NICU). Currently, the leading causes of infant death are congenital malformations and disorders related to short gestation and low birth-weight. ⁽¹⁾ Maternal complications of pregnancy are another leading cause of newborn death. ⁽¹⁾

In order to better meet the challenges in caring for dying infants and their families, Alta Bates Summit Medical Center (ABSMC) implemented an interdisciplinary team approach to neonatal palliative care in 2003. ABSMC's NICU is a 55-bed community Level III nursery with approximately 1,100 infant admissions each year from the hospital's labor and delivery unit, high-risk perinatal program, and transports from other facilities. The racial mix of infants admitted to the NICU is black 36%, white 20%, Asian 13%, and other 31%; 32% of the infants' ethnic origin was Hispanic. In the past 5 years approximately 18–24 infant deaths occur in the NICU annually.

Formation of the NICU Palliative Care Team

Implementation of a Palliative Care Team (PCT) approach came after the death of an infant that was particularly challenging for the NICU staff. ⁽²⁾ The original planning committee was comprised of the neonatal Clinical Nurse Specialist (CNS), chaplain, social worker, and several staff nurses. To gather ideas and resources for improving care, the planning committee conducted a comprehensive literature search and contacted several other NICUs to identify best practices. Approval for the interdisciplinary team approach was given by the neonatology medical team and NICU nursing leadership and the team was expanded to include the medical staff, NICU pharmacist, lactation specialist, parent support group leader, Support After Neonatal Death (SAND) leaders, and bedside nurses. Initially five bedside nurses from each shift were on the team; currently there are 20 bedside nurses from each shift. Attendance by bedside nurses at meetings is paid. The team met every two weeks during the first months of implementation, then monthly. Currently the team meets approximately every six weeks to review all infant deaths, any known families with a prenatal diagnosis where Palliative Care is an option, and also to review current resources that may need revising or to develop new resources.

Resources

To support staff in providing optimal care to dying infants and their families, the team developed the following resources: a Palliative Care Protocol, a Palliative Care Pathway, a palliative pain management resource, a cultural grief resource, a lactation resource ⁽³⁾, and a family-centered informational guide for decision making following the death of their infant. Catlin and Carter's article "Creation of a Neonatal End-of-Life Palliative Care Protocol" ⁽⁴⁾ served as the primary



source for the protocol. The PCT received additional guidance from Dr. Catlin during the development of these resources.

- Books, booklets for parents and other family members.
- Quilts, blankets, Teddy bears for memory making.
- Two brochures for parents describing palliative care in the NICU or perinatal units.
- Postpartum discharge instructions specifically written for mothers following loss.

Family Follow-up

Two PCT members, the chaplain and the NICU parent support group leader, organized a system to send remembrance cards to families one month after the infant's death. An initial phone call is made by the SAND (Support After Neonatal Death) leader seven to ten days after the infant's death. The leader offers support, an opportunity to talk, and information as requested by the parent. If the family is receptive, the leader calls again; caregivers who were close to the family may also call, and families are invited to call the chaplain for additional support. In September, all families who have experienced a perinatal or neonatal loss are invited to participate in the annual "Walk to Remember"; this annual October event is an opportunity for families not only to share their grief but also to remember and celebrate the life of their child.

Staff Education and Support

Staff education and information dissemination strategies about palliative care included presentations at staff meetings, NICU skills days, a day-long workshop, and Resolve Through Sharing ⁽⁵⁾ training. In addition, the authors also participated in End of Life Nursing Education Consortium-Pediatric Palliative Care (ELNEC-PPC) training. ⁽⁶⁾

In addition, the PCT identified the need for a structure to provide grief support for staff as one of its goals. After every neonatal death the need for a caregiver grief support meeting is evaluated. These (paid) meetings, facilitated by the NICU chaplain, provide an opportunity to discuss feelings, grief responses, coping strategies, and encourage peer support, and are completely confidential. The meetings have been attended by as few as two staff and as many as 15. The most common sources of need for grief support are unexpected patient deaths, traumatic deliveries, and difficult situations with families.

Lessons Learned

Every neonatal death is unique and presents its own challenges. Anecdotal reports from staff indicate that the skills and comfort levels of the entire nursing team caring for dying babies have improved due to staff education and utilization of the new resources and supports.

Infant deaths do not come in a predictable pattern. Sometimes months pass without a death; conversely in one six-week period 15 infants died from widely varying causes. Grief support meetings for staff are scheduled at convenient times (for example, at the end of night shift or the hour before the beginning of the evening shift). To emphasize the importance of these activities attendance is paid time. Feedback from nursing staff has been generally appreciative, especially for the improved grief support and additional caregiving resources.



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We have learned from the grief support groups that for some nurses the care of dying infants is too distressing. For some, memories of previous losses and traumas may be triggered; for others, emotional responses are too strong to be comfortably controlled. Discussion among staff has heightened our awareness of differences in each other, provided a forum for listening and support, and improved awareness of and access to the cost-free psychological services available through the Employee Assistance Program.

Involvement of the physicians and the NNP (neonatal nurse practitioner) in the development and implementation of the PCT program was pivotal. Their support for needed improvements in end-of-life policies made it possible for the work of the committee to proceed smoothly. The chaplains' role in educating caregivers about cultural and spiritual needs of individual families has been a tremendous asset to bedside caregivers and the PCT. Further, since the inception of grief support meetings facilitated by the chaplain, staff on all shifts has greater familiarity with services the chaplain can provide to families and themselves. As a result, nurses recommend chaplaincy services to families more often and also call for chaplaincy support more readily during challenging end-of-life situations.

