



# E-NEWS

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## ChiPPS Pediatric Palliative Care Newsletter Issue #27; May, 2012

*Edited by Charles A. Corr, PhD, Christy Torkildson, RN, PHN, PhDc,  
and Maureen Horgan, LICSW*

### **Issue Topic:**

### **What about Schools? Creating Systems to Support Children, Families, and Communities**

Welcome to the twenty-seventh issue of the ChiPPS electronic newsletter. This issue of our e-newsletter offers a PDF collection of articles that explore some issues involving our schools and the role of pediatric palliative and hospice care in creating systems to support children, families, and the community. Our goal in this issue is to help encourage a dialogue with educators and school personnel to help them to work more closely and more effectively with providers of pediatric palliative and hospice care to meet the complex needs of children with life-threatening or life-limiting diseases and their family members.

This newsletter is produced by ChiPPS (the Children's Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by NHPCO's E-newsletter Workgroup, co-chaired by Christy Torkildson and Maureen Horgan. Archived issues of this newsletter are available at [www.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics).

Comments about the activities of ChiPPS, its E-newsletter Workgroup, or this issue of the newsletter are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues of this newsletter. Please contact Christy at [torkc@sbcglobal.net](mailto:torkc@sbcglobal.net) or Maureen at [Maureen.Horgan@providence.org](mailto:Maureen.Horgan@providence.org).



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## Issue #27

### What about Schools? Creating Systems to Support Children, Families, and Communities

(Click on the "bookmark" tab on the left-hand side of the PDF document for links to the following articles.)

#### ***The Impact of My Faith on My Decisions with Francesca***

**p. 4**

**Jean Frisone, RN, BSN**

*Jean Frisone, pediatric nurse and mother of 9, eloquently shares how her faith helped to sustain her during her pregnancy after the baby she was carrying was diagnosed with "a constellation of cardiac defects so severe she was not expected to live" and during the journey since Francesca's birth and death.*

#### ***The Apprentice***

**p. 7**

**Scott Newport**

*Scott Newport, a poet, carpenter, and bereaved father, is also a patient and family advocate. He shares with us a project he started at C. S. Mott Children's Hospital, University of Michigan. The "E-Box's", the three points are Engage, Educate, and Empower. There may very well be a lesson and a tool that we can use and learn from.*

#### ***Children with Complex/Chronic Conditions in School: The Role of Pediatric Palliative Care***

**p. 9**

**Denise Powers Fabian, MSSA, LISW-S**

*The importance of school in providing "normalcy" to a child's life is usually unquestioned. Denise Powers Fabian provides an excellent overview of the challenges children with complex/chronic medical conditions and their families may face with the public school system in the U.S. She offers resources and guidance for pediatric palliative care teams to better advocate for their patients and families.*

#### ***Education and Civil Rights Legislation to Support Students with Serious Illness***

**p. 13**

**Kathy Davis, MSED, PhD**

*Kathy Davis provides a comprehensive look at the legislation and civil rights pertaining to students with complex/chronic illness, while providing guidance and suggestions on how to best support the various needs of students and families. Dr. Davis identifies common challenges providing tips and a list of resources for additional information and guidance.*

#### ***Helping Children Cope with Loss, Death, and Grief: Tips for Teachers and Parents***

**p. 20**

**National Association of School Psychologists**

*This article was adapted from material first posted on the NASP website after September 11, 2001. NASP has made these materials available free of charge to the public in order to promote the ability of children and youth to cope with traumatic or unsettling times. The materials may be adapted, reproduced, reprinted, or linked to websites without specific permission. However, the integrity of the content must be maintained and NASP must be given proper credit. Although written following Sept 11th, principles and tips discussed are pertinent in most situations dealing with loss, death, and grief.*

#### ***School Reintegration: Tips and Tools for Students, Parents, and Teachers***

**p. 24**

**Sima Zadeh, MA, and Lori Wiener, PhD**

*Sima Zadeh and Lori Wiener focus their article on ways to assist both children and their parents in returning to school after an extended illness/treatment/hospitalization. Providing tips and tools for communication, information, and policies, Sima and Lori take this assistance further by touching on the impact this may have with peers and siblings.*



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***How to Support Grieving Children in the School Environment*** **p. 28**

**Jana DeCristofaro, LCSW, and Donna Schuurman, EdD, FT**

*Jana DeCristofaro and Donna Schuurman, both of the Dougy Center in Portland, Oregon, provide guidance to support children who have suffered a loss and are grieving whether it is the loss of a parent, a sibling, or pet.*

***Tools for Supporting Siblings in a School Setting*** **p. 31**

**Valorie Johnson, MSW, and Jill Meyers, MA, CCLS**

*Valerie Johnson and Jill Meyers of the Safe Crossings Program at Providence Hospital in Seattle, Washington, focus this article on their work "building bridges" with siblings providing both anticipatory and bereavement support for children in school.*

***Some Resources for Supporting Children, Their Families, and Faculty/Staff in School Systems when a Child is Seriously Ill, Dying, or Bereaved*** **p. 34**

**Compiled by Ann Fitzsimons, BS, MBA**

*Ann Fitzsimons, the family voice for the ChiPPS e-Newsletter workgroup, provides additional resources that were identified in the compilation of the submissions for this issue.*

***Resources for Ways to Engage Grieving Siblings*** **p. 35**

**Safe Crossings Team, Providence Hospice, Seattle, Washington**

*The Safe Crossings Team provides a bibliography for children, teens, and parents along with a section for activities.*

***Reader's Corner*** **p. 36**

**Suzanne Toce, MD**

*Dr. Toce summarizes a review article on the importance of advance care planning discussions, especially at end of life, for children who are likely to die prematurely. The article forms the background to the Child and Family Wishes document, whose history and format are reviewed. A copy of the Wishes document follows this Reader's Corner contribution.*

***Items of Interest*** **p. 45**

*ChiPPS customarily shares items that may be of interest to our readers.*

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Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its Communication Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.

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## THE IMPACT OF MY FAITH ON MY DECISIONS WITH FRANCESCA

Jean Frisone, RN, BSN  
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My faith journey began right from the beginning of my life. I was baptized as an infant, went to church every Sunday, and attended private school where I was instructed in the foundation of my faith. At home we read the Bible, prayed before meals, and were taught to be in service to others. So when I was called to the vocation of marriage, I had every intention of carrying out this way of life as I had in my youth. My faith, woven like the vibrant threads of a tapestry, was as essential to me as food and shelter.

My denomination accentuates the sanctity and preciousness of human life from conception to natural death. We are encouraged to "be open to life" and not control fertility artificially. Therefore, having a large family was a natural consequence of this aspect of faith, one that brought deep joy and fulfillment to my life.

At the 20 week ultrasound of my 9<sup>th</sup> child, my physician could not clearly see the four chambers of my baby's heart. He referred me to the local children's hospital to see a brilliant cardiologist who specializes in fetal echocardiograms. Our lives were never the same after that day. My baby was diagnosed with a constellation of congenital heart defects so complex that she was not expected to live. Obstructed TAPVR, just one of her defects, is one of the last emergencies in pediatric congenital heart conditions. I was diagnosed in the 2<sup>nd</sup> trimester, so I had the option to abort the baby. Not only is that against the tenets of my faith, but I wanted to give her every opportunity to declare herself. Following one's religious beliefs does not always make life easier but does guide one to make a morally right decision when faced with difficult choices. Consequently, every kick and movement of my developing child filled me with conflicting emotions. Fear and anxiety battled it out with hope and anticipation as she continued to form in my womb.

We were extremely grateful for the expertise of the cardiologist. Diagnosing obstructed TAPVR in utero is difficult to do because of the size and complexity of the minute vessels of a baby's heart. We were able to prepare more adequately for her arrival because of this early diagnosis. He illustrated a picture of her malformed heart, listing all her ailments on the drawing that I carried with me her whole life. As the reality of her condition set in, my husband and I were able to start researching the maladies that plagued her little heart.

Francesca Jordan Frisone was born August 26, 2004, and named for St. Francesca Cabrini (the first US citizen to be canonized) and Sr. Jordan Haddad, a feisty Lebanese nun who taught me how to serve God in the everyday and ordinary. Sister recognized my desire to raise conscientious children and gave me the support every mother craves. It was her counsel that encouraged me. Even if my baby did not live long, I had raised a saint for God; a soul to live for all eternity. Even as an infant, Francesca showed remarkable fight and spirit.

During a harrowing 3-week admission, she survived open heart surgery within hours of her birth, multiple complications, and feeding issues. We endured even the drama that befell the world renowned cardiac surgeon we had selected to care for our child as he had an emergency himself: his retina detached just days before he was to operate. Eventually Francesca was well enough to come home.

There are no words to describe this experience. Roller coaster ride is inadequate. Space Mountain on steroids meets the movie "Groundhog Day" still does not describe the daily highs and lows of caring for a child with a life-threatening condition. Many times making choices about her care was like playing "Let's



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Make a Deal" with your child's life. Select Door #1 or Door #2 with no guarantees, and each outcome was uncertain. Surrendering my precious child was agonizing. I had no assurance that she would come back to me alive. The helplessness one sometimes feels as a healthcare worker is multiplied exponentially as a parent. It is my job to protect her but I was unable to mitigate the multiple procedures that became necessary to preserve her life. It was in these times that I turned to prayer. Calling on the help of the Almighty increased my ability to cope by being able to take some kind of positive action. Knowing that others were praying fervently for our family gave me great comfort, as well.

Being a mom of a big family, I was very accustomed to the practical. I had endured long, full days and many sleep-deprived nights whether nursing a newborn, comforting sick children, or working night shift at the hospital. Both my husband and I are college educated, in a stable marriage, and experienced parents. Even though I am a pediatric nurse, it took every ounce of my being to monitor her condition and to stay on top of her ever-changing medicine schedule, not to mention providing for the needs of my other children. Educating my children at home had always given us flexibility but after homeschooling for years, my oldest sons went to school because I could not keep up with their coursework while caring for Francesca. Needless to say, I was overwhelmed.

Where was God in all of this? Why would he give me a child with such complex needs when I was already consumed with the very essential role of wife and mother? Many days her condition would deteriorate to the point of being hospitalized again. I would load her into the car with oxygen and tube feed running, passing my husband in the driveway, leaving crying kids in the doorway, with no idea how long I would be gone and no promise that she would return alive. I often traveled, white-knuckled through snow storms, passing stranded motorists on the median, terrified that if that were us, she would not survive. To say I was frazzled is an understatement.

How does one cope with such incredible stress? I would think about the lives of holy people. How did Joan of Arc summon bravery, commanding troops at such a young age? How did St. Thomas More remain courageous and convicted as he was separated from his family, confined in a cold, damp cell, and eventually murdered because he would not publicly condone the king's divorce that clearly went against church teaching? What about the fortitude of Gladys Aylward, a Christian missionary to China, who led 94 orphaned children to safety over a mountain during a war while being injured herself? I sought the example of Mary, Jesus' mother. She was responsible for raising the Savior of the world. I am sure she struggled with the same feelings of inadequacy that also plagued my life. I explored countless examples of ordinary folks who chose to cling to the promises of God and His word despite often dire and desperate circumstances. I hung on to these bits of insight which kept me going for another day.

CaringBridge, the free website where I could journal about Francesca's progress, was also a tool that bolstered my ability to cope. Family and friends could stay abreast of her condition but also send me notes of encouragement. These were life giving. Hearing from others dispelled some of the isolation I experienced during Francesca's long admissions to the hospital, separated from the rest of my family. The supportive words of people we knew and some I had never met, acted like a balm for my weary soul. As I desperately searched for some meaning in Francesca's suffering, I sought Bible verses and inspirational writings. I figured that I may as well post what I was reading because others may be enduring hardships as well. Another mother had given me the pamphlet, *The Art of Suffering*, which truly provided something worthwhile to contemplate and helped temper some of the adversity I was facing.

Francesca's last open heart surgery was in January 2007. This hospitalization spanned 3 months, and the surgery which was meant to correct her condition ultimately led to her demise. The chambers and valves that were newly formed began to leak. She also went into renal failure and withstood an agonizing fluid restriction for weeks in which she would constantly beg for fluid. After 3 open heart surgeries, 9 heart catheterizations, and 3 abdominal surgeries, she threw a clot to her lung and died on April 10, 2007. No matter how hard I worked, how many nights I stayed up, how I had forsaken the needs of my other



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children, or how valiantly she fought, I was unable to save her life. One of the few consolations for me was picturing her in the arms of Jesus, basking in the beauty and glory of heaven, free from the incessant suffering she endured and released from a body that had failed her.

