ChiPPS Pediatric Palliative Care Newsletter  
Issue #26; February, 2012

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

Issue Topic
Social Media and Electronic Communications: Networking by Families and Practitioners

Welcome to the twenty-sixth issue of the ChiPPS electronic newsletter. This issue of our e-newsletter offers a PDF collection of articles that explore some issues involving social media and electronic communications, with emphases on networking by families and practitioners in the field of pediatric palliative and hospice care. We hope the articles in this issue will be useful for all readers, but especially for those who are new to working in this field and for those who have previously worked primarily in palliative and hospice services for adults. These are, of course, merely a limited number of the vast assortment of issues that arise in this broad subject area. Nevertheless, we hope this sampler will help to bring out some useful discussions and guidelines for readers of this issue.

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 Communications Work Group, co-chaired by Christy Torkildson and Maureen Horgan. Archived issues of this newsletter are available at www.nhpco.org/pediatrics.

Comments about the activities of ChiPPS, its Communications Work Group, 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 or Maureen at Maureen.Horgan@providence.org.

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.
Issue #26: Social Media and Electronic Communications: Networking by Families and Practitioners
(Click on the “bookmark” tab on the left-hand side of the PDF document for links to the following articles.)

Sunday
Scott Newport
We begin this issue with a poem by Scott, who has often contributed to this newsletter. Here, Scott reflects on his work as a volunteer with dying children.

Captive in the Moment
Diane Stonecipher, RN, BSN
Luke’s mother, Diane, writes a letter to a palliative care physician to give an update on his condition and reflect upon his 20 years of living with serious illness.

How One Family Uses CaringBridge to Update Family and Friends
Jennifer Medley
CaringBridge can decrease the feelings of isolation for a family whose child is living with a progressive neurodegenerative disease. Jennifer Medley writes about the support that the site offers and security considerations for both professionals and family.

CaringBridge: A Lifeline for Patients and Caregivers
Melissa Maggio, BA
The article provides an overview of the CaringBridge resource: free personal and private websites that connect persons living with serious illness to their community and beyond.

The Many Benefits of Social Networking with a Purpose
Missey Moe-Cook
The Executive Director of CarePages provides an overview of the CarePages social network resource.

Social Media and Advertising in Hospice and Palliative Care
Kelly Komatz, MD, MPH, FAAP, FAAHPM
Palliative care is both a philosophy of care and a business. Social media is a key element in marketing the business. Dr. Komatz invites readers to consider privacy obligations and state laws when telling the story of hospice with our patient stories.

You’ve Come a Long Way, Baby
Connie Bergh, MSH, RN, CHPPN
Do you want to feel more confident and responsible in your use of social media? If so, this is the article for you. Connie writes about the use of social media both personally and professionally, and encourages users to “ponder before you post.”

Infusing Social Media into Your Pediatric Palliative Care Program
Kathy Davis, PhD
Kathy’s article provides encouragement to providers who may be hesitant to engage in the realm of social media. She offers context for this hesitancy and a review of various social media tools. Her final encouragement is to just give it a try.

Using Social Media Responsibly to Provide Education about Pediatric Palliative Care
Denise Powers Fabian, MSSA, LISW-S, and Lisa Long, BA
Social media exists as a powerful tool for education about pediatric palliative care. Denise and Lisa present an overview of social media tools, approaches to using them for education, and practical tips for integrating social media into your organizational approach to education.
Reader’s Corner: Keep Fighting, Stop Struggling: The Miles Levin Story: p. 27
Miles Alpern Levin
Reviewed by: Ann Fitzsimons, BS, MBA
“Keep Fighting, Stop Struggling: The Miles Levin Story” chronicles the journey of a young man living with cancer. His “CarePages” were published in a book format in 2011 that is reviewed here by Ann.

Practical Pointers: How to Gracefully Decline a Facebook Request p. 28
Maureen Horgan, LICSW
This is a new occasional feature in the newsletter that we hope will offer practical tips related to pediatric palliative care. In this issue, Maureen provides ideas for how to decline a Facebook request.

Re-Introduction to ChiPPS p. 29

Items of Interest p. 31
ChiPPS customarily shares items that may be of interest to our readers.