Program Evaluation

In early 2007 the NICU nursing staff were asked to complete a survey regarding the Palliative Care program to ascertain whether they found the program and resources helpful in their care of the dying infant. The survey revealed that many of those who responded were unaware of the palliative care team program or available resources. Further exploration provided one possible explanation for this apparent lack of knowledge. It appears that each shift has a core group of nurses (all are members of the PCT) who volunteer or are regularly requested to care for dying infants and their families and in fact provide the majority of palliative caregiving. As a result of this survey those who had responded and declared an interest in providing Palliative Care have been invited to join the PCT.

Why is the majority of staff not aware of the program and its resources, despite the extensive education efforts in 2003-2005? Staff who do not routinely care for these infants have become over time unfamiliar with this care. In 2006, for example, there were 18 deaths in the NICU out of 1100 admissions. Fewer than 50 nurses out of a possible pool of 200 staff provided palliative care for these babies during last year. In staff meetings and skills days we will continue to explore staff attitudes towards palliative care and ways to support professional growth in this field.

Next Steps

We are collaborating in the development of policies that better support the families and staff facing the death of an infant in the L&D unit. Currently we are collaborating with the perinatal medical team to develop and implement guidelines for the borderline viable infant, including prenatal consultation with families regarding the location of care of the dying infant. It is hoped that this will lead to the development of a pre-printed order set for the provision of Palliative Care in labor and delivery that is similar to one already established in another Bay area facility.

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Providing Emotionally Supportive Care to Parents Facing the Choice between Palliative End-of-Life Care and Intensive Care in the NICU

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In any neonatal intensive care unit (NICU) there are babies who will clearly do well, and there is no question that aggressive medical intervention is the right path. Parents are involved in their baby's care, informed about their baby's condition and treatments, and included in decisions when there are treatment options to choose from. At the other end of the continuum are the babies whose prognoses are clearly grim, and there is no question that intensive care is futile and palliative care is the right path. These parents are also involved in their baby's care, informed about their baby's condition and treatments, and included in decisions when there are palliative care options to choose from. In both of these instances, health care practitioners are *decision leaders*, letting parents know that the clear prognosis points clearly to an appropriate treatment path.

In the middle of this continuum are the babies for whom the prognosis is unclear. These instances include preterm babies born at the edge of viability; infants who are born with a life-threatening condition for which there are only risky, experimental, or questionable treatment options; infants who are deteriorating in spite of intensive care. For infants whose recovery or intact survival is uncertain, it's possible that intensive care would offer more harm than benefit.

With an unclear prognosis, the best treatment plan is also unclear, and practitioners become *decision collaborators* with parents. Parents are involved in their baby's care, informed about their baby's condition and treatment options, told about the uncertainties and possibilities, and offered the heart-wrenching choice—to pursue aggressive medical intervention or palliative end-of-life care.

As a health care practitioner who may work with these families, whether you are a counselor, physician, midwife, or nurse, you already know that decision-making discussions with parents are never easy. For parents, the emotional landscape is fraught with painful feelings of grief, guilt, and overwhelming responsibility. It can be mighty tempting for you to focus on medical issues and ignore the emotional ones. And of course, you do need to convey important medical details and options to the parents. But when parents are in emotional shock or turmoil, they won't be able to absorb the information you wish to impart, and collaborative decision-making can be supremely challenging. To enhance communication and your working relationship with parents, providing emotional support is key. Specifically, "*providing a safe holding environment*" and "*maintaining therapeutic boundaries*" are key elements of effective emotional support, which can be a lifeline to parents as they make pivotal, agonizing decisions. Continuing emotional support can also help parents cope with their baby's journey and adjust to their baby's outcome.

These key elements of emotional support, "providing a safe holding environment" and "maintaining therapeutic boundaries," are described in the previous issue (#7) of this newsletter,



in the article *Providing Emotionally Supportive Care to Parents as They Face Decisions After Prenatal Diagnosis of a Baby's Life-Limiting Condition* (pages 22-25.) Please turn to this resource for more information:

http://www.nhpco.org/files/public/ChiPPS/ChiPPS_May_2007_final.pdf

To review, when you provide a safe holding environment, you offer parents the opportunity to process their feelings, which enables them to participate in these difficult conversations, and to do the heartfelt work of clarifying their values, evaluating the options, and determining the best interests of their precious baby. When you maintain therapeutic boundaries, you can offer clear information about aggressive treatment options *and* palliative, end-of-life care, and you can see parents as competent to face these tough decisions and figure out for themselves whether it is best to continue intensive care, take a “wait-and-see” approach, or go directly to hospice care.

After making the pivotal decision, parents' emotional ordeal is not over. Whether they turn toward intensive care or toward end-of-life palliative care, they must cope with the uncertainties of their baby's medical course, struggle to be a parent in a crisis situation, figure out how to spend their time most meaningfully with their infant, and grieve for their shattered dreams of a healthy newborn. But it's the parents who turn toward end-of-life palliative care who most often face the additional challenges of making peace with their decisions and dealing with judgment from others. Why? Because in our society, parents who choose aggressive intervention in the NICU are mostly lauded for their courage in the face of great obstacles, admired for choosing “heroic medicine,” and praised for seeking a “medical miracle.” In contrast, parents who choose hospice care for their babies can face criticism from others and second thoughts in themselves. Letting go can feel so much more painful than holding on. You can offer these parents additional support in the form of helping them process and reframe their doubts, and giving them ideas of how to respond to others who may judge them.