The atomic loss of her life devastated my once-intact family. After a 3-month absence, I came home to a house that was a disaster, a husband and children that were distraught, and I was emotionally defunct – not at all prepared to deal with any of it. Breathing was difficult then. I wore the anguish of her death like a lead apron which slowed my every movement. My mind was lost in a profound fog of grief. People say many things to try to console one who has lost a child. The trite phrases do nothing to comfort and much to annoy. The hope of seeing her again coupled with the responsibility to my other children kept me from succumbing to the granite cover of depression that enveloped me.

In the beautiful song, “Blessings,” contemporary Christian artist Laura Story writes so articulately of the dilemma of the faithful when God does not answer in the way for which we prayed. Each of us ultimately has to decide to count on God’s promises through our trials or judge Him by the circumstances that surround us at the time.

Without my faith, I do not know how I would have continued to withstand the extenuating circumstances that plagued our lives. I am so grateful for the gift of Francesca’s life and attribute God’s grace for the ability to persevere. My reliance on God sustained me through devastating loss, and was responsible for my personal growth and ultimately the emotional healing I am experiencing today. My faith is the continual sustenance on which I will depend for the rest of my earthly life and the basis for the joy I feel in anticipation of our heavenly reunion.

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## THE APPRENTICE

By Scott Newport

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Like every children's hospital in the U.S.A., not only are there thousands of children visiting every year, there are also just as many families, families also needing appropriate care and treatment for their visit.

As our reform for health care keeps moving forward we have also started to embrace the core principles of Patient and Family Centered Care initiatives. One of these families who had a child with many visits to C.S. Mott Children's Hospital at the University of Michigan has taken a new approach how to help care for new families when they are introduced to the way we do hospital.

Scott Newport is a father and knows what it is like to live in a hospital with his child and the rest of the family. For the last few years Scott has been striving to help others like him and his family. He is currently a Patient Advisor at Mott and also works with the state-funded Children's Special Health Care, sharing his family voice to providers.

Not only is Scott an advocate for staff, faculty, and families at Mott, he is also a carpenter. A few months back as he was supporting a family, he found himself in the play area with a sibling. Anna May was determined to use a small plastic tool box to go help others. Her imaginary homeowner, Mrs. Allen, needed her wooden rocking chair repaired. After she finished, Scott asked, "Anna May, how much should we charge?" Anna May looked confused and peeped out, "We did it for free."

After that, Scott decided to build her a tool box of her own.

Seeing the look on Anna May's face after she received her box, Scott knew there must be more here than he understood. On the way home from the hospital Scott came up with an idea that would help even more families than just the Wilsons. He thought, "I can use these tool boxes in a grander way."

He decided to call his box's "E-Box's." The three points are Engage, Educate, and Empower.

Scott felt if he could present them in some way to families with children with life-long conditions he could make an impact, inspiring not only the families but also the staff and faculty at children's hospitals.

His plan was to first engage families and to use the concept the hospital caregivers were experts and the families were the apprentices. This would help families, especially fathers, grasp the knowledge and acceptance of them being learners.

The second point would be to educate the family. Scott would tell them everyone at the hospital will have a tool for the box. He believes if he can use this metaphor it will help families understand each caregiver has something different to give, helping families understand the attending doctor is not the answer to all. If families could absorb this information in the early part of their journey they could really improve the outcome by understanding one of the core concepts in a hospital: it is all about the team, the team including the patients and families. The first tool they would receive would be from Scott. It's a plaque of sort he calls, "The Warrior Mentality."

### Warrior Mentality

- Warriors know how to take on affliction
- Warriors may get knocked down but they always get back up
- Warriors know the greater the battle the greater the reward
- Warriors never go into battle alone



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The last E would be the empowerment point. Just think if a family had all the right tools and instruction on how to use them. They could then go on and help their child with confidence and an ability to better engage with the care team. Scott knows as a father that in the beginning he felt helpless with all the new things he had to learn. If only someone would have acknowledged him as an apprentice, he didn't need to feel like a failure because he was ill equipped.

Scott also thinks this could in the end save money and frustration for families as they become an expert, ready to take on the challenges that will likely arise for years to come enduring life as a family with a child with special needs or a chronic illness.

Maybe even the National Health Care initiatives existing today will also embrace this as one more way for us all to live healthier and happier with expert advice to teach the apprentice.

The tool box also has other implications. The handle is made of oak and represents a family's strength. Their strength may be faith or a strong family dynamic, something to hold on to as they travel on their journey of learning.

The end of the handle is held to the sides by a wedge. As we know, childhood disease can often be a wedge in a family driving them apart. The wedge in this tool box is driven in to make the joint stronger and never to come apart.

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## CHILDREN WITH COMPLEX/CHRONIC CONDITIONS IN SCHOOL: THE ROLE OF PEDIATRIC PALLIATIVE CARE

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Thirty-seven years ago in early June, I received my high school diploma earned over a decade of my participation in the public school system. On that same day, my peers with developmental disabilities, many like those we serve in pediatric palliative care, were barred from attending public schools. These children were not afforded the right to a free public education. The law securing that right would not exist until five months later, and was not fully implemented until 1978, with the landmark legislation of P.L. 94-142, The Education for All Handicapped Children Act.

Fueled by the Civil Rights Movement and the 1954 Supreme Court decision, *Brown v. Board of Education*, it was established that:

*In these days, it is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education. Such an opportunity...is a right, which must be available to all in equal terms.*

Despite this legal opinion, children with disabilities remained excluded. Yet the movement had begun, and through the passion of parents who would not accept anything less for their children, today all public schools must provide a free, appropriate education to all children in the least restrictive environment with their non-disabled peers. This legislation is commonly referred to as the Individual with Disabilities Education Act (IDEA, amended in 1997), and it mandates that children with disabilities be served from ages 3-22 years in the public school system.

The goals of pediatric palliative care are to enhance quality of life and minimize suffering for children with chronic and/or complex conditions or disability and their families. In that same spirit, a holistic approach to these goals acknowledges that normalization, i.e. allowing our patients and families to have typical life experiences like those without these conditions, is an integral part of quality of life. Additionally, while physical suffering is globally acknowledged, other types of suffering, including social, emotional, and spiritual suffering, are equally as important in providing comprehensive pediatric palliative care.

The social world of children is their life in school with their peers. Those days are so imprinted on children that most adults can recall the names and faces of their teachers many years after. The circles of friendships established in childhood evolve among classmates that attend neighborhood schools. Robert Fulghum's 1990 poem, *All I Really Needed to Know I Learned in Kindergarten*, became very popular in America as it resonated with the experiences of so many "grown up" children as they reflected on their school days. Given this, part of offering quality of life to our patients must consider a life in school as much as possible, which meets the social, emotional, educational, and spiritual needs that all children possess.

### **The Law**

While having patients with complex medical needs in the public school system may seem more complex than the needs themselves, it's important to keep in the forefront a very fundamental concept. The



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foundation of IDEA is about **equal access** and providing what is necessary for our patients to receive the educational experiences afforded children without disabilities.

A full spectrum of viewpoints of the role of the public educational entity to provide “medical” interventions to children at school can be found among individual local school districts. Despite conflicting agendas and local school policies, one must look at the position of the courts in previous decisions and the law to determine the role of the public school system. Accordingly,

1. “Medical Services” – i.e., services that can **only** be performed by a licensed physician – are not considered related services required to be provided by the school district **unless** a medical diagnosis by a licensed physician is required to determine the need for special education services for a student.
2. A bright-line test (*i.e., a clearly defined rule or standard composed of objective factors, which leaves little or no room for varying interpretation*) determining what health care supports **are** the responsibility of the school was adopted by the Supreme Court, who determined:

Health care support services (any medical support that can be administered by a person other than a physician) **are** part of the related services required by the local school district to fund so a child can access education in the least restrictive environment. Because this support allows a child with medical complexities to access education in the public school, *and thereby receive educational benefit from such supports*, it is considered to be part of the school's educational responsibility. Such supports must be documented in the student's IEP.

These determinations are well documented in the 1999 Supreme Court decision in *Cedar Rapids v. Garrett F. Garrett*, injured in a motor vehicle accident at 4 years of age, required long-term ventilator support to sustain life. As stated in the article, *The Supreme Court and School Health Services: Cedar Rapids v. Garret F.*:

“The Supreme Court's decision **requires** that when a medically fragile student with disabilities, like Garret F., needs complex health services to enable him or her to receive meaningful access to special education, it will be the school district's responsibility to pay for or provide these services.” [emphasis added]

The entire article can be found at

[http://findarticles.com/p/articles/mi\\_hb3130/is\\_3\\_66/ai\\_n28769208/pg\\_5/?tag=content:col1](http://findarticles.com/p/articles/mi_hb3130/is_3_66/ai_n28769208/pg_5/?tag=content:col1) .

## Relationships

Clearly the right for our patients to receive school health services in school has been upheld in the highest Court of the land. With the legal support in place, it has been my experience that the greatest accomplishments in obtaining services for these patients come from the efforts of establishing and maintaining trusting relationships between the pediatric palliative care team and school personnel, in collaboration with the parents who know their child best.

These relationships are consistent with the medical home concept of “sharing our unique knowledge with others for the betterment of our patients,” as stated in a training presented by our nurse practitioner, Margaret Farrar-Laco, CPNP. While the fiscal costs of care are an administrative reality, more often the school's underlying issue is their lack of knowledge, individual experience, and experience the district has in serving a medically-complex child. It is not unusual for a small district never to have had a medically fragile student in one of their school buildings.



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Working together on an education plan for a patient/student can provide a unique opportunity for the pediatric palliative care team to share their knowledge, skills, and expertise, collaboratively with the parents, with those providing educational services to patients. To be most effective, this should involve both medical staff and pediatric palliative care social workers. It is a sound investment for the pediatric palliative care team to have social workers who have a working knowledge and understanding of the special education system, as well as refined skills in advocacy. Providing this support to the local school not only helps assist the child in meeting the goals defined in pediatric palliative care, but also enhances community support for your program.

At times, either due to the complexity of a specific case or the risk of adversarial confrontation, a referral to the family to pursue independent legal advocacy and advice may be warranted. Additionally, an entity solely dedicated to this role may be better able to address an urgent need in a timelier manner. For example, a school district of one of our patients with PRN oxygen needs while at school, refused to allow an oxygen tank to be made available to him in the school office if needed. The school claimed it would be a liability issue with no one trained to administer the oxygen. Our patient was returning to school after an inpatient admission, with only a few weeks before the end of the school year, and he expressed strongly his desire to return to his high school. In light of these factors, an inability to resolve this situation quickly would have caused socio-emotional suffering for our patient. In this case, we referred the family to Ohio's protection and advocacy agency, Ohio Legal Rights Service. Because of our relationships with this agency, the case was accepted quickly and resolved within a week through two phone calls, at no cost to the family.

This resource is available in every state: a dedicated agency that provides protection and advocacy services for individuals with developmental disabilities, in accordance with the federally-funded DD (Developmental Disabilities) Act, at no cost. Further details of these agencies and a listing by state can be found at <http://www.acf.hhs.gov/programs/add/states/pas.html>.

### Specifics Regarding DNR/DNARs in School

Part of providing services to children and families is assisting them with decision-making with regard to goals of care. According to the American Academy of Pediatrics, "it is ethically acceptable to forego CPR when it is unlikely to be effective or when the risks (burdens) outweigh the benefits, including the parents' and child's assessment of the child's quality of life." While this is well known to most palliative care professionals, school personnel are generally not knowledgeable about the nuances of benefits and burdens in health care decision-making.

The primary purpose of IDEA is "to ensure that the **rights of children with disabilities and parents of such children are protected**" [20 U.S.C. § 1400 (d) (B)]. Unfortunately, individual states have adopted statute that may or may not establish the rights of minors to out-of-hospital DNR/DNAR orders. In some states where this right is established, the school district is not relieved in statute from liability. While these orders are becoming more accepted, many school districts still adopt policies that they feel are in the school's best interest, even when statute supports honoring these requests; unfortunately, this stance generally does not protect the rights of children and parents.

In a conversation with Peter W. D. Wright, Esq., a leading special education law attorney in the country, he stated that this issue had never been presented to the Supreme Court, so there is no precedent established. However, citing the main purpose of protecting the rights of children and parents in IDEA, he believed this right would be upheld if challenged. In Pennsylvania, case law in favor of the child/parents was established when a school district challenged an attending physician's DNR order to limit the kinds of intervention which should be performed on the child should an apneic episode or cardiac arrest occur in school. *Halderman v. Pennhurst State Sch. & Hosp* in 1997 in U.S. District Court established that the rights of parents, as guardians of a minor child, include the right to refuse medical treatment for their



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child. The validity of the order was not the issue; rather, it was assurance that the rights of the child and parents were to be protected in public institutions as part of the protection of IDEA.