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.
Taking a break from
   It all
Death forced
   Outside
No key to enter

We laughed together
   Talking ‘bout
Good ol’ boy stuff
   I knew where they
Were…… at least today

I embraced the moment
Football, hunting and fishing
   Were the course
For my visit

Three little children
   Resting quietly
Some with smiles
   All with terminal
   Illness

Tomorrow may
Never come for some
   Laughs may never erupt-
Like they did that day

But I remember those
Days when my child
   Was still alive and
Doing well

I hope I helped
CAPTIVE IN THE MOMENT

Diane Stonecipher, RN, BSN
Mother of Luke
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Luke turned 20 on Sunday. A birthday we did not anticipate that he would see. His birthdays have always been a mixture of triumph and pathos. This day, this 20th year, was appreciated on a level so deeply there was room for little else, save a reverent peace. I think that Luke brought this tranquility to himself, to all of us. It almost seems as though he willed himself to a size that he could manage. All cheekbones, knees, and knuckles, he is as beautiful as I have ever seen him.

From this time last year to spring, to the early summer, he struggled in every way possible. We shared in that struggle to such a degree that we, having endeavored to help him do what he sometimes cannot, were perhaps, as tired as he was. Still, letting go seemed harder than holding him. We were holding on to everything. Our home, our other sons, our jobs, extended families. We have straddled “his” world and everything in the other world, for a long time. Because we are of that world and he is not, we had imagined ourselves a finish line. Perhaps when his brothers fledged the nest, it may get easier. Perhaps if Bob quit his job for a while, we would catch our breaths, catch up financially later. The pace and effort was simply unsustainable.

Even Luke seemed to move forward until he could move no more; not backwards, not sideways, not at all. That night in the hospital in Seattle there seemed to be no place to retreat to. Vomiting bile, drenching in sweat, and panting, he looked at us with such resignation. My heart, beating as fast as his, was ripping. There was no fear or defeat in that face, only courage. If he was letting go, I would champion that with as much faith as I did all other endeavors. But as the hospice doctor remarked, the answers were unsatisfactory. He had simply made this body last longer than it really could. It was true, and unsatisfactory, yet the peace of opening that door, usurped the unrelenting tension of the months prior. As if my fingers, always so tightly gripped, were rolled off the future, one at a time. Each meal he took readily was without the angst of him needing to eat. Each sleep-filled night was a treasure. Each walk was a poem in itself. The future was scarier, but the present was more peaceful than it had been for months. Quiet in his recliner, he seemed to be glad to just be. To feel my own abject sadness without the weight of tension was almost soothing.

Exactly 3 months to the day of that night, we celebrate in awe, in truth, and in peace. He has given us this. His achievements, so much larger than the body that has carried them, sit upon him like a crown. He has used his body to the outskirts of its capabilities, his heart as openly as humanly possible, and shared his will generously with all of us.

In this space and this brief time, I feel that he and we have taken it all in. I have learned from his fearlessness because it is not the reckless kind. It is real enough for him to show it and me to believe it. When he is ready to let go, he most certainly will. The pure love that he has both received and given has seeped in to me like a long, slow rain. It nourishes parts of me that I will know and feel long after he is gone. In the meantime, we hold him, like he holds us, captive in the moment.
HOW ONE FAMILY USES CARINGBRIDGE TO UPDATE FAMILY AND FRIENDS

Jennifer Medley
Jake's Mother
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Jake is our sweet 7-year-old boy who is suffering from a neurodegenerative disease called late infantile Neuronal Ceroid Lipofuscinoses, or Batten Disease. Jake was born a healthy baby boy on September 24, 2004. He was developing normally until age three, when he began having seizures and losing skills he had already learned. By age four and a half, Jake had lost his abilities to walk and talk, was losing his eyesight, and was no longer able to do anything for himself. By age five he was finally diagnosed with late infantile Batten Disease. The symptoms of Jake’s disease are mental impairment, worsening seizures, and progressive loss of sight and motor skills. Batten Disease is a genetic disorder linked to a buildup of substances called lipopigments in the body's tissues. Lipopigments are made up of fats and proteins. The lipopigments build up in cells of the brain and the eyes as well as in skin, muscle, and many other tissues.

Jake lacks an enzyme that would normally filter out these fats and proteins. There is currently no treatment or cure for Batten Disease, and the life expectancy for Jake's form of the disease is between ages 8-12. Jake is now tube fed and is almost completely blind. He is surrounded by loving friends and family, including his mom and dad, Dean and Jennifer, and his big sisters, Caroline and Anna. Jake enjoys his time spent at his school, Mandarin Oaks Elementary, where he is well taken care of by dedicated teachers, nurses, and therapists. He loves listening to music and watching "Dora the Explorer," and loves being outdoors. Our family has received many blessings through Jake. Thanks for taking the time to read Jake’s story!