ADDRESSING PARENTS' WORRIES AND DOUBTS

When parents express any anxiety, worries, guilt, or doubts about their decisions to seek end-of-life palliative care for their critically ill infant, first assure them that their feelings are normal, a healthy part of grieving, and shared by many parents. They can find great comfort in knowing that they are not alone, and that their intense experience and reactions aren't abnormal or crazy. Second, when you take the time to engage parents and listen to what they are struggling with, you can also offer specific reassurances. Typically, parents benefit from assurances that their decision is ethical, in the best interests of their child, and an indication of their love and devotion. Helping them reframe their decision in these positive ways can help them move through the natural feelings of guilt and responsibility, and toward making peace with their decision—and their baby's short life. Here are some questions that many parents ask, and answers that you might offer them.

(Note: Parents may entertain these worries and doubts while their baby is still alive, and perhaps even more after their baby has died and they are in the thick of grief. The following questions and answers are written in present tense for parents whose baby is still alive, but you can also rephrase them to respond to parents whose baby has already died.)



Have I missed some critical information or advice?

It is natural to go over and over the facts and retrace your steps. You may wonder if you've overturned every stone, if there are other choices to consider. But the bottom line is, given the options, information, and resources available, you are making the best decision possible. Remember, your choices are rightly based on what you can see, hear, or know, not on what is invisible or unattainable.

Should I trust the doctor's advice to turn down medical intervention?

Relying on your doctor's judgment can be a reasonable course. Your doctor has the benefit of years of training, experience, and consulting with specialists. If you discover later that your doctor is giving different advice or using new techniques, it's because certain things will be possible that are impossible, risky, or experimental now, in your child's time.

Does my baby feel rejected?

You are not abandoning your baby. You're allowing your baby to follow his or her destiny. What your child feels is your devotion and nurturing. Letting go is an act of courage—and love.

Does my stress interfere with my judgment?

With or without stress, these decisions cannot be totally rational. There is a crucial emotional component to the situation. Your emotional intensity actually enables you to make this decision with your heart and gut, as well as your mind.

What if we'd continued treatment and to our surprise, our child thrived?

If you could look into a crystal ball and see that your child would die or be in a painful or vegetative state if you chose intensive care, you'd stop second-guessing yourself. Since you have no crystal ball, you can only make assumptions. You can choose which ones: those that let you live in peace, or the ones that plague you. Assume that you are tapping into an accurate assessment of your baby's chances. Assume that your decisions are best for your child.

Are my decisions what my child wants?

No one is closer to your baby in blood, body, and spirit than you. You may feel as if you are merely making your best guess, but your best guess is the best one of all. No one else can do this for your child as carefully, thoughtfully, purposefully, and solemnly as you are. Trust in your sense of what this child wants.

What about the ethics of my decision?

On some level, you're engaging in complex ethical thinking. You are drawing on your basic values about life and death; you are weighing costs and benefits and striving to determine "best interests" and "higher good." You're coming to some of the same conclusions that respected and renowned ethicists have spent years honing. Your decisions are ethical.

It's such a burden to bear. Shouldn't someone else make these difficult decisions?

There is no such person. These decisions deal heavily in matters of the heart. You, the parents, are the most appropriate decision makers. It is a heavy responsibility to bear, but your baby would want you, not strangers, to decide. If you had been barred from making these decisions, you would probably feel even worse. You are not deciding to let your child die. You are deciding to let nature take its course, or to let God's will be done.



Will second thoughts always haunt me? How can I stop questioning my decisions?

Asking “What if?” is a natural part of grief. Having doubts does *not* mean you made any wrong decisions. As you work through your grief and come to terms with your baby’s life and death, you will come to accept reality, rather than wishing things were different. “What if’s” become gentler: “If only he hadn’t gotten sick/been born with problems/arrived so prematurely.” Over time, as your grief diminishes, so will second thoughts.

ADDRESSING THE HARSH JUDGMENT PARENTS MAY FACE

When they face the harsh judgment of others, you can encourage parents by asserting that other people have no right to criticize. You can also affirm parents by explaining that harsh judgment is more descriptive of the person it’s coming from. Judgment tends to arise in self-righteous, moralizing people who presume to know what’s best for everyone else. Judgers also tend to cling to a black and white view: “Life is good and death is bad.” Or their capacity to reason shuts down when they hear the word “baby.” They may fear that if we “allow” the sick babies to die, next thing you know, we’ll be putting pillows over the faces of healthy children. And there are those who only see hospice care decisions as abandonment because of their own buried feelings of rejection. Those feelings of abandonment and rejection don’t belong to the baby, but to them.

Sadly, it may be close family members who voice the strongest opposition. They may try to distance themselves from their feelings of responsibility by vehemently disagreeing with decisions made. The more they disagree, the more they can try to shield themselves from any painful feelings of guilt. Others may feel angry and deprived of a beloved child and the parents can become their target of blame. This can be very painful. Remind parents that they don’t require others’ approval to know they’ve made the best decision, the right decision for their baby. However, in the thick of grief and doubts, it is normal to be upset by rude, confrontational remarks. Also, a criticism can painfully echo a parent’s own doubts, and incite a cascade of guilt or worry.

Sometimes, not responding to doubters and judgers is a valid option. But if destructive comments come from someone with whom the parents have an ongoing relationship, it may serve them best to stand up and assert themselves. A blanket statement may well be effective, such as, “I really need your support, not your judgment.” If parents can share their grief and love for their child, that may help others understand that these decisions are heartfelt.

The following is a list of judgments and responses that you can offer parents to strengthen their resolve and resilience. Many of these judgments also reflect parents’ worries during and after decision-making, so these responses can offer affirmation and pacify second thoughts as well.

How could you let your baby die?

Medicine couldn’t cure my baby. I didn’t choose death, death chose my baby.

I would’ve tried anything to make my baby survive.

In our case, it would have only prolonged her dying.



What if the diagnosis was wrong?