I also posed this issue to an attorney for the largest metropolitan school district in the service area of our children's hospital. Her response seemed reasonable: in such cases where a DNR/DNAR is on record, the building principal, or other school staff working directly with the child, would contact the Emergency Medical Squad (EMS). Comfort measures would be implemented while EMS was en route. Upon arrival, EMS would be provided the DNR/DNAR order to exempt them from standard protocol, just as if they had been called to the child's home.

In most cases, where ongoing positive relationships between the pediatric palliative care team and the school have been established, these issues are easily resolved. This is particularly true when the school feels supported by the team, which helps to alleviate fear and uncertainty of educational staff. When this cannot occur through informal means, the state's protection and advocacy agency (see list mentioned previously) should be called upon to provide free legal representation to the family. These independent agencies have the ability to file due process on behalf of the child and family, as well as represent them all the way to the Supreme Court level. This part of IDEA, however, has yet to be tested at this level to ensure these difficult family choices are being honored individually in the school setting.

School is the social world of children and should be the experience of all children of all abilities as much as possible. The role of pediatric palliative care should include support in this arena for children and families as part of the goals of enhancing quality life and minimizing suffering. As pediatric palliative care becomes more accepted as a standard approach of care for our patients, forming relationships with those serving these children in their community – and thereby educating them – will make these goals more and more achievable for all of our patients.

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## EDUCATION AND CIVIL RIGHTS LEGISLATION TO SUPPORT STUDENTS WITH SERIOUS ILLNESS

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Academic achievement, learning difficulties, motivation, social interactions with peers, behavioral concerns; each of these may prove to be difficult at various times throughout a student's school career. Good health may help mitigate some of these factors and enable the student to continue on a path of success. But, what if the student has a serious health condition? Perhaps she has frequent absences resulting in declining grades, or she may be fatigued at school causing difficulty with concentration and attention. Socialization with friends may be difficult due to changes in physical appearance, or peers may be uncomfortable knowing what to say to their friend who has a serious illness.

There are many variables that exist in the school experience of a child with a serious illness. As a result, it is imperative to have a written plan to keep everyone on the same page when providing supports for the student. Parents, school professionals, health care providers, and, most importantly, the student will all have a clear understanding of expectations, supports, and how to navigate the potential challenges that exist at school when a student has a serious illness.

Fortunately, there are federal laws that aid in supporting the educational needs of students with serious illness. These laws include both educational legislation and civil rights laws that address the rights of persons with disabilities. Each type of legislation has application for different needs related to being a student with serious illness. Some students will benefit from civil rights supports designed to eliminate discrimination against persons with disabilities, while other students will need plans that focus on their unique learning needs and, thus, will best benefit from an education plan. This article will discuss two of those laws, Section 504 of the Vocational Rehabilitation Act of 1973, which provides accommodations to students in regular education, and law that governs special education, the Individuals with Disabilities Education Act. These are the two laws that govern education for students with serious illness. The Americans with Disabilities Act and No Child Left Behind may be of interest and the Resources section includes links to more information on these laws.

No two students are likely to need the same services and supports at school, even if their diagnoses are the same or similar. Identifying the areas of strength and the areas of need of the child will provide information to help determine what is needed and, therefore, which type of plan provides the best fit for that particular student. For example, one child's plan may need to address special education needs, while another child's plan may need to identify required accommodations that will enable the child to learn optimally. Some students will struggle with socialization with peers and others may exhibit changes in behavior at school. Individualized health plans may consist of simple oversight in one case and extensive healthcare interventions in another. Therefore, evaluating the unique needs of the individual student will ensure the development of the best plan for each unique learner in need of educational supports due to a serious health condition.



This article will

- outline the Section 504 of the Rehabilitation Act of 1973 and the Individuals with Disabilities Education Act and how they provide supports for the student;
- offer guidance regarding what type of plan may provide the best supports for various student needs
- include suggestions for who should be involved in the development of school plans for students with serious illness
- identify common school challenges for students with serious illness
- provide tips for supporting students and parents as they work to determine the best type of educational support for their specific needs
- provide a list of resources for additional information and guidance.

### **Section 504 of the Rehabilitation Act of 1973**

Section 504 of the Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 394 (Sept. 26, 1973), guarantees certain rights to persons with disabilities. Now commonly referred to as "Section 504" or "the Rehab Act," this legislation is recognized as the first civil rights statute for persons with disabilities. Although enacted in 1973, the statute took effect in 1977 and was fully implemented over the next several years. Initially focusing on employment issues, it was several years later before "504 Plans" for students with disabilities began to be developed.

Section 504 is easy to understand in regard to the needs of the student who requires accommodations to "level the playing field" and, thus, provide the young person with the same opportunities for successful growth and development as enjoyed by his or her typically developing peers. Section 504 states (in part):

No otherwise qualified individual with a disability in the United States, as defined in section 705(20) of this title, shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.

According to this law, *individuals with disabilities* are:

"persons with a physical or mental impairment which substantially limits one or more major life activities."

Major life activities include:

"caring for one's self, walking, seeing, hearing, speaking, breathing, working, performing manual tasks, and learning."

Thus, if a student has a physical or mental impairment which substantially limits caring for one's self, speaking, performing manual tasks, learning, etc., that student will be eligible for qualification under Section 504 and, therefore, a 504 Plan to provide accommodations at school. Without such accommodations, disability in these major life functions can delay growth and development and may negatively affect the youngster's achievement in school. Section 504 affords accommodations that may ensure that the student is able to fully access *all* aspects of the school curriculum, including extracurricular activities. Section 504 provides accommodations in the classroom, in the marching band, in theater, related to bus transportation, for accessing field trip opportunities, and in virtually every activity that is sponsored by the school.



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Early intervention, as soon as the diagnosis is made, will afford the opportunity to begin to address student needs before the child develops habits and skills that may not be optimal. Both Section 504 and IDEA have provisions that emphasize the importance of early intervention. Time limits for completing evaluations of students help school districts ensure that students are receiving appropriate accommodations as soon as possible.

Section 504, and related 504 Plans, are recommended for students who may need additional supports in the regular classroom in order to have the best experience possible. Accommodations may be to the physical environment (providing an elevator pass; moving the student's desk to an easier location to accommodate a wheelchair; preferential seating in the classroom); educational delivery (teaching with multimodal sensory input, breaking assignments down in small increments, recording classes during extended absences); classroom management (allowing breaks during extended learning periods, including additional feedback regarding behavior, pairing student with more verbal classmates to encourage participation); improving social opportunities (ensuring classmates are an active part of the student's palliative care team by sending cards, pictures, visiting when appropriate, "lunch bunch" – assigning classmates to eat with the student when he/she is returning after an absence, introducing the student to various clubs or other extracurricular opportunities). These are a sampling of ways that 504 Plan may "fill the gaps" that are created when a student has a serious illness. The options are limitless and should be based on what each individual child needs.

## **Individuals with Disabilities Education Act (IDEA)**

The Individuals with Disabilities Education Act, or IDEA as it is commonly known, is federal legislation, which governs how states and public agencies provide early intervention, [special education](#), and related services to children with disabilities. Prior to 1975 when the Education for All Handicapped Children Act (the original legislation, later renamed IDEA) was enacted, only 1 in 5 children with special needs were in school. Until that time, many states had laws that explicitly excluded children with certain types of disabilities from attending public school. The [Education for All Handicapped Children Act](#), arose from federal case law holding the deprivation of free public education to disabled children constitutes a deprivation of due process. Since that time, the law has not only been renamed the IDEA, but has grown in scope.

IDEA addresses the special education needs of children with disabilities from birth to age 18 or 21 in cases that involve 14 specified categories of disability. Several of these categories – orthopedically impaired, traumatic brain injury, learning disabled and other health impaired – are disability categories that may include children with serious illness, thus affording special education services to this population of students.

Special education is instruction that is specifically designed to meet the unique needs of a child with a disability. In order to qualify for special education, a student must first show that he/she is not responding to regular school interventions (Response to Intervention or RTI). For example, if a student is receiving regular education services and does not do well in math using Curriculum A, then Curriculum B, C, and D may be tried before referring the child for further evaluation to determine if he/she is a student in need of special education. If the student is unable to succeed on Curriculum B, C, or D, he/she will then be evaluated to determine eligibility for services under IDEA.

To fully meet the eligibility criteria as a "child with a disability," a student must meet two criteria. The student must: (1) have one of the disabilities listed under IDEA; and (2) the child's educational performance must be [adversely affected](#) due to the disability. School districts and individual schools have different criteria for determining if the child's educational performance is "adversely affected" by the disability. For example, in one school district, excessive absences may be considered to be criteria that show that the student's educational performance is adversely affected while, in the adjacent school district, absences may not be considered adequate criteria. If you have a question about how a child is



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determined to be eligible for special education services, talk to the director of special education in the school district where the child attends school.

Once a child has been qualified by the school district as a student eligible for special education, an Individualized Education Program (IEP) will be developed. Each IEP is developed for only one student, and must be tailored to that student's needs. The IEP is a legal document that all will look to for guidance in helping the student. It will enable teachers, parents, school administrators, related services personnel, and students (when appropriate) to work together to improve educational results for the child with a disability.

The IEP is what defines special education for the child with a serious illness and is the foundation of a sound education for the student. The student's needs define what will be included in the IEP. Therefore, an IEP may identify strategies, interventions, and materials that address learning, access to school programs, socialization, transition planning for post-secondary goals, materials necessary to optimize learning, and any other special education or accommodation which will improve the learner's ability to succeed.

A word of caution: although the preceding paragraph states "any other accommodation or application..." this does not suggest that a school district is required to provide whatever a family may request. For example, if a learner cannot write, the school may choose to provide a tape recorder for recording answers, rather than a laptop. The school is required to provide a *solution* to the student's need, but is not required to supply the most expensive option or to provide something that parents may ask for but the school does not believe is essential. Similarly, very few students have "personal paraprofessionals (paras)" or aides who are assigned only to them. That was common several years ago, but the practice was found to be both costly and limiting to many students as the para would often do the work for the child, limiting the student's ability to learn new material.

An effective IEP is developed when parents, teachers, other school staff, and often the student, work together to address the student's unique needs. These individuals comprise the IEP team, and will share their knowledge and expertise to guide the delivery of the most effective special education supports and services for the student with a serious illness.

### **Which is best: 504 Plan or an IEP?**

Neither plan is better than the other; they are just different. It is helpful to remember that 504 Plans are accommodations in the regular classroom – changes that are designed to remove barriers to accessing education for students who are otherwise capable academically. An IEP defines the special education supports and services to be received by a student who cannot learn with traditional teaching strategies and/or materials. The following examples illustrate how which plan to use is determined by which student is using it!

A 504 Plan may be a good solution for the student with metastatic Ewing's sarcoma, who is only able to attend school half days, or who needs the opportunity to rest in the nurse's office for 20 minutes twice a day. Another student with metastatic Ewing's may need to be evaluated for special education due to brain metastasis and, if qualified, an IEP could include methods to help the student complete his 5<sup>th</sup> grade year so he can "graduate" and go on to middle school.

The student with sickle cell disease may realize fewer hospitalizations, increased school attendance, and greater success in academics after a 504 Plan is implemented that reinforces the student's need for adequate hydration, and allows for unlimited bathroom breaks. For a sophomore student with sickle cell disease, an IEP may be more appropriate after a stroke and subsequent 3 months in rehabilitation. The IEP team will provide a comprehensive evaluation to determine if the student is eligible for an IEP and then develop a special education plan that meets her unique needs.



The high school student with cystic fibrosis, who has always enjoyed playing the drum in the marching band, no longer has the stamina to march. The band is his school "family" and the source of his support related to his illness. The 504 Plan will identify a student or faculty "pusher" who can push the student in a wheelchair while he continues to play in the band. A third grade student with cystic fibrosis finds herself in a different situation, which may require special education. Due to poor nutrition throughout the child's life she is now falling 2 years behind her peers in school. After a comprehensive evaluation, the school determines that she would benefit from an hour a day with the special education teacher, while spending the rest of the day in the regular classroom.

Thus, there is no way to know exactly which type of plan will "fit" with specific diagnoses or situations. The key is to work closely with the student's school district to ensure that the right plan is being developed for that individual student. Some school districts are hesitant to develop 504 Plans because it is an unfunded mandate. Despite the fact that there is no funding for services under Section 504, most accommodations are free or low cost. IDEA does have associated funding, and school districts are reimbursed by the federal government for each special education student who receives services. In addition, yearly audits of IEPs by the State Department of Education ensure that IEPs are always up-to-date and monitored closely. There is no automatic oversight of 504 Plans, but one can call the Office of Civil Rights to request technical assistance if concerns over 504 Plans exist.