I have known about CaringBridge for several years, as I have followed a few people that were ill through their sites. When Jake was diagnosed with Batten Disease in October of 2009, it was suggested to me that I use the site to update friends and family. At the time I was not ready to put Jake’s story “out there” for so many people to see. I felt that Jake’s illness was more of a private matter and that it was not
necessary to use a site such as CaringBridge to update people of Jake’s progress. Well, about 14 months after Jake was diagnosed and I had some time to adjust to our new life, I had a change of heart. I really thought it would be a good tool to update our friends and family on Jake, and to share our story with others and spread some awareness for Batten Disease. I began the site in December of 2010, and I have found that the support we receive through the messages people write on the site has really helped us to not feel so alone in our daily struggles. The site lets our friends and family know specifically how to pray for Jake and our family. If people choose to follow Jake on his site we are not forced to answer the same questions over and over about Jake. Though we know people mean well to always ask how he is doing, it is just easier for them to read for themselves. In addition, I have found it rather therapeutic at times to write journal updates on the site. Overall, it has been a really positive experience for us to use CaringBridge. I try to update Jake’s CaringBridge page about once a month when things are rather stable. During times that additional problems arise with Jake or he is in a medical crisis I update much more regularly, about every one or two days.

I really think it would be a good thing for more health care professionals to access their patients’ CaringBridge pages. I have shared the link with most of the professionals that work with Jake. Some have gone onto the site and some have not. I understand that after a long day at work in the health field most professionals don’t want to spend their time after work viewing a CaringBridge site for one of their many patients, and they most likely don’t have time to do so during the work day. When I do see that a health care professional is keeping up with Jake’s site I am honored that he or she cares enough to take the time to learn as much as he or she can about Jake. I feel like it is perfectly fine for anyone that reads Jake’s CaringBridge site to share anything from the site with other friends or other health care professionals. I think that anytime people put information on the internet they have to understand that this information can and might be seen by anyone.

I have not had any bad experiences with CaringBridge; I am very satisfied with the security precautions that CaringBridge uses. As administrators, my husband and I have the option to set up the security level as low, medium, or high. “Low” means that visitors do not need to log in and there is open access for visitors who know the website address. “Medium” means that visitors need to log in to CaringBridge and it allows us to see the names and e-mail addresses of visitors. “High” means that visitors need to log in and must be on an "approved list" (created by us) and allows us to see the name and e-mail addresses of visitors. Only visitors we approve can access the website when the security level is set on high. At first we chose to use the medium security level, but as the list of visitors grew and grew, it turned out that we don’t know who a lot of the people are on the site. That makes us just a little bit nervous, as we would like to always make sure we are protecting Jake’s privacy and maintaining his dignity. We have now changed the security level to high, as we feel that this will eliminate any visitors that are just purely being nosy or viewing Jake’s site for the wrong intentions.
Families unprepared for a loved one’s health diagnosis can be overwhelmed by medical terminology, treatment decisions, and hospital visits. It’s times like these that families need support from extended family and friends. But even trying to respond (much less reaching out) to them using the phone or personal emails can be overwhelming and exhausting.

CaringBridge was created to help these families stay in touch and provide information, while increasing time available for the patient and his or her caregiver. CaringBridge sites can be an important tool for families dealing with the stress of a health situation, giving them an appropriate outlet for sharing their feelings and receiving support.

**Simplify Communication**

CaringBridge provides free personal and private websites that connect people experiencing a significant health challenge to family and friends, making each health journey easier. The nonprofit is supported by donations so anyone can use the site for free at their time of need. The site provides a place for users to post journal entries and photos, as well as receive messages of hope and encouragement in a guestbook.

Using CaringBridge to centralize communication during a health journey makes it easier to share news, saving time and emotional energy. Everyone can stay in touch, regardless of time zones and area codes. CaringBridge is different from other social media sites because it is focused on the health journey and privacy is deeply respected – there are no advertisements, user information is not sold or shared with anyone, and there are many privacy options to choose from.

**How to Create a CaringBridge Website**

A CaringBridge website can be created by visiting CaringBridge.org. By following a few simple steps, a personalized website complete with privacy options can be started in just minutes. The author introduces the reason for the CaringBridge site in “My Story” and provides ongoing updates through entries in the journal. Authors can forward their unique and private CaringBridge website name and address to family and friends.

CaringBridge can be used by patients and families in all types of medical situations including childhood cancer, premature birth, organ transplant, extended hospitalization, and rehabilitation.