That doesn't change the fact that my baby died from something that was fatal.

What if your information wasn't accurate? There's this specialist or procedure I've heard about...

I could only make decisions based on the facts and options at hand.

What if your doctors were wrong?

The best I could do was to rely on the doctors' education and experience, and I had to trust that.

Your baby wasn't really dying; you shouldn't have refused treatment.

I was there. You are entitled to your opinions; I am blessed with my knowledge.

You just took the easy way out.

For me, the easy way would've been to hold on. Letting go is the most difficult thing I've ever done.

You just didn't want a handicapped child. You're selfish.

I refused to burden her with a debilitating existence. Letting go is the most unselfish thing I've ever done.

Maybe a miracle would've happened.

I prayed and hoped for a miracle but my child still died.

Miracles happen to those who have enough faith.

Well, then it's too bad you weren't more involved.

What gives you the right to play God?

When the machines were disconnected, that's when I placed my child's life in the hands of God.

What about the right to life?

That's simplistic. We have a right to autonomy, choice, dignity, and peace. The right to life must be linked to those rights. A mere physical existence only mocks life.

What about the sanctity of human life?

Sentencing her to a debilitating existence would've dishonored that ideal. It is the soul that is sacred, not physical existence.

I thought euthanasia/mercy killing was against the law.

My child received the best palliative care medicine could offer, and he was able to die a natural and gentle death.

Don't you feel like you killed your child?

Her death was beyond my control. I tried to make her life and death peaceful. I held her and loved her and let her go instead of prolonging her suffering.



Maybe you should've...

But the reality is..., and that is what I need support for.

I guess it was easy to let go since he was so sick and impaired.

Letting go is never easy. It was clearly best for him, but doing so is heartbreaking for me.

If you let her die, you must not have loved her enough.

Letting go is the ultimate act of love. I didn't want her to continue suffering just so I wouldn't have to face her death. Now, she is at peace. The grief I feel knows no bounds.

A Note to Parents:

If you can't respond at the moment, it may be helpful to confront the offender later. If you don't have the nerve to respond in person, write a note (you don't have to send it) or imagine yourself responding, leveling them with your conviction. You don't have to try to change their views, but do insist that they respect yours. They can refrain from being hurtful. If necessary, avoid them while you heal.

As you grieve and adjust, you can look back and see that you played an intense, indispensable role in your child's life. For most parents, decisions weighing the "best interests of the child" don't get much more serious than choosing between cloth and synthetic diapers, or which car seat to buy. Making end-of-life palliative care decisions is surely one of the most passionate parenting experiences. Your relationship with this child was extraordinarily profound and poignant, concentrated and heartfelt. This relationship is a treasure that you can claim.

* * *

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Twins A and B: The Story of Alfred and Bubba

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Introduction

Parents of multiples recognize that they are afforded a place of esteem (Holditch-Davis, Roberts, & Sandelowski, 1999; Swanson-Kauffman, 1988). Parents expecting more than one baby are familiar with their own and others' interest in twins in strollers or television coverage of a family with quintuplets. Hopes and dreams for two or more may include built-in playmates, matching clothes, and photos on the first day of school. Yet hope is often tempered with uncertainty in a multiple pregnancy. Parents learn that the pregnancy will be carefully monitored to detect any problems with the babies' growth or signs of early labor. Such was the case for John and Sarah.

John and Sarah's story of uncertainty began when Sarah started bleeding at 12-13 weeks of pregnancy, and intensified at 15 weeks when Twin A's (Paul's) amniotic sac ruptured. The next 13 weeks were a mix of apprehension and gratitude, as each week the babies remained inside was a milestone. But at 28 weeks, contractions began. At first, Sarah tried to ignore them, hoping they would go away. But labor had started, and Sarah wasn't ready.

Sarah's goal was to "OK, I'm not going to settle for just barely making the viable gestation weeks, I want to go more" ...Up to the day of delivery, she was probably somewhat in denial that she was actually in labor because she didn't want it to happen. (John)

The twins, Paul and J. T. (Twin B), affectionately dubbed "Alfred" and "Bubba" by their expectant parents, were admitted directly to the neonatal intensive care unit (NICU) from the delivery room. Paul died two days after birth. J. T. is now a healthy 4-year-old with a new baby sister. The purpose of this article is to highlight the aspects of John and Sarah's experience that have particular meaning and relevance *to them*. Juxtaposed with their story are reflections by four experienced NICU nurses and a neonatologist about caring for twins or other multiples.

When multiples are admitted to the NICU and the healthcare team is quite certain that one or more will die, technical competence and emotional sensitivity provide the framework for caring for the babies and their anxious parents (Swanson, 1990). From that standpoint, the needs of bereaved parents of multiples are similar to those of bereaved parents of singletons.

Getting and Staying Connected with Parents

Right after delivery and admission to the NICU

When twins or other multiples are admitted to the NICU immediately following birth, establishing a communication link is critical. Parents can find themselves separated from one or more of their babies by many miles. For John and Sarah, the NICU and labor and delivery units were



across the hall from each other. A nurse from the NICU was specifically assigned to keep John and Sarah updated. Sarah, who had a cesarean birth, was taken to see her babies within the first hour after delivery. John spent most of his time with Sarah in the recovery room, rather than in the NICU. But had he been in the NICU, he would have found that the NICU nurses and physicians encourage parental involvement in any way possible during admission and resuscitation.

*I constantly remind the family members that they're not in the way.
(Valerie Olson)*

During resuscitation, in that time of extreme busyness, it's important for them to see because they will see how hard we're working. And I think in the future that may be an important key to them. (Melody Schmitz)

I think it's important, too, when one isn't doing well and the other is fairly stable to allow quality time with both of them. You want them to have that time when you can see that it's going to be short. (Liz Hole)

Despite good communication from the NICU, John and Sarah would have liked more interaction with the nurses taking care of Sarah.