Parents, health care providers, and others may request that the plan be updated or revised at any time. IEPs must be updated annually and the recommendation is to update 504 Plans yearly, as well. Reevaluation of the student, under IDEA is required every three years. That ensures that a child does not get "stuck" in special education when they no longer need it, and also identifies any new needs the child may have. Reevaluations may also be requested sooner than 3 years if changes are observed in the student's performance.

Although there is time, effort, and even some red tape involved in developing a 504 Plan or an IEP for a student, it is well worth it in the end. A written plan keeps everyone on the same page and helps foster effective communication between all players. Ultimately, the plan may help ensure that a child with a serious health condition has every opportunity to learn, develop, and grow alongside her healthy peers.

### **Who Should be Involved in Developing 504 Plans or IEPs?**

As previously stated, parents, teachers, the student when appropriate, the school nurse, school administrator, health care providers, and other pertinent parties should be invited to the IEP meeting. This team is required in the IEP process, but there is no reason why a similar team should not be assembled in the 504 Plan development. Ensuring that all aspects of the child's life are represented is essential, and including athletic coaches, music teachers, youth ministers, etc., is also allowable. Each member of the IEP or 504 Team sees the child through a different lens, and it is important to represent the *whole* child. If a child is a gifted athlete, for example, and that is not represented as her school goals are being developed, it may limit the student's ability to achieve her goals.

It is also beneficial for members of the health care team to have the opportunity to see where the child spends most of his/her day – at school! Meeting teachers, school administrators, and the school nurse may foster lines of communication that will, ultimately, lead to enhanced success for the student.

### **Common School Challenges**

It is imperative to have a written plan for a student with a serious illness, whether that plan is a 504 Plan or an IEP, and to include ways to address the following concerns. Every young person with a serious illness will face challenges in school – period. It is not possible to move through the curriculum without some missteps when treatment, absences, fatigue, social issues, etc., etc., etc. are going on. Regardless



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of what the serious illness may be, here are some common perils and pitfalls for youngsters who are seriously ill.

- Excessive absences. Missing school frequently makes a difference! The American Academy of Pediatrics Policy Statement of School Absences reinforces that whether absences are clumped together or spread out over a school year, they are disruptive to learning. An IEP or 504 Plan should include a plan for what to do when the student returns to school. How does the teacher know, when a child goes back and forth from home to hospital, what skills have been missed? How will the teacher ensure that the gaps are filled? What is the plan? Who will teach those skills to the child? Problems ensue when a child is handed a stack of homework and told, "Turn this in when you can." If children did not need teachers to help them succeed, we would not have schools.
- Fatigue. Returning to school after an exacerbation of an illness, hospitalization, or period sick at home is very tiring. Some medications cause fatigue. Some illnesses cause fatigue. How do we know when a child is especially fatigued? How do we assess how the fatigue affects the child's attention and concentration and, therefore, learning? Teachers and health care providers may talk about this together to find solutions for individual students.
- Medication side effects. Weight gain, weight loss, unable to sleep, excess sleep, eating too much, loss of appetite, peripheral neuropathy, frequent urination, dry mouth, moodiness, nausea, constipation – ah, the joys of medication side effects. Certainly, all of these side effects are a nuisance for anyone, but even more so for the child with a serious illness at school. Teachers should learn about the possible side effects of a student's medications and be prepared to help him/her through those symptoms.
- Psychological concerns. Research reminds us that youngsters with serious illnesses have a higher incidence of depression, anxiety, and symptoms of posttraumatic stress disorder (PTSD). In addition, children may have concerns about money, their parents' concerns, the burden they place on the family, the direction in which their illness seems to be heading, and much more. Kids with serious illness are bringing a lot of "stuff" to school with them. Providing time with the school counselor, psychologist, or other trusted adult may be a welcome – and needed – respite for children with serious illness.
- Social concerns. Missing the birthday party of a good friend, prom, the first softball game of the season, observing Johnny getting in trouble with Mrs. Smith, seeing who was sent to the principal's office, or hearing that Mariah broke up with Sam – all of these represent the things that happen at school that make school interesting. Being part of the group and an accepted friend are critical parts of growth and development for all kids. When you are on homebound, in the hospital, or away from school, these are the items that are missed the most by kids. And missing these "happenings" results in kids who feel left out or out of sync with friends and classmates. It is important to have a plan for reintegrating the student in the classroom, the lunchroom, and the playground after each absence. It will make them want to come back to school the next time!
- Homebound education. For some students, homebound comprises the only method of receiving education services. A typical homebound program consists of a teacher going to the hospital or child's home 3-5 hours per week. It is a band-aid on a gaping wound and certainly does not provide the level of educational services that students need. Homebound should be reserved for only those students who absolutely cannot go to school, and should not continue one day longer than absolutely necessary.

## Supporting Parents and Students

Challenges and barriers to school success exist all along the way for students with serious illness. It is difficult for health care providers to determine exactly what each patient may need to achieve optimal success. Even more challenging is the job of school professionals as they attempt to address the needs of the student with a serious illness, in addition to addressing the needs of every other student in the



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class. But neither of these challenges is as difficult as the job held by the parents of the student and the student himself.

Parents and students are busy trying to process and understand the information they receive from health care providers regarding the child's serious illness. This is often being processed amidst a great deal of fear and feelings of being overwhelmed. Children are scared, angry, sad, and confused by all of the new information they are receiving. Parents feel about the same as their child. They hear that their child should not be exposed to infectious diseases, and that the medication and treatment regimen is very complex. Parents are encouraged to do everything the "right way" in order to ensure their child's health does not get worse. In the middle of all of this, the health care team says something like, "And we want you to get Mary back to school as soon as possible."

A word of caution: There are many websites that look "official" which contain inaccurate information about 504 Plans and IEPs. Some reputable organizations even have flawed information about education law. Others appear to have partial accurate information or may draw conclusions based on 1 or 2 families' experiences. Referring to the government websites listed at the end of this article may provide a safer alternative to ensure up-to-date and accurate information about Section 504 and IDEA.

In conclusion, and borrowing from an old, African proverb, we are reminded that "It takes a village to raise a child." At no other time is that more true than when talking of a child with a serious illness at school. School programming is being adjusted to ensure that we are preparing an ever-growing number of children, who a decade ago may not have survived, for adulthood. Children with a wide range of serious illnesses are moving out of pediatrics and into the brave new world of college, employment, marriage, and family life. As a result, parents, health care providers, education professionals, and, when appropriate, the child himself must come together to develop a plan that will enable all to feel successful at the end of the day.

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## HELPING CHILDREN COPE WITH LOSS, DEATH, AND GRIEF: TIPS FOR TEACHERS AND PARENTS

National Association of School Psychologists

[www.nasponline.org](http://www.nasponline.org)

Schools and communities around the country will be impacted by the loss of life associated with the war in Iraq. The effects may be significant for some people because of their emotional closeness to the war and/or their concern over terrorism. How school personnel handle the resulting distress can help shape the immediate and longer-term grieving process for students, staff, and families. Children, in particular, will need the love and support of their teachers and parents to cope with their loss and reach constructive grief resolution.

### Expressions of Grief

Talking to children about death must be geared to their developmental level, respectful of their cultural norms, and sensitive to their capacity to understand the situation. Children will be aware of the reactions of significant adults as they interpret and react to information about death and tragedy. In fact, for primary grade children adult reactions will play an especially important role in shaping their perceptions of the situation. The range of reactions that children display in response to the death of significant others may include:

- **Emotional shock** and at times an apparent lack of feelings, which serve to help the child detach from the pain of the moment;
- **Regressive (immature) behaviors**, such as needing to be rocked or held, difficulty separating from parents or significant others, needing to sleep in parent's bed or an apparent difficulty completing tasks well within the child's ability level;
- **Explosive emotions and acting out behavior** that reflect the child's internal feelings of anger, terror, frustration, and helplessness. Acting out may reflect insecurity and a way to seek control over a situation for which they have little or no control;
- **Asking the same questions over and over**, not because they do not understand the facts, but rather because the information is so hard to believe or accept. Repeated questions can help listeners determine if the child is responding to misinformation or the real trauma of the event.

### Helping Children Cope

The following tips will help teachers, parents, and other caregivers support children who have experienced the loss of parents, friends, or loved ones. Some of these recommendations come from Dr. Alan Wolfelt, Director of the Center for Loss and Life Transition in Fort Collins, Colorado.

- **Allow children to be the teachers about their grief experiences:** Give children the opportunity to tell their story and be a good listener.
- **Don't assume that every child in a certain age group understands death in the same way or with the same feelings:** All children are different and their view of the world is unique and shaped by different experiences. (Developmental information is provided below.)
- **Grieving is a process, not an event.** Parents and schools need to allow adequate time for each child to grieve in the manner that works for that child. Pressing children to resume "normal" activities without the chance to deal with their emotional pain may prompt additional problems or negative reactions.
- **Don't lie or tell half-truths to children about the tragic event:** Children are often bright and sensitive. They will see through false information and wonder why you do not trust them with the



truth. Lies do not help the child through the healing process or help develop effective coping strategies for life's future tragedies or losses.

- **Help all children, regardless of age, to understand loss and death:** Give the child information at the level that he/she can understand. Allow the child to guide adults as to the need for more information or clarification of the information presented. Loss and death are both part of the cycle of life that children need to understand.
- **Encourage children to ask questions about loss and death:** Adults need to be less anxious about not knowing all the answers. Treat questions with respect and a willingness to help the child find his or her own answers.
- **Don't assume that children always grieve in an orderly or predictable way:** We all grieve in different ways and there is no one "correct" way for people to move through the grieving process.
- **Let children know that you really want to understand what they are feeling or what they need:** Sometimes children are upset but they cannot tell you what will be helpful. Giving them the time and encouragement to share their feelings with you may enable them to sort out their feelings.
- **Children will need long-lasting support:** The more losses the child or adolescent suffers, the more difficult it will be to recover. This is especially true if they have lost a parent who was their major source of support. Try to develop multiple supports for children who suffer significant losses.
- **Keep in mind that grief work is hard:** It is hard work for adults and hard for children as well.
- **Understand that grief work is complicated:** Deaths that result from a terrorist act or war can bring forth many issues that are difficult, if not impossible, to comprehend. Grieving may also be complicated by a need for vengeance or justice and by the lack of resolution of the current situation: the conflict may continue and the nation may still feel at risk. The sudden or violent nature of the death or the fact that some individuals may be considered missing rather than dead can further complicate the grieving process.
- **Be aware of your own need to grieve:** Focusing on the children in your care is important, but not at the expense of your emotional needs. Adults who have lost a loved one will be far more able to help children work through their grief if they get help themselves. For some families, it may be important to seek family grief counseling, as well as individual sources of support.

## Developmental Phases in Understanding Death

It is important to recognize that all children are unique in their understanding of death and dying. This understanding depends on their developmental level, cognitive skills, personality characteristics, religious or spiritual beliefs, teachings by parents and significant others, input from the media, and previous experiences with death. Nonetheless, there are some general considerations that will be helpful in understanding how children and adolescents experience and deal with death.

- **Infants and Toddlers:** The youngest children may perceive that adults are sad, but have no real understanding of the meaning or significance of death.
- **Preschoolers:** Young children may deny death as a formal event and may see death as reversible. They may interpret death as a separation, not a permanent condition. Preschool and even early elementary children may link certain events and magical thinking with the causes of death. For instance, as a result of the World Trade Center disaster, some children may imagine that going into tall buildings may cause someone's death.
- **Early Elementary School:** Children at this age (approximately 5-9) start to comprehend the finality of death. They begin to understand that certain circumstances may result in death. They can see that, if large planes crash into buildings, people in the planes and buildings will be killed. In case of war images, young children may not be able to differentiate between what they see on television, and what might happen in their own neighborhood. However, they may over-



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generalize, particularly at ages 5-6—if jet planes don't fly, then people don't die. At this age, death is perceived as something that happens to others, not to oneself or one's family.

- **Middle School:** Children at this level have the cognitive understanding to comprehend death as a final event that results in the cessation of all bodily functions. They may not fully grasp the abstract concepts discussed by adults or on the TV news but are likely to be guided in their thinking by a concrete understanding of justice. They may experience a variety of feelings and emotions, and their expressions may include acting out or self-injurious behaviors as a means of coping with their anger, vengeance, and despair.
- **High School:** Most teens will fully grasp the meaning of death in circumstances such as an automobile accident, illness, and even the World Trade Center or Pentagon disasters. They may seek out friends and family for comfort or they may withdraw to deal with their grief. Teens (as well as some younger children) with a history of depression, suicidal behavior, and chemical dependency are at particular risk for prolonged and serious grief reactions and may need more careful attention from home and school during these difficult times.