**The Power of Connection**

When faced with a significant health challenge, connecting with family and friends to receive love and encouragement can make the journey easier as well as reduce isolation and stress. In a 2010 survey of CaringBridge users, 91 percent of patients agreed that using CaringBridge helped make their health journey easier. Not only that, 88 percent of patients agreed that having a CaringBridge website positively impacted their healing process.
Using a personalized website makes updating loved ones much more manageable, reducing the number of phone calls needed to be made and allowing patients to focus on healing. For many patients, writing about their experience on a site like CaringBridge also serves as therapy and a source of healing, allowing them time to reflect on what really matters.

**CaringBridge at the Hospital**

Hospitals and healthcare professionals are a core source of referrals for CaringBridge. There are over 1,800 hospitals and healthcare facilities that partner with CaringBridge by actively recommending the service to their patients.

Because families often lean on hospitals’ care staff for emotional support, engaging patients’ personal support networks early and often through CaringBridge relieves pressure on hospital employees and helps them focus on patients’ health.

Registered nurse Bonnie Bice, says, “CaringBridge alleviates some of the family’s tension and stress and that makes it easier for us. We can’t always be the emotional support that the families need.”

The hospital staff is also often the contact point for well-meaning family and friends who desire updates on a patient’s status. By using CaringBridge, patients and their families can help reduce calls to nurses’ stations, providing more time for nurses to focus on providing quality clinical care.

“The phone interruptions are big,” says NICU registered nurse Sam Warrington, “so it’s nice [when a family shares updates through CaringBridge] because there are a lot fewer interruptions for us at the bedside.”

**PERSONAL STORY SIDEBAR:**

**Connection to Hope, Love, and Shared Trials for Joneses**

Like the star in a fairy tale, little girls dream of being a princess, dancing with a handsome prince at the majestic ball. While not a knight-in-shining-armor, thousands of people bestowed the title of princess upon Taylor Jones as they followed her battle against Acute Myeloid Leukemia (AML) on her CaringBridge site.

Diagnosed on September 30, 2008, then three-year-old Taylor rarely let the illness or treatments dampen her spirit. She faced four rounds of chemotherapy to kill her cancer and her bone marrow; a bone marrow transplant on February 5, 2009; and a long recovery. Without a bone marrow transplant, Taylor had a 0-20 percent chance of survival.

She has done more than survive. Somehow, through even some of the hardest days, spunky little Taylor managed smiles that sustained her parents. During treatments, she and her mom, Gina, danced and watched the movie “Happy Feet.” “If her toes were tapping, we knew she was okay,” Gina said.

**Cheering for the Little Princess**

So many moments and photos of this little princess’s journey have been captured on her CaringBridge site, which was created during her first week of treatments. Gina was pleasantly overwhelmed by the guestbook entries and the connection to people who checked in daily. “It still just blows my mind that there are people all over the world praying for not just Taylor but for all kids with cancer,” she said. In less than two years, “Honey Bear’s” site has amassed nearly 500,000 visits and more than 10,000 guestbook greetings.
With Gina and her husband Shane’s relatives spread out across the United States, Gina originally saw CaringBridge as a connection for them. She soon found an even greater purpose.

Helping Others

“We were blindsided because we couldn’t find personal stories or non-medical information on AML, treatments, and bone marrow transplants,” she said. “I wanted to help other families understand the process.” CaringBridge is Gina’s means of connection with those families.

She begins her daily posts with “Day 189” or “Day 365” to give families an idea of what to expect and when.

Of course, treating cancer is not routine. Taylor faced difficulty along the way with cytomegalovirus (CMV), septic shock, and the BK virus, which nearly claimed her life. Connecting with other cancer parents via CaringBridge was a source of encouragement for Gina because she realized they weren’t alone. Now, she often expresses support in others’ guestbooks to return the favor.

Staying Strong

Taylor remembers that she wasn’t alone through her cancer treatment and recovery. Her dance therapist, the child-life specialist, and the nurses are more often recalled than the pain and vomiting. And, of course, she won’t forget her family. Her mom never left her side and her dad and brothers were there for her treatments in Colorado Springs through the transplant and recovery in Denver.

Shane said he was able to manage the day-to-day activities by focusing on the future. “I kept going in the hope that one day she would be all better and this would be behind us. And I had faith in Taylor’s strength.”

One year after her bone marrow transplant and now nearly five years old, Taylor has a 90 percent chance of survival. As she’s gone from being too weak to walk to taking her first ballet class, CaringBridge has been there to capture it all…and all her smiles, too.
THE MANY BENEFITS OF SOCIAL NETWORKING WITH A PURPOSE

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CarePages is an online network of millions of people coming together to share in the challenges, hopes, and triumphs of anyone facing a life-changing health event. Through the CarePages social network, members can relate their stories, upload photos, and update friends and family instantly. A CarePages patient blog allows families to build a community of support and make connections with families who are in similar situations. CarePages gives members the ability to share their stories and receive messages of love and encouragement from their followers. Membership in the CarePages social network ensures that nobody will face a health challenge alone.