*We felt pretty lonely in the recovery room.... Things happened so quickly that we didn't know what we were supposed to do or go or how we should be feeling.
(John)*

After Paul died

The NICU staff continued a connection with John and Sarah.

After Paul's death, they all [NICU staff] extended their sympathies so graciously, and you could tell, it was hard for them, too, to lose a baby. In retrospect, you just appreciate that so much and that his life was here and it was not forgotten. They're sorry that he's gone. (Sarah)

They gave us time initially [after Paul died] to deal with those initial thoughts.... But after that, a day or so, they came with the grief packet and let us know what services were available at the hospital ... even though at the time I wasn't ready. It was hard, it was very, very hard. I didn't want to look at it, but I knew it was there when I was ready. (Sarah)

The Importance of Knowing Their History

The NICU staff did not know about Sarah's pregnancy history.

The nurses weren't aware of the situation with Paul, the premature rupture of membranes. They were perplexed as to why they were having so much trouble with him as far as how he was doing. It was stressful to them that they couldn't give us better information. (Sarah)



With Sarah and John's twin boys being in the NICU right across the hall from where they were born, it may seem strange that staff on both sides of the hallway wouldn't know the whole story of the pregnancy. In fact, the 13 weeks between the rupture of Paul's amniotic sac and the twins' delivery was a near record. Knowing all of Sarah and John's story was important for meeting their emotional needs, specifically assessing their level of *hope*.

Both twins continued to kick throughout the pregnancy, and when Twin A (Paul) cried at birth, John and Sarah's hopefulness soared. Perhaps that is why the admitting neonatologist's first words to them were difficult:

... the first words out of the neonatologist[']s mouth were], "You have two very sick boys on your hands." It took a while to recover from that. (John)

Since Paul and J. T. were born, current practice standards have evolved to include an antenatal consult with the neonatologist and a review of the mother's pregnancy history and plan of care with team members. Parents like John and Sarah would be counseled about the increased risk of death from pulmonary hypoplasia.

Specialness of Multiples

Pector (2004a; 2004b) reminds NICU caregivers to keep all multiples in mind when caring for parents and their baby(ies). "The surviving twin will always be a single twin," according to Swanson-Kauffman (1988, p. 80). A neonatologist tells the story of admitting three surviving quads to a NICU.

My experience in a previous NICU was memorable when I cared for a set of quads and we'd been involved in counseling the family prior to delivery and the mother had been in the hospital for many weeks prior to delivery. As it turned out, quad C died the day prior to the delivery of the other quads. As the nurses were admitting the three live babies into the intensive care nursery, they wanted to admit them as triplet A, B, and C. And I said 'No, you can't do that, they're quads A, B, and D.' (Suzanne Toce, MD)

Sarah and John referred often to Twin A or Twin B as they discussed their experience.

They had a sign that they put in the isolette with the date of birth ... and it said "Twin B." I liked that because people visiting or new nurses would be aware of that [that J. T. was a twin]. (Sarah)

Generally, parents appreciate having all their multiples acknowledged in some way. However, sensitive caregivers should check with parents to be sure that keeping a "Twin A," "Triplet C," or "Quad D" sign on a surviving baby's isolette is in keeping with their preferences. Not all parents want such an acknowledgment (Pector, 2004a).

It is important for staff to hold in mind other sets of multiples who are in the NICU. As J. T. got older and closer to discharge, he was moved into an overflow room. Shortly thereafter, twin girls joined him.



When they moved them in, it was kind of bittersweet. They were such cute little girls, but it made me think, "What if I would have had my two boys?" A nurse rushed in a little later, asking if they should take them out. They were up front and asked if they should be moved. I said, "No." (Sarah)

This story is an important one because it demonstrates that caregivers don't have to be perfect. What Sarah needed was for the nurse to acknowledge what happened and offer to change the arrangements. She said she thought about it, but decided the situation was OK as it was, an experience living in the real world without your precious twin.

Acknowledging Paul

John and Sarah had different reactions to coming back into the NICU for the first time after Paul died. John's focus and energy were drawn to J. T.

Nothing stands out too much, other than that they were not next to each other. The main thing was that, it wasn't difficult, there was so much going on ... the main thing is that we were just focusing on our son, J. T. (John)

Sarah has clearer memories of that first time.

I do remember the day I walked back into the nursery after Paul had died because I had burned into my memory where he was.... But I will remember that day just because I wish I could see that isolette again. (Sarah)

Their differing perspectives provide guidance to caregivers to listen for and be open to how parents individually may perceive the same event.

Parents value being able to hold and have photographs of their multiples together.

When the babies are so sick, they each have separate nurses and when the one baby dies, you begin to do all the mementoes. And if the other baby is really sick, you have to remember to take photos of them together. (Juliene Sloane)

For the same reason that I keep on my desk a picture of Paul and J. T., and Paul had just expired. But they're together and for me, I like that. It helps me really remember things. I actually have good memories of that. And people, I think, like that, too, to see that. (John)

Dr. Suzanne Toce concurs with Pector (2004a) that parents generally appreciate the staff remembering their baby or babies who died. Staff should be attuned to what's right for each individual parent; some may be comforted by a simple acknowledgment, while others may want to talk in more depth.

After the death of the baby, we try to make sure that the baby is not forgotten. And the twin could be in the hospital for weeks to months. I always try to give the family an opportunity to talk about the baby who died Give them suggestions



for when they go home and they've lost one baby and the other baby is still in the hospital. Some people find that carrying a stuffed animal is helpful in that situation.