### Tips for Children and Teens with Grieving Friends and Classmates

Seeing a friend try to cope with a loss may scare or upset children who have had little or no experience with death and grieving. Following are some suggestions teachers and parents can provide to children and youth to deal with this “secondary” loss.

- Particularly with younger children, it will be important to help clarify their understanding of death. See tips above under “helping children cope.”
- Seeing their classmates' reactions to loss may bring about some fears of losing their own parents or siblings, particularly for students who have family in the military or other risk-related professions. Children need reassurance from caregivers and teachers that their own families are safe. For children who have experienced their own loss (previous death of a parent, grandparent, sibling), observing the grief of a friend can bring back painful memories. These children are at greater risk for developing more serious stress reactions and should be given extra support as needed.
- Children (and many adults) need help in communicating condolence or comfort messages. Provide children with age-appropriate guidance for supporting their peers. Help them decide what to say (e.g., “Steve, I am so sorry about your father. I know you will miss him very much. Let me know if I can help you with your paper route....”) and what to expect (see “expressions of grief” above).
- Help children anticipate some changes in friends' behavior. It is important that children understand that their grieving friends may act differently, may withdraw from their friends for a while, might seem angry or very sad, etc., but that this does not mean a lasting change in their relationship.
- Explain to children that their “regular” friendship may be an important source of support for friends and classmates. Even normal social activities such as inviting a friend over to play, going to the park, playing sports, watching a movie, or a trip to the mall may offer a much needed distraction and sense of connection and normalcy.
- Children need to have some options for providing support—it will help them deal with their fears and concerns if they have some concrete actions that they can take to help. Suggest making cards, drawings, helping with chores or homework, etc. Older teens might offer to help the family with some shopping, cleaning, errands, etc., or with babysitting for younger children.
- Encourage children who are worried about a friend to talk to a caring adult. This can help alleviate their own concern or potential sense of responsibility for making their friend feel better. Children may also share important information about a friend who is at risk of more serious grief reactions.
- Parents and teachers need to be alert to children in their care who may be reacting to a friend's loss of a loved one. These children will need some extra support to help them deal with the sense of frustration and helplessness that many people are feeling at this time.



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## Resources for Grieving and Traumatized Children

At times of severe stress, such as the trauma of war or terrorist attacks, both children and adults need extra support. Children who are physically and emotionally closest to this tragedy may very well experience the most dramatic feelings of fear, anxiety, and loss. They may have personally lost a loved one or know of friends and schoolmates who have been devastated by these treacherous acts. Adults need to carefully observe these children for signs of traumatic stress, depression or even suicidal thinking, and seek professional help when necessary.

Resources to help you identify symptoms of severe stress and grief reactions are available at the National Association of School Psychologists' website— [www.nasponline.org](http://www.nasponline.org). See also:

### For Caregivers

- Deaton, R.L. & Berkan, W.A. (1995). *Planning and managing death issues in the schools: A handbook*. Westport, CT: Greenwood Publishing Group.
- Mister Rogers Website: [www.misterrogers.org](http://www.misterrogers.org) (see booklet on Grieving for children 4-10 years)
- Webb, N.B. (1993). *Helping bereaved children: A handbook for practitioners*. New York: Guilford Press.
- Wolfelt, A. (1983). *Helping children cope with grief*. Bristol, PA: Accelerated Development.
- Wolfelt, A. (1997). *Healing the bereaved child: Grief gardening, growth through grief and other touchstones for caregivers*. Ft. Collins, CO: Companion.
- Worden, J.W. (1996). *Children and grief: When a parent dies*. New York: Guilford Press
- Helping Children Cope With Death, The Dougy Center for Grieving Children, [www.dougy.org](http://www.dougy.org).

### For Children

- Gootman, M.E. (1994). *When a friend dies: A book for teens about grieving and healing*. Minneapolis: Free Spirit Publishing.
- Greenlee, S. (1992). *When someone dies*. Atlanta: Peachtree Publishing. (Ages 9-12).
- Wolfelt, A. (2001). *Healing your grieving heart for kids*. Ft. Collins, CO: Companion. (See also similar titles for teens and adults)

*Adapted from material first posted on the NASP website after September 11, 2001. NASP has made these materials available free of charge to the public in order to promote the ability of children and youth to cope with traumatic or unsettling times. The materials may be adapted, reproduced, reprinted, or linked to websites without specific permission. However, the integrity of the content must be maintained and NASP must be given proper credit.*

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## SCHOOL REINTEGRATION: TIPS AND TOOLS FOR STUDENTS, PARENTS, AND TEACHERS

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After undergoing treatment and being away from peers, going back to school may not be the first thing on a child's mind; but returning to their friends and the normal activities of school is something they will eventually do as part of their recovery. Many will feel nervous about going back to school after being in the hospital or undergoing treatment. However there are a lot of things you and those who support the child can do to help make this transition easier.

It is important to recognize that school for children is like jobs for adults. It provides an anchor for them in life from which they can grow and develop purpose. School is not only a place for learning, but also for fun and friendship. School reintegration gives the child a clear message that they have a bright future ahead of them and allows for a larger sense of normalcy in the family.

In this article, we will review ways to help both the parents and the child in returning to school. We will also briefly address the impact of the child returning to school can have on his or her siblings.

### **HELPING THE PARENTS**

There are three general barriers to successful school reentry: a lack of communication, a lack of information, and school or health system regulations and policies. The remainder of this article will offer suggestions to counter these barriers and facilitate an effective school return.

#### **Communication**

Parents frequently respond to illness with a sense of crisis that often leads them to cut communication with outsiders while managing the situation at hand as best they can. In this frame of mind, parents may delay contact with the school believing that school issues are no longer a priority or that school-related issues can be postponed and dealt with at a later time. Other parents may feel confusion about when and how to communicate with the school. It is never too early to set the stage for good communication. Health care providers should encourage parents to establish effective communication habits with the child's school system. Communication should occur at time of diagnosis, during the hospitalization, and when the child is preparing to return to school.

#### **Information**

In addition to effective communication, it is important that there is an appropriate exchange of information. At the school, the principal, teachers, a school counselor, and the school nurse should be made aware of the child's diagnosis, treatments, reactions to treatments, and length of expected absence. Within the



hospital, a social worker, a school liaison, and a child life specialist can work with the parents to develop a plan in conjunction with the medical team in order to facilitate the child keeping up with schoolwork while in the hospital or when requiring home-bound services.

When the child is ready, the school should have records of:

- Any medicines the child will need to take and instructions on how to give them
- A list of signs/symptoms to look out for
- Emergency management instructions for possible problems (for example, immediate measures if the catheter becomes dislodged, nausea and vomiting)
- Information regarding what kinds of treatments that your child cannot have
- An emergency contact list should any questions arise that includes the child's oncology team for urgent medical needs

### **Regulations and Policies**

It is also important to recognize that parents may not be familiar with the resources that a school can provide to help their child. Educating parents on specific schools regulations surrounding special education needs is very necessary in facilitating successful school reentry. Information on homebound instruction services, policies about school absence, and participation in testing programs that can significantly impact a child should be provided, as well as assistance understanding and applying for IEP development and appropriate accommodations.

A school or health system's regulations and policies concerning the sharing of information are also frequently identified as a barrier. Parents should be advised to sign the appropriate release of information forms to ensure that necessary parties involved are able to communicate with one another. Additionally, teachers may not have the information needed to correct or deal with rumors, misinformation, or questions by other children in the classroom; therefore, meeting the parents, and possibly even along with the child, can be helpful in assisting teachers to manage these situations appropriately.

## **HELPING THE CHILD**

### **Asking For/Receiving Help**

It may be helpful for the child to meet with key school administrators, the school nurse, and school counselor prior to returning to school in order to help the child know who to go to if problems arise.

Let the child know that most children are welcomed back into the classroom with kindness. Their peers will likely want to help but might not know how to go about this. Some will ask directly and others will wait for them to be asked for help. Let the child know it is helpful if they can be honest and direct with their friends and classmates. This may include asking for help with tutoring, note-taking, or even carrying books from class to class. Remind them that most of their friends and teachers will want to make the transition back to school as smooth as possible and they do not have to go through this alone. Children are also naturally curious. Therefore, they may be asked direct questions such as "Will your hair grow back?" "Can I try on your wig?". Helping the child to be prepared for these questions and how to answer these questions will be helpful. Usually these questions end within a few days of the child's return.

### **Preparing the Peers**

Dealing with the unknown is difficult for most people. Since the child's peers may not all have been informed on why the child has been away from school, or understand fully the diagnosis and treatment the child has received, it can be very helpful to talk to them about the child's diagnosis and the treatments they received/are receiving. Young classmates' major concerns are often about whether they can catch the illness (like a cold) from your child. Students of all ages need to know that having a chronic illness is no one's fault; and sometimes even scientists cannot understand why the illness happens. Therefore, if possible, consider having someone go to the school to prepare classmates for the child's return – even if



someone had already met with them after the child was diagnosed. Elementary school children usually want someone they trust from their medical team to go to their school. This is less often the case for middle and high school youth, for whom the need to not be different is paramount. In fact, adolescents sometimes wish to tell only teachers and a close group of friends. It is important that these wishes are respected, but it is equally important to ensure that the teen is fully aware of available services and support and how these services can benefit them. If the child has agreed to a classroom or teacher presentation, the parent and the child should make time to review the exact content of the presentation so that they know what their classmates are being told. Always ensure that children agree to what will be covered in the presentation. Children have found it very helpful to be assisted in anticipating some of the questions they are likely to encounter.

### **How can the school provide support during the re-entry period?**

Potentially stigmatizing situations, nausea, extreme fatigue, or frequent need to use the bathroom during classes can be stressful and a reason some children are hesitant to return to school. Others, particularly those returning to large schools, may be concerned about being knocked over or being late to classes due to physical limitations. It is helpful to identify the child's current level of ability as well as their prior level of achievement and school adjustment (children who disliked school or were poor achievers before their diagnosis may have more difficulty with school re-entry).

Support the child in a manner that is developmentally appropriate. Remind them not to be discouraged if their transition back to school does not go as smoothly at first as they hoped. If their medications or treatments have resulted in some short or long-term learning problems, consider strategies to reduce frustration and ways to help the child be successful. For example, if they are having a tougher time trying to concentrate or understand new concepts, it is taking them longer to complete assignments, and/or study habits that worked in the past are no longer effective, a 504 plan or an Individual Education Plan (IEP) may be appropriate so that accommodations such as additional time for exams can be put in place. Having an extra set of books at school might help the child with physical limitations, while audio textbooks might be useful for those whose auditory skills are better than their visual ones. Other accommodations that do not require a 504 plan include providing the child extra time to move from class to class, being excused from physical education or recess, permission to wear a hat or scarf in school (due to hair loss) or to use the elevator. Concern about falling behind academically or having to repeat a grade can be a tremendous stress for the returning child and continual assessment on how the transition is going should be conducted. These are intensified for adolescents where academic pressures are greater.

### **The importance of peer relationships**

It is peer relationships that often most worry the child when going back to school. If this is problematic and not addressed, in more extreme cases the anxiety about returning to school can lead to school phobia. They may fear peer rejection or ridicule because of hair loss or other changes in appearance. They may be sad if they are no longer included in after school or weekend activities with those they hung out with before the diagnosis. The longer the child has been away from school, particularly if there has been little communication with peers, the more anxious he or she may feel about returning. Anxiety about returning to school may be manifested by somatic symptoms including stomachaches, headaches, and fatigue. These can be hard to sort out when medical problems have caused similar symptoms in the past.

Discussion in advance about possible stressful events and how they will be handled can significantly help ease the transition. Some families have found it helpful to have some of the child's friends over before returning to school, so that they can have a chance to get caught up and to become comfortable being together again. This can be especially helpful for children whose appearance is very different from when they were last seen by their peers. Arranging at least one friend to walk from class to class with, take the elevator with, or go to lunch with can also tremendously reduce the returning child's anxiety.



# Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care  
Organization



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Children with chronic illness have been observed by parent and teacher report as being more sensitive and isolated than peers. Good social support from classmates has been identified as the most consistent predictor of adaptation and problems with the maintenance with friends has been associated with poor school performance. Therefore, careful observation during the re-entry period is advised.

## **Siblings**

The child's return to school can also impact his or her school-age siblings. The sibling may receive a lot of questions about their brother or sister (where have they been, why they may look different, if their sibling still has an illness). Parents should prepare their healthy children that such questions may be asked. Knowing what to say (words they can use) can greatly increase the well sibling's comfort.