CarePages is used by many families of pediatric patients as a way to stay connected with family and friends during ongoing treatment and recovery; sometimes the service is used as a memorial. It has allowed pediatric patients to keep in touch with their friends and classmates, with adult supervision. CarePages makes it easy to update everyone who cares about the patient and their family, without the exhausting litany of telephone calls, and the service allows users to share pictures, keeping their whole community up to date on their loved one’s treatment. One family commented that “CarePages allowed them to keep their entire caring community nearby, even though they had to travel back and forth across the country for their son’s treatment. No matter what time zone they were in, or how many airplane rides they had to take, CarePages kept their entire caring community by their side.”

The CarePages social network is set apart from other social networks by its unique and easily controlled privacy settings. Hospital branded CarePages are both private and secure. Instead of spending time and energy worrying that someone could Google your child’s health history and story, you can feel secure in knowing that CarePages cannot be found using a search engine. The manager of the site, generally a parent or close family member, chooses what level of security their CarePage has.

As with any social network or internet forum, it is important for users to only post information that they are comfortable with sharing. CarePages is unique in its privacy features, which allows families to share their feelings and experiences as openly as they want to. The privacy setting for each page can be customized, allowing each family to choose who is able to see their CarePage and read updates. CarePages users can feel free to be honest and upfront, because they have the option and ability to control exactly who can see their CarePage.

CarePages allows users to update their entire community without making one phone call—at a time when every moment is precious. Managers can also send personal messages to supporters, as well as allowing them to comment on the update posts that Managers make. Supporter comments are where a CarePage and network of support come alive. A CarePages user commented, “Thanks so much for making this available – having a new baby with a heart condition this serious causes SO much stress on so many people, it’s wonderful for her parents NOT to have to try to interact with so many people, trying to tell the same story repeatedly.” CarePages allows loved one to stay connected, and to feel like they’re involved, even if they are half way around the world. Making back-to-back update phone calls is exhausting, CarePages allows loved ones to read and respond to updates about the patient on their own time. CarePages allows you to stay connected when you need it the most, without being bombarded with unannounced hospital visits and the stress of repetitive phone calls. It’s a way for loved ones and friends to show that they care, and to grow a larger community that cares about you and your child. One CarePages user told us, “CarePages really helps you feel like you’re not alone and that people are helping you and supporting you.” It helps keep everyone near when you have to travel long distances to hospitals for treatment, and when relatives and loved ones live far away.
An especially poignant note from a CarePages user told us, “without CarePages I would have never made it through some of my days. It was a way for parents of our kind to relate, bond, vent, ask questions, cry, whatever we needed to do to make it through the day. Thank you for helping me make it through my days of need!”

CarePages has a dedicated customer service team that is available via email or telephone to assist CarePages users in registering for CarePages and troubleshooting their difficulties. The customer service team also monitors posts and uses a content filter on hospital branded CarePages sites, looking for inappropriate language or negative comments about the hospital. When inappropriate content appears, customer service contacts the user, and makes sure that inappropriate posts are removed. The customer service team can be reached at help@carepages.com or at 888-852-5521.

Pediatric families also appreciate the CareCompliment feature, which is an easy way for them to acknowledge staff that went above and beyond in their level of care and compassion. Through CareCompliments Families share heart touching stories about staff members who helped them care for a sick child. The Care Compliments come from the surrounding Community as well as from around the world. CarePages helps patients and families build a network of love and support that extends beyond their home base.

CarePages also allows users to reach out to the doctors and caregivers who have touched their lives. The CareCompliment feature allows family, loved ones, friends, and the patient to compliment staff from the hospital who have made their treatment and recovery easier. In the hectic time of treatment for a serious illness, it’s easy to forget to say thank you to that great night nurse, or the doctor who always has a smile. A CareCompliment is an easy, personal way to let caregivers and hospital staff know just how great they are, and how much they have improved a child’s life. CareCompliments are sent to CarePages hospital partners, and then distributed to the individual it’s intended for.

CarePages are free to families, and there is no user subscription fee. Hospitals subscribe to the CarePages service, which gets them their own CarePages link code, with full branding including their logo and hospital colors. They can also run free banner ads for their programs and services, and they can link to hospital website pages from CarePages. Having branded CarePages at a hospital increases brand recognition and users who recognize branding are more likely to recommend the hospital to friends and family. There are also unbranded CarePages, where families can seek the solace of the CarePages community if their hospital does not provide branded CarePages.