Supporting Caregiving of J. T.

One of Sarah's most precious gifts from the NICU nurses was their support of her breastfeeding J. T. One particular moment stood out for John in terms of support for their role as J. T.'s parents.

One of the nurses would, if he just saw us scrubbing in, he'd almost always walk right up to us and [ask] how are we doing and "this is what we're going to be doing this evening with your son." He asked us if there was anything we wanted to know. Just in general being available. (John)

Funeral Arrangements

Sarah and John were at a party a few weeks before Sarah went into labor with the twins. At the party, John met a local funeral director and they talked for a while. After Paul died, both parents thought immediately of the person they met. When John called the funeral home, he recognized the voice on the other end of the phone as the man he'd met at the party. The funeral director said he would come to the hospital to pick up Paul. John was able to place Paul in the funeral director's arms himself.

Spiritual Care

The parents, nurses, and neonatologist I interviewed for this article all stressed the importance of spiritual care for the parents and for the staff. Sarah's father is a pastor. He baptized Paul and prepared a bulletin for the service, which was held in a private room just outside the NICU.

In the same way that parents remember the baby who died, so do staff members. Preparing the isolette that was occupied by the baby who died for a new admission, walking by the surviving baby's space, seeing the "Twin A" sign—all serve as reminders of the recent loss. Relying on team members who are chaplains or social workers provide those doing bedside care with support, encouragement, and a place to share heavy hearts, both before and after the death.

When it is clear that one or more of the multiples is in imminent danger of dying, we utilize a special member of our team, who is the chaplain. (Dr. Suzanne Toce)

Being Held in Mind

One of the most influential articles I've ever read describes the power of being held in mind by someone else in your absence (Pawl, 1993). Caregivers from the NICU often comment on how excited they are to see families come back and visit in the months and years after their NICU experience, knowing that families remember them and think enough of them to come back. John expresses the same idea from a parent's perspective:

Even years after, I think in our minds, we were made to feel special, really taking an interest in what we were going through...Despite a very busy NICU, I think we both felt special, that we were unique, or that people would remember us. (John)



Whether a baby lives or dies, *remembering* is important for all involved.

Take-home Points for Caregivers:

- Focus on technical competence and emotional sensitivity as a framework for caring.
- Establish communication links among parents and their care providers.
- Assess parents' level of *hope* for their babies' survival.
- Keep all their babies in mind when caring for parents of multiples.
- Be sensitive to the presence of other multiples in the NICU.
- Seek sources of spiritual care for family members and caregivers.

My sincere appreciation to John and Sarah Herath, parents of Paul, J. T., and, most recently, Maggie; nurses Liz Hole, Juliene Sloane, Valerie Olson, and Melody Schmitz; Suzanne Toce, neonatologist; and Elizabeth Pector, family physician and medical writer, for their assistance with this article.

* * *

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www.trafford.com/05-0937

Always My Twin is available through Trafford Publishing. Their description reads: A book for young children who have experienced the death of their twin sibling. Story of love and loss told through the eyes of a young girl whose twin died when they were infants. By Valerie R. Samuels; Illustrated by Najah Clemmons.

www.bereavementservices.org

Click catalog to order the brochure *Loss of One or More Multiples*. There is a chapter on loss of one or more multiples in the book *When a Baby Dies: A Handbook for Healing and Helping* (Limbo and Wheeler), also available on the Bereavement Services Website.



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www.climb-support.org/

CLIMB, the Center for Loss in Multiple Birth, Inc., represents parents throughout the United States, Canada, Australia, New Zealand, and beyond who have experienced the death of one or more of twins or higher multiples at any time from conception through birth, infancy, and childhood. See "Multiple Birth Loss and the Hospital Caregiver" by Jean Kollantai and Lisa Fleischer.

www.synspectrum.com/multiplicity.html

This page, developed by physician and bereaved parent Beth Pector, provides an excellent listing of organizations, print, and Web site resources that may be helpful for parents facing the challenges of raising multiples, working through loss of one or more multiple, or raising one or more premature or special needs child(ren).

www.twinlesstwins.org

contact@twinlesstwins.org

1-888-205-8962

The organization provides support for twins and other multiples who have lost their twin due to death or estrangement at any age. National conferences, regional meetings, online discussion, and a quarterly newsletter are available.

<http://health.groups.yahoo.com/group/elimbo/>

eLIMBO, (electronic) Loss In Multiple Birth Outreach is a Web-based support network for parents who have lost one or more babies from a multiple pregnancy. The list is for parents only, and membership is requested and approved through the list moderator.



Moments Held: Healing with Documentary Photography

Todd Hochberg

Touching Souls Photography
1-888-818-8908

www.touchingsouls.org
www.momentsheld.org
info@toddhochberg.com

Photography holds an important place in our personal lives. We employ it to record both significant and everyday moments, from family milestones and events to the more mundane. Yet many of these images hold incredible meaning for both those viewers who were present when the picture was taken and those who were not. How many times have we heard the reply to the question about the single most important possession to grab when running from one's burning home; "my family photographs," "photo albums," "important pictures," etc.

Photographs are storytellers and in story we find richness and meaning about ourselves and those we love. We rely on photographs to build and pass on our family histories. Photographs are capable of evoking a sense of place, time, emotion, relationship, or connection for the viewer without telling all. Indeed, viewers complete the picture from where they sit, often arriving at clarity of self. It is all of these qualities that are so effective in aiding the dying and the bereaved.