## **Final Thoughts**

Although school reintegration can be a difficult time for everyone involved in the child's life, it can be an exciting time as well as the focus shifts away from the acute medical environment. It is important to balance the medical, psychosocial, and educational needs of the child returning to school in the most productive and positive setting possible. This can be achieved with open communication between the health care providers, school staff, and the child's caregivers, appropriate exchange of necessary information, understanding school and government policies and regulations, as well as providing developmentally appropriate support to the child.

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## HOW TO SUPPORT GRIEVING CHILDREN IN THE SCHOOL ENVIRONMENT

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Regardless of your role in the lives of grieving children, you may be faced with the question of how to provide support in the school environment. In our 30 years of working with grieving families, we've listened to many stories of what they experienced as helpful, and sometimes not so helpful, responses from teachers, administrators, and peers.

Imagine this scenario: 32 third graders seated in a circle, sharing stories with each other about grief and loss. From the death of family members and pets to moving and leaving friends behind, each of these students share something when asked, "What losses have you had in your life?" Providing these students with the chance to talk openly with one another helped to normalize their reactions and created a safe environment for questions. Whether it's a sibling, parent, or a classmate who has died, here are some basic tenets for how to best support students in the school setting.

### **Sharing the News**

One of the first questions that arises after a death is, "What do we share and how?" The answer often depends on who died and what kind of connection they had with the school community. We encourage schools to have a policy in place that can guide their actions around sharing news about a death. A school's response may be different, depending on if the person who died was a student, teacher, or a family member who was well connected to the community (classroom volunteer, PTA member, coach) or a student's family member who was not closely involved with the school. In either case, we recommend that any news be shared in person and not over the loudspeaker or in a school newsletter. If the person who died was a member of the school, it is important that everyone in the community receives the same information, in a timely manner. This goes a long way to minimize the risk of rumors and the spread of false stories as misinformation can be hurtful to the family as well as spark anxiety and uncertainty for others.

If the person who died was a family member who was not connected to the community, it is important to contact the family and talk with them about how and what they want to be shared. In this case, it's common for children to say that they don't want anyone to know what happened because they fear being seen as different or treated awkwardly. If this comes up, it is helpful to talk with children about how it's inevitable that classmates will find out, either from each other or their family members and that the information is likely to be inaccurate. It can be useful to say something such as, "I know you value privacy and are worried that people will treat you differently if they find out. Given that they will likely hear it from someone, is there a way to share with them what happened that feels okay to you?" Some children will want to tell their classmates themselves. Others will want their teacher to do so. It can be reassuring to children if you tell them what words you will use to talk about what happened and then ask them for suggestions on what to say or not say.



## Reaching Out – The Importance of Staying Connected

We hear over and over how much families appreciated when the school took the initiative to reach out to them in the time leading up to a death and afterwards. It's important for this contact to happen right after the death and also as part of an ongoing relationship between the family and the school. This open communication helps parents/caregivers to know how their child(ren) is doing in the classroom and gives teachers the opportunity to put their students' behavior in the context of what is happening at home. By reaching out and talking with families about what support they need, schools can do a lot to minimize the disconnection and isolation that grieving families often encounter.

## What to Expect

While children experience and express grief in unique and individual ways, there are a number of common elements. While grief is stereotypically characterized as an emotional phenomenon, it affects children in multiple arenas including:

- Behavioral: high/low energy, inability to sleep, distracted behavior, over-achievement, trying to be perfect, regressive behavior.
- Physical: somatic complaints (stomachaches, headaches, aches & pains), frequent colds/flu, increased number of sick days from school.
- Cognitive: difficulty concentrating, focusing, following directions, and completing homework. Inattentiveness/day dreaming.
- Emotional: anxiety, agitation, sadness, withdrawal, anger, relief.
- Spiritual: questioning the inherent justness of the world, wondering/doubt about religion/spirituality.

In the classroom, these reactions can present in many different ways, including what appears to be no reaction at all. Some children will have very high energy and be unable to sit still or focus for any length of time. Others may be more quiet and withdrawn. While it's common for children's performance and grades to decline after a death, some will do better than ever, pushing themselves to get the best grades possible.

As a teacher or professional who is helping a child transition back to school after a death, it's useful to be prepared for any number of reactions. How a child acts in school may change day to day or even moment to moment. If the death is one that impacts the entire classroom, there can be a number of questions about the person who died and the details of the death, as well as increased concerns about other people dying or the world no longer feeling safe.

## In the Classroom: What Helps

### *Homework Challenges*

For children who struggle with completing homework, it is helpful for teachers and caregivers to collaborate on strategies to best support the child. These might include assigning a homework buddy to help the child, being flexible about assignments (extending due dates, excusing certain ones), and breaking down projects into smaller parts. In this, it is important to maintain structure and expectations, while also being willing to adapt to changes in a child's capacity. As one mother said to her child, "I want you to pass this year, but I don't expect you to get all A's."

### *Behavioral/Emotional Changes*

A good place to start when supporting a grieving student is to recognize that you can't take away the feelings of pain, fear, loneliness, or being different that come with grief. Understand that your role is not to get rid of those feelings, but to create an environment where children feel accepted and understood. Grieving children can swing between wanting to be treated as if nothing is different and needing adults to



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recognize that their world has changed significantly. One way to attend to both of these needs is to continue to provide structure, routine, and consistency while remaining open to making changes and adjustments. This approach helps children to feel safe and trust that the people in their lives are responsive and understanding.

### *Other Tips*

**Listen, Listen, Listen:** After a death, many children want to share their story. They may want to tell you what happened, where they were when they were told about the death, and what it was like for them. Telling their story can be a healing experience. Adults can be too quick to offer advice, give opinions, and make judgments. Unfortunately, while adults are busy talking it is easy to miss important messages from children about what they need and how to best help them.

**Provide Choices Whenever Possible:** Giving children choices allows them to regain a semblance of power and control in their lives. It is important to give them the chance to have input on decisions both large and small. In the school setting, this might look like asking a child what color paper she'd like to use or how she would like to help clean up after a project. If you find yourself wondering about the best way to handle something related to the child and her grief, we encourage you to start with asking her what she thinks would be best. If the person who died was a classmate, teacher, or other member of the school community, be sure to include students in discussions about how to honor and remember that person. Ideas might include: creating a memory wall, writing cards to the person's family, holding a remembrance ceremony, lighting a candle...etc.

**Difficult Day Safety Plan:** An effective strategy for providing tangible support for grieving students is to co-create a safety plan for dealing with difficult days. This plan helps students know what they can do if they are having a particularly challenging day. This might include identifying a safe person and/or room in the school that the student can go to if he or she starts to feel overwhelmed. It's helpful if the teacher and student devise a non-verbal signal for these times, as having to say out loud that they are having a hard time can be intimidating for children. One teacher and student came up with a pebble system – the student had three pebbles a day and he could put one on the teacher's desk every time he needed to go to the office and take a break. Any type of non-verbal indicator will work; what's most important is to involve children in creating the plan.

**Create a Support Network for Staff Members:** Often, students' grief brings up adults' personal loss experiences. Find ways to discuss your own grief with colleagues so that you can remain available to students. This also includes providing education for teachers and other school personnel about children and grief. Families tell us that the number one thing they wished for in terms of support from the school was for teachers to have better training about how grief affects children.

As children spend so many hours of their lives at school, it is vital that teachers and other staff members have an understanding of what grief looks like and strategies to be supportive. There are many opportunities for children to feel understood in the school environment when they are dealing with the death of a sibling, classmate, or caregiver. As a teacher or other supportive adult, remembering to listen, be flexible, and allowing children to make choices are great first steps to ensure that they will continue to be successful in the educational setting.

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## TOOLS FOR SUPPORTING SIBLINGS IN A SCHOOL SETTING

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The Safe Crossings program through Providence Hospice of Seattle provides grief support and education to children, teens, and families. Our program allows young people to learn about their grief process while expressing feelings within a safe, supportive environment. The following article details a few examples of how Safe Crossings supports siblings in a school setting, both in anticipatory and bereavement situations.

### **Figuring Out What Kids Need at School During the Tough Times**

Parents worry about how their children will fare in school when there is a sibling at home who is seriously ill. Carefully observing behavior and emotional changes is important. Actually, behavior changes may be the strongest barometer of how children are reacting to a difficult situation. Here are some behaviors and concerns which may indicate intervention and more support is needed:

- struggles with concentration and focus
- poor school performance and grades
- unusually strong emotions at school or home like excessive worry and fears, irritability, anger
- behavior that is out of character or erratic
- regressive behavior in terms of the child's developmental stage
- changes in sleep or appetite

### **Privacy and Boundaries**

Children and teens need privacy and boundaries too, especially at school, where information and rumors can spread rapidly. Kids need to feel safe at school, not as if they are under a microscope. Though informing the school of a difficult situation at home is important, it needs to be helpful to the child or teen:

- make sure the child or teen is OK with the school knowing
- ask who they feel should know
- in case of sibling death, assess how much the surviving sibling wants the school to know and when

Though the school needs to be informed appropriately, it can be really difficult for a child or teen to find out "everyone" knows their sibling is really sick or has died. Mostly siblings worry that other kids will ask them many questions at school. They fear they may cry or the questions and comments will be hurtful or insensitive. They need some boundaries and control over who is to know and how they will be informed. When the school handles the information with respect and according the child's or teen's wishes, a solid foundation of trust is then built for them to feel safe and get support at school.

### **Illness Free Zone**

On one end of the spectrum are the kids who feel school is an escape from the sadness and difficulty of home life with a sibling who is ill. They may find that school is a place where there is a predictable routine, and they take comfort and security in this. They may find the type of support and attention they need at school, while they may rightfully feel like less of a priority at home than their sibling who is ill. Talking to anyone at school about what is happening at home may feel like their school life is being invaded. They may need to compartmentalize and keep home issues at home. As long as they are not struggling in school, this seems to work well for many kids.



## Empowerment

On the other end of the spectrum are the kids who worry often, even during the school day. They may worry that their sibling will have to go back to the hospital, or that their sibling could die and they won't have a chance to say goodbye, or generally about the unknown. There are ways to help these kids decrease their worry and find ways to focus better at school:

- give the child a sense of control and offer choices whenever possible and appropriate
- ask them what they think would help
- working with the school, give them a chance to call home when they need to check in

## Concentration Stations

As with adults, kids may have difficulty concentrating when someone they love is seriously ill. They may worry about the person and their family while at school or during homework time, or feel more tired because of the stress at home or poor sleep.

- parents may need to ask for extra academic support at school if grades are suffering
- structured time and space may be needed for getting homework done
- parents may need to help more, enlist the help of an adult family member, or possibly hire a tutor if resources allow

## OK Go Pass

For the child or teen struggling at school and needing someone to talk to, it can be awkward and intimidating to go up to the front of the classroom and ask the teacher for a pass to go to the counselor's office. There is no guarantee that the teacher will handle this as the child or teen needs. Many kids may have difficulty advocating for themselves in this situation, so a special pass given them by a school counselor, who has informed teachers of the purpose and intent, can help the child or teen feel much safer in seeking support.

## Building Bridges between Families, Schools, and Grief

Whenever a child or teen has experienced the death of a sibling, all of the strategies mentioned above apply to the bereaved sibling as well, as they often feel isolated in their grief at school because they may not know of any other students who've experienced this type of loss. Following these guidelines will insure that the child feels appropriately supported at school, and that school performance can be optimized during bereavement. Communication with the school should occur as soon as possible so that staff can prepare a grief support plan, hopefully before the child or teen returns to school after the death. As mentioned previously, confidentiality and clear preferences need to be understood from the bereaved child or teen before discussing the death with the school. Here are some important elements for a solid grief support plan:

- appropriate communication between family, school, and grief counselor
- grief education provided by grief counselor to the child or teen, the family, and the school support team
- identified strengths of grieving sibling
- identified concerns of school personnel
- collaboration in development of a grief support plan
- grief support group opportunities

## Building the Bridge: Case Example

The following segment is a clinical example from an experience supporting a grieving school age sibling named Sam. Recounting this process will hopefully provide useful guidance for others. During a routine home visit, Sam's parents requested that the grief counselor attend a meeting with school personnel. The request originated from the school counselor with the hope of learning grief support tools to help bridge the support network for this child.



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Within a week's time the principal, three teachers, the school counselor, both parents, and the Safe Crossings counselor gathered in a conference room after school. Sam had been previously informed of the meeting by his parents explaining: *He was not in trouble*, reinforcing: *We were coming together to find ways to best support his grief process*. He was offered a choice to attend, and he declined.