CarePages is an incredible resource for patients and their families, especially during the emotional and exhausting time that a child is in treatment for a serious illness. CarePages allows families to build a community of loved ones and to extend their network to people around the world. The messages of love and support that CarePages users receive help them to make it through this stressful time. CarePages has helped so many families to reach out and get help, love, and support from those people who care about them.

* * *

If you’re interested in finding out more about CarePages, or offering it at your hospital, please contact Missey Moe-Cook, Vice President and Executive Director. You can reach her at rmoecook@everydayhealthinc.com or at 646-728-9679.
SOCIAL MEDIA AND ADVERTISING IN HOSPICE AND PALLIATIVE CARE

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As we have entered into the digital age there are inherent new questions, dilemmas, and ethical questions with this information age. No longer is the printed article in a newspaper, a flyer, or advertisement in a journal the only way to reach the public about your product. There are almost endless opportunities for a business to reach the consumer, such as Facebook, websites, and “Google.” Hospice and palliative medicine is not only a philosophy of care for patients living with chronic life-threatening conditions and those approaching end of life but it is a business as well. As a business, hospices are placed in same situations as any other business—namely, marketing; and in certain situations where the hospice agency is incorporated as a non-profit agency, fundraising.

As healthcare providers, we are educated and reminded on a daily basis about privacy regulations as detailed in the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy and Security Rules. This rule requires that all providers of health care take reasonable precautions to protect the privacy and security of “Protected Health Information.” However, as social media continues to evolve, at what point does HIPAA no longer apply to patient’s privacy—blogs, Facebook, etc. Physicians’ offices are establishing their own websites as a means to attract new patients and offer electronic newsletters, patient testimonials, and dialogues with the practice.

Transition now to the social media marketing for hospice and palliative care organizations. Patient stories are important to speak to the public about the benefits of hospice/palliative medicine. However, it is prudent for the organization to continuously evaluate and monitor their marketing practices to ensure “appropriateness” of continuing to use certain patient stories. For example, if a patient has died after the story was written and/or video-taped, and used for marketing purpose; should that patient’s story continue to be utilized, or does your organization have policies in place to remove the story from their archives? What is your state’s law for the statute of limitations on using consent for continuation of utilization of the patient’s story/photos? For example, in the State of Florida, the original consent is only good for one year.

The National Hospice & Palliative Care Organization has excellent resources when it comes to these difficult questions. The NHPCO has a document readily accessible on their website addressing these same questions “Hospice and Palliative Care: Ethical Marketing Practices” (PDF). This document includes an ethical decision making process for marketing strategies using the four box method. Furthermore, the NHPCO has a dedicated team to answer and guide such decisions.

Social media is here to stay and with it enhanced opportunities to bring the stories of hospice and palliative medicine to the general public. Social media is a great resource; but like all good things, we need to be mindful of any short-falls that this opportunity presents. Remember the golden rule in your daily interactions as a guiding principle” “Do unto others as you would have them do unto you.”
YOU’VE COME A LONG WAY, BABY

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You don’t have to be a smoker or a man to appreciate that line. As someone who remembers spending hours even days probing my local library’s card catalog to find one morsel of interesting information, I more than daily engage in online searching, surfing and interaction. In our time of instant gratification through the use of Facebook, Twitter, LinkedIn, MySpace, YouTube, Blogging (should I go on), we often partake before we ponder. There are a multitude of sites, each with its own objective, focus, and mission. Many are used by individuals for personal and professional reasons, and increasingly they are used by many organizations including healthcare. Online communities help members connect with new or existing friends and colleagues or those with like interests and purpose. Sites may promote a cause, offer advice, foster debate, or spark competition. Information, messages, photographs, video, bookmarks, blogs and other online activities are only some of what is shared by users of online sites.

The use of social media may give the sense of detachment and anonymity leading to disinhibiting behavior. Social cues may be absent, leading to actions and interactions that would not occur in person (Shuler, 2004). For the healthcare professional this could be especially detrimental. Misinterpretation of character may be exaggerated and misleading and lean toward the negative. However, appearing unprofessional is not the worst consequence. A breach in patient/employer confidentiality by healthcare providers using social media can result in civil liability, job loss, and disciplinary action by licensing boards, and even criminal investigations and sanctions (U.S. Department of Health & Human Services, n.d.).

Attempts to halt or even discourage the use of social media would be unenforceable and counterproductive. It is important that we are responsible and feel confident about how we communicate and interact when using these services (Guseh II, Brendel, & Brendel, 2009). Professionals need to be highly aware of implications of use and ensure that patients’ rights are protected.