Leroy

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Natalie

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When a baby dies parents are caught unaware as typically they move through pregnancy with awe and wonder and joyful anticipation of the day of birth. Whether a miscarriage, stillbirth, or infant death, each parent embarks on a unique path of grief facing an awful disruption of life assumptions. This is not the natural order of things. Often this may be young parents' first encounter with death. Family, friends, and community are subsequently struck with the challenge of how to respond to and support these parents, in addition to coping with their own grief. There is oftentimes an awkward dance that occurs during bereavement where would-be supporters are not sure how to behave or communicate with bereaved parents for fear of stirring up more pain. They, too, are faced with a need to reconstruct their own realities. Some wind up doing 'less than' or offering platitudes they think will comfort that often do harm. For their part, some bereaved parents concerned with being the downer in social settings, may not share or socialize at all. Yet they may yearn for

acknowledgement and acceptance of their baby's existence in the family and their own place in grief—wherever that may be. When they don't receive this acknowledgement, parents may feel



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the additional pain of isolation. As parents move through grief they also may struggle with holding on to memories and feelings about this short time with their baby, in the extreme some may wonder if their baby ever was.

Typically, families possess a myriad of photographs and video of their children. Families whose babies need intensive care tend not to photograph as much and consequently have few images to hold if their baby dies. Parents of stillborn babies have even fewer mementos. Documentary photographs taken of these babies in the time parents have to spend with them can help to tell their "story."

My documentary bereavement photographs are made after delivery, in the hospital labor and delivery area or in the neonatal intensive care unit; during the private time parents have to hold their dying or dead baby. I work to create photographs that can serve as a gentle link to memories and feelings pertaining to the precious short time spent with their baby. Working unobtrusively as a willing participant, I make images about this experience without posing or electronic flash. Though the images typically show mom and dad with their baby, often other family and caregivers are included, and religious rituals may be performed. These significant caring relationships and rituals are important to render and I also strive to elucidate the emotional and spiritual energy in the room.

During more than nine years of this work, I've learned from parents that the photographs facilitate their grieving by:

- making their baby's life and death real for them—a significant issue with perinatal death and an acknowledgement so important for parents;
- validating their feelings, both at the time of their baby's death and up to the present;
- being an affirmation of parenthood;
- providing a tangible record of their time with their baby, including cherished close-up details of their baby's physical features and evidence of loving familial bonds;
- allowing them to connect with the many feelings and memories that may have gotten lost in the torrent of overwhelming grief at the time or in the weeks since;
- offering them an illustrated narrative of "their story" for themselves and the loved ones they choose to share it with, fostering greater social support and connection.

Documentary photography, like documentary film, while not directly manipulating the scene being photographed, is yet a subjective activity determined by "the point of view" of the photographer. When I come to these sacred places with grieving families, I need to exclude busy thoughts and hold mindfulness for "this" moment. I must slow down and diffuse any expectations and judgments within. I strive to be open to the emotional energy and the visual information I find in the room "now." Only then am I prepared to make the most meaningful photographs for grieving parents. When I am successful, the images seem to make themselves.



Sierra

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This presence brings me closer to the family; I become more engaged personally, thereby infusing the photographs with collaborative energy—their's and mine.

All the parents I photograph share that these photographs play a significant role in helping them grieve and heal. As time passes, the images enable parents to hold onto precious memories even as they move forward in their lives. Photographs also help parents find the treasure in their adversity. They are an affirmation of these beloved babies' lives, and are held dear by bereaved parents.



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Educational Resources

Karen Paradise Baranowski, RN

Karen.baranowski@intermountainmail.org

This section identifies a broad array of educational resources relevant to neonatal loss in pediatric palliative care. These include links to web resources and an unannotated bibliography of resources. Many resources related to both perinatal and neonatal loss were previously listed in Issue #7.

Web Resources—Neonatal Loss

Angel Teddy Bears Foundation

www.angelteddybears.org/index.html

Deliver teddy bears to hospitals which are in turn given to parents of stillborn children, miscarriages, and neonatal loss.

Babyloss

www.babyloss.com/

Information, support, forums, stories, and dedications for women and their partners who have experienced the devastating loss of a baby.

Center for Loss In Multiple Birth, (CLIMB) Inc.

www.climb-support.org/

A support network by and for parents who have experienced the death of one, both, or all babies from a twin or higher multiple pregnancy, during pregnancy, at or after birth, or in childhood.

Empty-Cradles.com

www.empty-cradles.com/index.html

Organization run by parents to provide support, understanding, and information on how to cope with the death of a baby

Haven of Hope and Healing

www.havenofhopeandhealing.org/

Nonprofit organization committed to providing mental, emotional, spiritual, and educational support to those who have experienced the loss of a baby through miscarriage, stillbirth, or infant death.

Infants Remembered In Silence, Inc.

www.irisremembers.org/

Offers support, education, and resources to parents, families, friends, and professionals on the death of a child in early pregnancy (miscarriage, ectopic pregnancy, molar pregnancy, etc) or



from stillbirth, premature birth, neo-natal death, birth defects, sudden infant death syndrome (SIDS), illness, accidents, and all other types of infant and early childhood death.

Maternal Grief page of obgyn.net

www.obgyn.net/women/women.asp?page=/women/loss/loss

Devoted to comfort the sorrow of hearts grieving the loss of babies through infertility, miscarriage, stillbirth, neonatal death, and sudden infant death, and to offer ongoing support.

M.I.S.S. (Mothers In Support and Sympathy) Foundation

www.misschildren.org/

Nonprofit organization dedicated to supporting parents one to one after the death of an infant or young child.

Missing Grace Organization

www.missinggrace.org/

Provides resources and support for families that have experienced: pregnancy loss, infant loss, infertility, or adoption, and to advocate for comprehensive, patient-focused prenatal care for all women

Multiple Birth Prenatal Education & Bereavement Support.

www.multiplebirthsfamilies.com/

Offers bereavement support for parents who have lost one, more, or all of their multiple birth children during pregnancy or in infancy.