After introductions, Sam's father asked the grief counselor to share what he observed to be "successful tools" used by the counselor while supporting his son. First, appreciation for the opportunity to collaborate was expressed. This established the foundation for a co-creative process. Acknowledging grief education as a key component, the discussion began with using the metaphor of a thumb print. The grief counselor explained: *Grief is a process as unique as the child we are here to support. There is no one way, time span, nor prescription for Sam; it is an individual journey*. In addition: *We have learned from children that support eases the feeling of isolation loss often brings*. Directly following, Safe Crossings packets detailing developmental considerations regarding children and grief were provided. These packets were tailored to support Sam's individual needs along with tools proven useful for him.

Next, examples were shared of identified strengths observed in Sam. The aim of this strength-based approach was to build the scaffolding for a support plan. For example, Sam loves to read. This was noted by the grief counselor as one of his self-regulating tools. Because reading appeared to be a grounding force, each support visit begins with a book. This ritual unfolded by following Sam's lead.

Another example: Sam is extremely physical. During each grief support visit, his need to discharge energy through extreme motor activity was observed. Early on, he gravitated to a yoga ball bouncing throughout the visits. This was viewed as another identified strength – Sam's ability to access coping tools. Acknowledging the differences within each classroom, the grief counselor then invited staff to brainstorm workable accommodations that could be applied in their given environments. Ideas unfolded, questions were raised and resolved collaboratively. This exchange culminated in working support strategies appropriate for each setting. Our meeting ended with an exchange of email addresses for access and continued consultation when needed. The bridge was firmly planted.

### **Constructing Student Bridges: School Grief Support Groups**

School-based grief support groups help youth come together in meaningful ways. Connecting with peers provides a unique network offering insight, normalcy, validation, affirmation, and the comfort in knowing: *When I see someone in the hall [from group], I know he understands*. Safe Crossings also provides singular support groups for sudden and/or traumatic loss. Groups are conducted at elementary, middle, and high school levels using a flexible Safe Crossing's curriculum to meet the needs of individual schools and classes.

### **Closing Thoughts**

It is nearly impossible to detail the depth of sibling grief. The essential ingredients of validation, empowerment, respect for privacy, and compassionate awareness help weave together a support network for a grieving sibling. By building a bridge between family and school both worlds become a refuge providing permission to pursue the hard work of each sibling's grief journey.

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**SOME RESOURCES FOR SUPPORTING CHILDREN, THEIR FAMILIES, AND  
FACULTY/STAFF IN SCHOOL SYSTEMS WHEN A CHILD IS SERIOUSLY ILL,  
DYING, OR BEREAVED**

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Outlined below are some additional resources that were identified in our compilation of the submissions for this issue. It was thought that they may provide some further help in working with seriously-ill children, their families, and the school system throughout the trajectory of a seriously-ill/dying child's illness. The Centering Corporation ([www.centering.org](http://www.centering.org)) and The Dougy Center: The National Center for Grieving Children & Families ([www.dougy.org](http://www.dougy.org)) offer some of these for a minimal cost through their websites.

*A teacher's guide to the grieving student: Guidelines and suggestions for school personnel grades K-12.* (2008). Mt. Joy, PA: Hospice of Lancaster County Pathways Center for Grief and Loss.

Barrett Lindholm, A. (2007). *After a death: An activity book for children.* Portland, OR: The Dougy Center.

Blackburn, L.B. (1999). *The class in room 44: When a classmate dies.* Omaha, NE: The Centering Corporation.

Cameron, J.B. (2008). *When grief enters your school: A guide for schools and families.* Omaha, NE: The Centering Corporation.

Deaton, R.L. & Berkan, W.A. (1995). *Planning and managing death issues in the schools: A handbook.* Westport, CT: Greenwood Publishing Groups.

The Dougy Center. (2008). *Helping the grieving student: A guide for teachers.* Portland, OR: Author.

The Dougy Center. (2003). *When death impacts you school: A guide for school administrators.* Portland, OR: Author.

The Dougy Center. (n.d.). *After a death: Ten ways you can help grieving students & their peers.* Portland, OR: Author. <http://www.dougy.org/books-dvd/brochures/after-a-death-ten-ways-you-can-help-grieving-students-their-peers/76/>

Gliko-Braden, M. *Grief comes to class: An educator's guide.* (2004). Omaha, NE: The Centering Corporation.

McGlaufflin, H. (1999). *Supporting children and teens through grief and loss: A guide for schools.* Portland, ME: The Center for Grieving Children.

Miller, S.D. (2000). *Mourning and dancing for schools: A grief and recovery sourcebook for students, teachers, and parents.* Deerfield Beach, FL: Health Communications, Inc.



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## RESOURCES FOR WAYS TO ENGAGE GRIEVING SIBLINGS

### Safe Crossings Team

Providence Hospice, Seattle, Washington

#### Books:

##### **Preschool: Ages 3- 6**

*Ethan's Butterfly*, by Christine Jonas-Simpson

An affirming book addressing the concept of continuing bonds after death

*When Dinosaurs Die: A Guide to Understanding Death* by Laurie Krasny Brown and Marc Brown

Answers children's questions and fears about death with clarity and directness

*LifeTimes: A Beautiful Way to Explain Death to Children* by Bryan Mellonie and Robert Ingpen

Explains life and death in a sensitive and natural way.

##### **School Age: Ages 6 – 12**

*The Invisible String*, by Patrice Karst

Shares a bond between children and their loved ones even when the loved one is not physically present.

*Magnificent Marvelous Me!*, by Art with Heart

An expressive art activity book specifically focused on siblings

*Ocho Loved Flowers*, by Anne Fontaine

The story of a young girl who learns how to say goodbye to her beloved cat while treasuring the memories. A sensitive way to support children through the anticipatory process.

##### **Teens: Ages 13 and older**

*The Empty Room*, by Elizabeth Devita-Raeburn

More theoretically and research based, describes the range of emotion and conditions that often attend to sibling loss along the pathway to healing.

*Help for the Hard Times*, by Earl Hipp

A guide that helps teens understand how they experience grief and loss, offering tools for coping with grief in healthy ways.

*Fire in My Heart, Ice in My Veins: A Journal for Teenagers Exploring Loss*, by Enid Samuel-Traisman

A journal for teens who have experienced the death of a loved one.

##### **Parents/Guardians**

*The Bereaved Parent*, by Harriet Sarnoff Schiff

Offers guidance to parents. Shows a way through day-to-day hardships and offers concrete suggestions for meeting the needs of the whole family.

*The Empty Room*, by Elizabeth Devita-Raeburn

More theoretically and research focused, describes the range of emotion and conditions that often attend to sibling loss along the pathway to healing.

*The Journey Through Grief and Loss: Helping Yourself and Your Child When Grief is Shared*, by Robert Zucker

Offers parents and other concerned adults important insights into managing their own grief while supporting grieving children.

##### **Activities**

*Bereavement Jenga/Bereavement Uno*: Using the common school games with added bereavement question cards. These cards can be found in bereavement games such as "Healing Hearts" and "The Good Bye Game."

*All About Me/All About My Sibling sheet*: Individual expressive sheets with "getting to know you" questions

*Class Letters to Sibling*: Depending on the bereaved sibling's comfort level, class letters sharing thoughts and support from students



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## READER'S CORNER

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Advanced care planning in children with life-limiting conditions – the Wishes Document  
J Fraser, N Harris, A J Berringer, H Prescott, F Finlay. *Arch Dis Child* 2010;95:79–82.  
<http://adc.bmj.com/content/95/2/79.full.pdf+html>

GUIDANCE FOR DISCUSSIONS ABOUT CHILD & FAMILY WISHES WHEN LIFE IS LIMITED (The Wishes Document). J Fraser, N Harris, A J Berringer, et al. *Arch Dis Child* 2010; 95:79-82 (web only data)  
[http://adc.bmj.com/content/suppl/2010/03/16/95.2.79.DC1/Child\\_family\\_wishes\\_guidance\\_notes\\_\(1\).pdf](http://adc.bmj.com/content/suppl/2010/03/16/95.2.79.DC1/Child_family_wishes_guidance_notes_(1).pdf)

Abstract: No abstract is available. This work is the 2009 product of a group of pediatric palliative care experts working under the auspices of ACT (Association for Children with Life-threatening and Terminal Conditions and their Families) in the UK. The review article discusses the importance of advance care planning discussions, especially at end of life, for children who are likely to die prematurely. The history and format of the Child and Family Wishes document is reviewed. The Wishes document is available as a web only supplement.

Who is the audience for this information? Anyone who deals with these important questions that appear at the beginning of the Wishes Document.

- *Would you be surprised if this child died prematurely due to a life-limiting illness?*
- *Would you be surprised if this child died within a year?*
- *Would you be surprised if this child died during this episode of care?*
- *Do you know what the child's and family's wishes are for the end of life?*

The multidisciplinary readership of the ChiPPS newsletter will be particularly receptive for this very easy to use tool to guide the discussion.

What is special about this article? The article starts with important context information:  $\frac{3}{4}$  of children who died in the UK had a pre-existing disability or medical condition;  $\frac{1}{2}$  to  $\frac{3}{4}$  of these children died in the hospital. Is that what they wanted?

In the UK (not so much in the US), there is important policy and guidance:

- Pediatric palliative care services should be available to all who need them
- Every child and family should be helped to decide on an end-of-life plan
- Appropriate children should have a written care plan, including a choice to be at home as much as possible
- Families should have continuous access to multidisciplinary community teams, as well as subspecialist support and advice
- Advance care planning including a resuscitation plan should exist for all children at risk of cardiorespiratory arrest. The wishes of patients with capacity (i.e., over 16 years of age) should be clearly identified

Barriers to achieving advance care planning are clarified:



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- Difficulty predicting the end of life
  - Uncertainty about exact timing of death is less important than anticipating the fact the death will be premature
- Difficulty of “raising the issue”
  - Parents appreciate open and honest discussion and do not regret disclosing this information to their children
- The third is my addition and is addressed by the Wishes Document: Inadequate tools to inform and document the discussion

Where and how can I apply this information? As noted in the review article, the concept of palliative care including advance care planning should begin at or soon after the diagnosis. The discussions require honesty, sensitivity, and balance. The best interest of the child must be met while addressing potentially unrealistic expectations of the parents. Members of the multidisciplinary team can utilize this tool from the point of diagnosis through death to guide the discussion and document the advance care plan.

The Wishes Document is designed to be child- and family-focused, and to evolve as the needs of the child and family change. Wishes during times of “life” or relative stability, during deteriorations, during acute life-threatening events, and after death care are addressed. As in the United States, this type of advance directive does not have legal status for minors in the UK. The document belongs to the child and family but should be shared with all care providers to ensure that the child’s and family’s wishes are followed. It will also avoid any confusion if there is a state child death review process in place.

This is a tool that empowers the child and family, and informs present and future care providers. It is very practical and sustains realistic hopes. The child and family's wishes are known and the plan is consistent with those wishes.

[A copy of the Wishes Document follows this article.]



## GUIDANCE FOR DISCUSSIONS ABOUT CHILD & FAMILY WISHES WHEN LIFE IS LIMITED

Advance care planning with families of children with life-limiting conditions is possible months or years before the end of life. Advance decisions evolve over time through the development of a trusting relationship and an ethos of shared decision making.\*

This document is offered as a *guide, to be used by any member of the Healthcare Team* in co-ordination with colleagues, in response to family needs and requests. These are difficult but necessary discussions and this guidance is offered to support the process. Staff should not feel under pressure to complete every aspect of the form by a certain time or at one sitting, but to be **led by the needs of the family** as to which parts need to be discussed or reviewed – with whom, where and at what time.

Staff should aim to offer all families an opportunity to talk about end of life issues (concerns or wishes) but with the awareness that in some cases, families will not want to take this up, or may need more time before they are ready to do so. A list of information resources and contacts can be found on the last page of this document.

### Begin by asking yourself the following questions:

- Would you be surprised if this child died prematurely due to a life-limiting illness?
- Would you be surprised if this child died within a year?
- Would you be surprised if this child died during this episode of care?
- Do you know what the child's and family's wishes are for the end of life?

**If the answer to any of the above questions is "No", this guidance is relevant.**

### The next steps are to:

- Find out who else is involved in the care of the child & family, e.g. a palliative care service.
- Find out if the family have already discussed an End of Life and/or resuscitation plan.  
(Prompt: *'has anyone had a discussion with you about what you would like to happen if your child becomes seriously ill?'*)

If the family already have a plan, you may wish to review it with them, to ensure that it is still relevant or to update it if required. If there is no plan, you can use **any or all** of the following pages to document the discussions using the templates, and the suggestions in the table below, as a guide.

The first page of the document should always contain general information about the child and family.