General Measures

- Stop and think before you post; every interaction with every digital device is captured and stored and may become public and permanent.
- Be knowledgeable on how information flows online and the context of information may be limited.
- Use a personal email address, not your work email address, when establishing access to personal social networking.
- Take time to read and learn about a new site you are considering joining; determine how community members interact before you join.
- Policies differ from one site to another; be familiar with privacy settings so that you know in advance what information is public; know what will be shared with everyone, only with your inner circle of friends, and what's private.
- Limit the ability of “friends” to post to your wall or account.
- Use good judgment when you decide what is appropriate to post and whom to associate with online.
- As in real-world social situations, it’s always a good idea to be genuine, friendly, and helpful in online interactions.
Blogs are available to everyone. If you blog, only blog on topics within your area of expertise. Focus on general information and do not identify patients or colleagues without their consent.

When taking on debates or discussions, back up your position with facts and keep your composure. Engaging in personal attacks will cause loss of credibility.

Social media is here to stay and there are a number of positive aspects for healthcare organizations. Sharing and interpretation of medical information can counterbalance the less reliable and erroneous information presented on non-reputable websites. Use of social media between healthcare providers, other organizations, and the public can educate and encourage understanding, reflection, and appreciation. Healthcare organizations may use social media to support corporate objectives, promote the health of the community, recruit staff, and attract donors. Patients, families, and care providers are able to connect within organizational web sites to learn from the organization and from one another.

Organizations are becoming more aware of the impact of social media. Protection of an individual’s personal information by such entities as law enforcement and governmental agencies, educational and social institutions, and healthcare organizations will come under increasing scrutiny. Those who are responsible for vulnerable populations will be held to even higher expectations (Fanaroff, 2011). The healthcare professional has an even greater added responsibility for appropriate behavior online. While both are HIPAA violations, an online slip-up can have broader impact on violating patient confidentiality than comments made in the elevator or over lunch. Unprofessional behavior online by colleagues should be brought to their attention so postings might be removed or other appropriate actions taken to remedy the gaffe (AMA Policy, 2011).

Most organizations have policies related to patient privacy and confidentiality, as well as the appropriate use of company assets and resources during work hours. Healthcare organizations are now developing specific social media policies that specify employee use and involvement at all times or during working hours (Social Media Governance, n.d.). We should all be familiar with our organization’s policy and protocol. Situations might occur that may not be specifically spelled out in policy. However, a lack of policy guidelines does not excuse inappropriate behavior for the professional. Use of personal social networking sites on or off the job will reflect not only on you but on your organization, too. Some suggestions below have become common policy in many healthcare organizations (Social networking professionalism, n.d.; Social Media Governance, n.d.).

**Social Media and Work**

- Online behavior should mimic behavior in the office or on the job; if you wouldn’t say it at work, and you wouldn’t want your co-workers to read it, you probably shouldn’t post it.
- Conduct any social networking activities during personal time, not on the job. Never use your work time or work resources when accessing social networking for personal use.
- Never post any photographs taken with or on your employer’s property and/or photographs that include other employees or patients, visitors, professional staff, or business associates.
- Respect the privacy of your co-workers and competitors by not posting or blogging about them.
- If you disclose working at a particular organization, you should only post or express opinions that are within your area of expertise and that those opinions are yours and not those of your organization.
- Become familiar with your organization's privacy settings and transmission of confidential information.
- Always assure that you are not violating any privacy laws.
When Posting on Your Employer's Website:

- Always disclose that you are an employee.
- Do not post comments on your employer's site or on behalf of your employer in ominous situations such as public health incidents, natural disasters, and issues involving litigation.
- Do not post contemptuous comments about your employer or organization, co-workers, or patients; you or the organization could be liable and lead to punitive action.
- Never disclose confidential or proprietary patient information—you could be subject to workplace discipline and/or personal liability.
- Don’t post anything that would be harmful to the organization’s reputation or information that may compromise business practices.
- Don’t make derogatory comments on race, age, disability, relationship, national origin, physical attributes, sexual preference, or health condition.
- Don’t violate copyrighted or trademarked information.

Sharing and interpretation of medical information with clients or patients can counter balance the less reliable and erroneous information presented on websites (Rosenberg, 2010). When carefully handled, social media can help strengthen the relationship between the patient and his or her healthcare provider. Online interaction, if organizationally and professionally supported, must have strong and positive position and policy established, addressing all potential and identified HIPAA standards. Develop a professional biography for patients and others to preferentially find when using search engines. Care and caution when interfacing with patients is advised; claims of patient abandonment and malpractice or legal action by networking sites or services is possible. Even acknowledging the care of a patient is an unacceptable disclosure of protected healthcare information. Recommendations specific to patient/client interaction are listed below (Social Media Governance, n.d.; Leiker, 2011).