Pregnancy and Infant Loss Network

<http://sids-network.org/pil.htm>

Has a home page which includes guest book, information, and information on joining a Pregnancy and Infant Loss discussion group, and/or a SIDS discussion group.

SPALS: Subsequent Pregnancy After Loss

www.spals.com/

Group of people who have experienced the loss of a child due to miscarriage, selective termination, stillbirth, neonatal death, sudden infant death, or accidental death.

Storknet's Pregnancy/Infant Loss Cubby

www.storknet.com/cubbies/pil/index.html

A special site of information and support for those who have experienced infant loss.

We will hold you in Heaven Support Group

http://health.groups.yahoo.com/group/we_will_hold_you_in_heaven/

An online "Yahoo groups" support group for anyone who has lost an angel due to SIDS/OID, miscarriage, ectopic pregnancy, or early child death and is looking to give and receive support.



Selected Resources on Neonatal Loss

The following resources are specifically focused on neonatal loss. It is recommended that you examine a specific title for yourself to determine its strengths, weaknesses, and suitability for those to whom you might offer it.

Always Precious in Our Memory: Reflections After Miscarriage, Stillbirth or Neonatal Death.

Kristen J. Ingram and Christine O. Lafser, ACTA Publications, 1999. ISBN-10: 0879461594

An Ambitious Sort of Grief: Diary of pregnancy and neo-natal loss. Marion Cohen, Liberal Press, 1986. ISBN-10: 0934659036

Angel Baby: A Journal of Healing After the Loss of an Unborn, Born Still, or Newborn Child.

Carey Knifong, PublishAmerica, 2005. ISBN-10: 1413747914

Bittersweet...Hello goodbye: A Resource in Planning Farewell Rituals When a Baby Dies. Jane

M. Lamb, SHARE-Pregnancy & Infant Loss Support Inc, 1989. ISBN-10: 0918533686

Coping with Infant or Fetal Loss: The Couple's Healing Process. Kathleen R. Gilbert and Laura

S. Smart, Brunner/Mazel Publisher, 1992. ISBN-10: 0876306792

Creative Acts of Healing: After a Baby Dies. Judith Van Praag, Paseo Press, 1999. ISBN-10:

0967267706

Forever Silent, Forever Changed: The Loss of a Baby in Miscarriage, Stillbirth, Early Infancy. A

Mother's Experience and Your Personal Journal. Kellie Davis, Booklocker. 2001. ISBN-10: 1931391572

Given In Love but Not Mine To Keep: Finding Strength In The Loss Of A Newborn Child. Jan

Wolfe Rosales, Erica House, 2000. ISBN-10: 189316215X

Grieving the Child I Never Knew. Kathe Wunnenberg, Zondervan, 2001. ISBN-10: 0310227771

A Guide For Fathers: When A Baby Dies. Tim Nelson, Tim Nelson, 2003. ISBN-10: 0965084841

Help, Comfort and Hope After Losing Your Baby in Pregnancy or the First Year. Hannah

Lothrop, Fisher Books, 1997. ISBN: 1555611206

I'll Hold You In Heaven. Jack Hayford, Regal Books, 2003. ISBN-10: 0830732594

I'll Hold You In Heaven Remembrance Book. Debbie Heydrick, Regal Books, 2003. ISBN-10:

0830732608

In Search of Hope: One Woman's Journey Through Despair in the Wake of Neonatal Death,

Infertility and Miscarriage. Susan R. Lowe, PublishAmerica, 2001. ISBN-10: 1588514846



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Making Loving Memories: A Gentle Guide to What You Can Do When Your Baby Dies. Mary L. Eddy and Linda Raydo, Centering Corp, 1990. ISBN-10: 1561230030

Mother Care: Physical Care and Beyond After a Baby Dies. Sherokee Ilse, Inez Anderson and Mary Funk, Wintergreen Press, 1995. ASIN: B0006QIDD4

Newborn Death. Joy Johnson, Centering Corporation, 1992. ISBN-10: 1561230197

Parenthood Lost: Healing the Pain after Miscarriage, Stillbirth, and Infant Death. Michael R. Berman, Bergin & Garvey Trade, 2001. ISBN-10: 0897896149

A Piece of My Heart: Living Through the Grief of Miscarriage, Stillbirth, or Infant Death. Molly Fumia, Conari Press, 2000. ISBN-10: 1573245100

Silent Birth: When Your Baby Dies. Sharon N. Covington, Fairview Press, 2004. ISBN-10: 1577491440

Stolen Joy: Healing after Infertility and Infant Loss. Anne. Barney, Icarus Press, 1993. ISBN-10: 0944806066

When a Baby Dies. Dr. Ronald H. Nash, Zondervan, 1999. ISBN-10: 0310225566

When a Meeting Is Also Farewell: Coping With a Stillbirth or Neonatal Death. Ingela Radestad, Books for Midwives Press, 1999. ISBN-10: 1898507759

When Hello Means Goodbye. Pat Schwiebert and Paul Kirk, Perinatal Loss, 1985. ISBN-10: 0961519703

For Children

Always My Twin. Valerie R. Samuels, Trafford Publishing, 2006. ISBN-10: 1412060362

Get Sad When Somebody Dies. Timony Shinada-Izotov, AuthorHouse, 2006. ISBN-10: 1425918506

I'm Still A Sister. Brooke Caputo, AuthorHouse, 2005. ISBN-10: 1420851195

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If you have any items you would like added to this section in future issues, please send information to the above email address.