	CHILD	FAMILY	OTHERS e.g. friends, school
<b>WISHES DURING LIFE</b>	e.g. special holiday	e.g. family holiday	e.g. fundraising
<b>PLANS FOR WHEN YOUR CHILD BECOMES UNWELL</b>	e.g. treatment options	e.g. what may happen?	e.g. visiting
<b>ACUTE LIFE THREATENING EVENT</b>	e.g. preferred place of care,	e.g. treatment options	
<b>AFTER DEATH</b>	e.g. funeral preferences	e.g. spiritual & cultural wishes	

**After discussion with the family, please ensure that a copy of the plan is included in all medical notes and a copy is given to the family, the child's GP & all other relevant services.**

\*Ref: L. Brook et al (2008) A Plan for Living and a Plan for Dying: Advanced Care Planning for Children; Arch Dis Child 2008; 93 (suppl): A61-A66



**CHILD & FAMILY WISHES DOCUMENT**

**GENERAL INFORMATION**

**Name:**

**Date of Birth:**

**Name of Parents:**

**Name and Age of Siblings:**

**Address:**

**Telephone No:**

**Diagnosis & Background Summary:**

**Key Professionals involved:**

Name:	
Position Held:	
Organisation:	
Tel no:	E-mail

Name:	
Position Held:	
Organisation:	
Tel no:	E-mail

Name:	
Position Held:	
Organisation:	
Tel no:	E-mail

Name:	
Position Held:	
Organisation:	
Tel no:	E-mail

<b>This page discussed by:</b>	
	Child / Parent / Carer
	Professional [Full name & job title]
Date	

Document Date: October 2008

Review Date: October 2009



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**CHILD & FAMILY WISHES DOCUMENT**

**WISHES DURING LIFE**

<b>Name:</b>	<b>Date of Birth:</b>
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**Child's wishes during life:**

**Family wishes during life:**

**Other's wishes during life: [e.g. school friends, siblings]**

<b>This page discussed by:</b>	
	Child / Parent / Carer
	Professional [Full name & job title]
<b>Date</b>	

Document Date: October 2008 Review Date: October 2009



# Children's Project on Palliative/Hospice Services

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CHILD & FAMILY WISHES DOCUMENT	
PLANS FOR WHEN CHILD BECOMES MORE UNWELL	
Name:	Date of Birth:
<b>What may happen?</b> E.g. deteriorating mobility, feeding, cognitive function, worsening seizures.	
<b>Preferred place for care:</b>	
<b>Preferred treatment options:</b> (Indicate if not applicable or inappropriate)	
<input type="checkbox"/> Antibiotics - e.g. Oral / IV / 'Portacath'	
<input type="checkbox"/> Feeding - e.g. NG tube / gastrostomy	
<input type="checkbox"/> Respiratory Support - e.g. mask ventilation	
<input type="checkbox"/> Seizure Management Plan	
If child deteriorates further, preference(s) for place of death & persons present.	
<b>This page discussed by:</b>	
	Child / Parent / Carer
	Professional [Full name & job title]
Date	
Document Date: October 2008	Review Date: October 2009



# Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care Organization



<b>CHILD &amp; FAMILY WISHES DOCUMENT</b>		
<b>PLANS FOR CARE DURING AN ACUTE LIFE-THREATENING EVENT</b>		
	<b>YES</b>	<b>NO</b>
Oxygen via face mask/nasal cannulae	<input type="checkbox"/>	<input type="checkbox"/>
Airway management using oral/nasopharyngeal airway	<input type="checkbox"/>	<input type="checkbox"/>
Bag & mask ventilation	<input type="checkbox"/>	<input type="checkbox"/>
Endotracheal tube & ventilation	<input type="checkbox"/>	<input type="checkbox"/>
External cardiac compressions	<input type="checkbox"/>	<input type="checkbox"/>
Defibrillation & adrenaline	<input type="checkbox"/>	<input type="checkbox"/>
Advanced life support requiring PICU admission [Including inotropic drugs and advanced renal replacement therapy]	<input type="checkbox"/>	<input type="checkbox"/>
<b>Please give further details if required:</b>		
<b>Other issues discussed:</b>		
<b>If child deteriorates further, preference(s) for place of death &amp; persons present.</b>		
<b>This page discussed by:</b>		
	Child / Parent / Carer	
	Professional [Full name & job title]	
Date		
Document Date: October 2008		Review Date: October 2009



# Children's Project on Palliative/Hospice Services

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CHILD & FAMILY WISHES DOCUMENT	
<b>WISHES FOR AFTER DEATH</b>	
<b>Preferred place of care of child's body:</b>	
<b>Funeral preferences:</b>	
   <small>[Seek detailed information or further advice if needed]</small>	
<b>Spiritual &amp; cultural wishes:</b>	
<b>Other child &amp; family wishes: e.g. what happens to possessions?</b>	
<b>Organ &amp; tissue donation:</b>	
<b>This page discussed by:</b>	
	Child / Parent / Carer
	Professional [Full name & job title]
Date	
Document Date: October 2006	Review Date: October 2009



## CHILD & FAMILY WISHES DOCUMENT

### RESOURCES & SUPPORTING INFORMATION

1. ACT The Association for Children's Palliative Care <http://www.act.org.uk/>
2. Children's Hospices UK <http://www.childhospice.org.uk/>
3. Child Bereavement Trust <http://www.childbereavement.org.uk>
4. Department of Health guidance relating to children's deaths: <http://www.everychildmatters.gov.uk/socialcare/safeguarding/childdeathreview>  
Since April 1<sup>st</sup> 2008, there has been a statutory requirement to investigate **unexpected and unexplained** children's deaths. The website summarises these processes.
5. Child Bereavement Network <http://www.childhoodbereavementnetwork.org.uk>
6. CLIC-Sargent (Cancer and leukaemia in childhood) leaflets/booklets, including: 'When there is no Longer a Cure', 'When our Child Has Died', 'Living Without your Child', available at [www.clicsargent.org.uk](http://www.clicsargent.org.uk)
7. Children's cancer and leukaemia group (CCLG) leaflets, including: 'Choices: When it seems there are none', 'Facing the Death of Your Child', 'Bereavement: Where to go for help', available at [www.cclg.org.uk](http://www.cclg.org.uk)

**This Child & Family Wishes Document has been developed by members of the Service Improvement Network Project (listed below) to support, and promote, End of Life planning for children with life-limiting conditions.**

Antonia Beringer	Research fellow/project facilitator, Centre for Child & Adolescent Health (CAAH), University of the West of England, Bristol
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Jan Berry	Charlton Farm Children's Hospice Nurse
William Booth	Modern Matron PICU, University Hospitals Bristol NHS Trust (UHB)
Pam Cairns	NICU Consultant, UHB
Avril Coihyo-Lewis	Chaplain, UHB
Nicola Eaton	Director Children's Palliative Care Research, CCAH
Karen Forbes	Consultant in Palliative Medicine, UHB
Piona Finlay	Community Paediatrician, Bath & NE Somerset PCT (B&NES)
James Fraser	PICU Consultant, Designated Doctor for Unexpected Deaths in Childhood, UHB
Nicky Galtsborough	Community Paediatrician, UHB
Nicky Harris	Clinical Director, Charlton Farm Children's Hospice
Helen Prescott	Clinical Psychologist, Lifetime Service, B&NES PCT

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## Items of Interest:

In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

**1. Subjects and Contributors for Future Issues of This Newsletter.** In past issues of this newsletter, we have addressed a wide range of subjects, including bereavement, sibling bereavement, self care, ill and dying teens, perinatal loss, neonatal loss, spirituality, unsung heroes in the circle of care, pain and symptom management for children with life-threatening illnesses and their families, families experiencing transitions associated with pediatric palliative care, complementary therapies, examples of programs illustrating the current status of pediatric palliative and hospice care in the United States, memory building and legacy making in pediatric palliative and hospice care, examples of many programs offering this type of care in various parts of the world outside the United States, ethical issues related to pediatric palliative and hospice care, help and healing in relationship to bereavement perspectives, stress and moral distress (identifying stressors and supporting staff), and using social media and electronic communications to network by families and practitioners. (Please note that you can visit archived issues of this newsletter at [www.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics).) For future issues, we are thinking about addressing subjects such as issues that are distinctive to infants and children ("children are not little adults"), and integrating volunteers and ancillary services in pediatric palliative/hospice care.

If you know of good topics and/or contributors (including yourself) for any of these and/or other future issues of this newsletter, please do not be shy! Step right up and contact any of the following: Christy Torkildson at [torkc@sbcglobal.net](mailto:torkc@sbcglobal.net); Maureen Horgan at [Maureen.Horgan@providence.org](mailto:Maureen.Horgan@providence.org); or Chuck Corr at [ccorr32@tampabay.rr.com](mailto:ccorr32@tampabay.rr.com). We will work with you!

**2. Reader's Corner.** Our Reader's Corner column provides brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric palliative care, but that may not be known to all readers of this newsletter. Contributions to the Reader's Corner include an abstract of the publication, a description of the audience for this information, comments on what is special about the publication, and suggestions as to where and how this information can be applied. We welcome suggestions for publications to include in our Reader's Corner and/or summaries and comments on such articles following the model in this issue. Please send all such suggestions to Christy Torkildson at [torkc@sbcglobal.net](mailto:torkc@sbcglobal.net).

**3. Forthcoming Conference--Save the Dates.** The Eighth Annual Seattle Children's Pediatric Bioethics Conference will be held in Seattle on July 27 – 28, 2012. The conference will explore "The Thin Ethical Line: When Professional Boundaries and Personal Interests Collide." During this conference, a distinguished panel of experts will address a range of challenging ethical issues, such as: Is it ever appropriate for a healthcare provider to "friend" a patient or parent?; Should a healthcare provider perform procedures or prescribe medications for their own family members?; Is "firing" a patient an appropriate response to parents who refuse to vaccinate their children?; Is it ever okay for healthcare providers to lie on behalf of their patients? To learn more about this conference or register, visit [www.seattlechildrens.org/pediatric-bioethics-conference](http://www.seattlechildrens.org/pediatric-bioethics-conference). Treuman Katz Center for Pediatric Bioethics, Seattle Children's Research Institute, 1900 Ninth Avenue, Seattle, WA 98101; ph: (206) 884-8355; email [www.seattlechildrens.org/bioethics](http://www.seattlechildrens.org/bioethics).

**4. NEW at NHPCO's 2012 CTC: Two-Day Pediatric Hospice and Palliative Care Training, Nov. 3-4.** NHPCO is proud to announce a new educational opportunity: NHPCO's Pediatric Hospice and Palliative Care Training (PHPCT) will be offered on November 3-4 in conjunction with NHPCO's 2012 Clinical Team Conference and Pediatric Intensive, at the Walt Disney World Dolphin Hotel and Conference Center in Lake Buena Vista, Florida. This two-day (6 hours each day) Preconference Seminar will prepare your organization to care for infants and children facing life-



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threatening conditions and their families. Taught by expert interdisciplinary pediatric hospice and palliative care faculty, the PHPCT is designed for hospice and palliative care clinical—nurses, physicians, social workers, spiritual care professionals, bereavement professionals and related disciplines – who are seeking intensive preparation to expand access to care to all individuals in your community who may need your services.

The major topics that will be covered in the PHPCT Training are:

- Principles and Standards of Practice
- Delivery Models
- Ethics, Decision-Making, and Advance Care planning
- Childhood Development in Health and Illness
- The Spectrum of Complex, Chronic and Fatal Conditions
- Assessment and Management of Pain
- Symptom Management
- Psychological Support of the Family and Community
- Bereavement Care
- Structure and Support of the Interdisciplinary Team

Visit NHPCO's website for more information on the [13<sup>th</sup> Clinical Team Conference and Pediatric Intensive](#) (held November 5-7) – registration information for the PHPCT will be available soon. The PHPCT and the CTC both offer valuable educational offerings on pediatric palliative care.

**5. CureSearch Website – Now in Spanish.** CureSearch for Children's Cancer has translated the Foundation's website, [www.curesearch.org](http://www.curesearch.org), in Spanish, making medical content about children's cancer available to parents and families whose children have cancer. Users will find that the entire site has been translated, while maintaining easy-to-use navigation and simple illustrations that depict medical tests and procedures. Content on the site is housed in four main categories: Medical Information, Research, Coping with Cancer, and Getting Involved.

**6. Calendar of Events.** As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the Web site, [www.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics). *ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at [www.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics).* Please e-mail Christy Torkildson at [torkc@sbcglobal.net](mailto:torkc@sbcglobal.net) to have your pediatric palliative care educational offering listed.

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Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work.

If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to [CHIPPS2@NHPCO.org](mailto:CHIPPS2@NHPCO.org) requesting to be added to our mailing list. If you are a member of NHPCO, you can go to the **Communications Preferences** tab in your individual member record online and “opt-in” for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the ChiPPS Web page at [www.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics) for further materials and resources of interest.

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