Social Media and Patients

- In order to draw clear lines drawn between interactions as a healthcare provider and those as a friend, some advise keeping separate personal and professional social networking accounts; complete separation may be impossible.
- It is important to clearly identify on whose behalf you are speaking. You might state The views expressed on this site are mine alone and do not represent the views of (organization, physician…)
- Advise patients that confidentiality may be compromised once they are identified as a “friend.”
- Use secure messaging and/or provide informed consent for e-mail.
- Perform self audits, establish and maintain a professional biography and personal brand (see http://mashable.com/2009/02/05/personal-branding-101/ for ideas on personal branding), maximize online privacy settings.
- Don’t post anything too personal, contentious, or that could be considered disrespectful of patients (or anyone else).
- Do not post identifiable vignettes unless you obtain patient consent.
- Remember that your patients may not have equal access to electronic resources.

The bottom line: at minimum don’t post it if you would not want your boss to read it, your patients to read it, or your licensing board to read it. Become and stay educated on the use of any social media that is used personally and professionally and know your employer’s policy. Remember that every interaction with every digital device is captured and stored. Footprints on the beach may be washed out with the next incoming tide but digital footprints are visible to all and everlasting. So please ponder before you post.
References


INFUSING SOCIAL MEDIA INTO YOUR PEDIATRIC PALLIATIVE CARE PROGRAM

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Introduction

Pediatric healthcare providers have not been, for the most part, early adopters of social media. Although others in healthcare seem to have jumped on the social media bandwagon a bit more quickly, pediatric professionals appear to be a bit more cautious, perhaps in the interest of protecting children. The historical perspective of social media, albeit brief, has left in its wake concerns that participation in social media may lead to harm for children. It is difficult to shed the memories of child predators online, or healthcare professionals who have been disciplined for sharing privileged information on their Facebook page. The good news is that a new day has dawned in social media, and participation in social media applications may occur with absolutely no danger to you or your patients.

Step one is straightforward and simple—get started. It is like any other new task; it does not get easier until we learn about it. The word on the street is that social media may improve the patient-physician relationship; that it is a great marketing tool for a practice or program; social media enables professionals to connect in areas of common interest; and that it is a great way to share and receive professional information.

The phrase "social media" describes a wide range of different applications. Blogging, Twitter, Facebook and LinkedIn are some of the social media applications that have most often attracted healthcare professionals. One may choose from the social media menu, selecting only the program(s) that suit a person's needs. For example, many professionals who are involved in social media for professional development and sharing resources only use Twitter. Others use Facebook to advertise their business and awareness of available services. One program may hope to educate patients or parents through a Blog. Still others choose LinkedIn to seek job opportunities or to engage in discussions with colleagues. There are no limits—the choice is yours!

One Professional’s Social Media Experience

This is going to be painful, but I am going to admit that I am not young. I did not exactly admit to being old, but my adult daughter recently brought to my attention that if I am "middle age," then I must be planning to live to the age of 120. That stopped me in my tracks.

I admit my age to my readers because I am having a wonderful experience with social media applications. In this circumstance, there is great truth to the statement, "If I can do it, you can do it." I imagine there are many reading this with much greater technological knowledgeable than I, but you do not have to be a techie to be successful at social media. If you can write an email, you are on your way.

I started my social media experiment by hiring a consulting firm, KLX Media, and working with Christian Sinclair, M.D. to learn the basics. Christian gave me lessons on blogging, Twitter, and Facebook, and coached me on how often (5 -10 tweets per day; 3-4 blog entries per week; a Facebook post daily) to speak in each environment. His tutelage was invaluable. Christian "invented" tweeting at the American Academy of Hospice and Palliative Medicine (AAHPM) conference several years ago, tweeting about what was occurring at conference sessions, and encouraging his compatriots to do the same. Today,
adult hospice and palliative medicine (#hpm – I’ll explain that under the Twitter section!) is a booming, thriving area of discussion on Twitter, complete with TweetChats on various topics. However, pediatric hospice and palliative care (#PedPC) is sorely lagging behind. There are many days when I talk to myself, and I am looking forward to others joining the discussion!

My journey did not hit all of the social media stops in the "correct" order. I started with Facebook (www.facebook.com/kukidshealingplace), progressed to LinkedIn (Kathy Davis, PhD), traveled off the beaten path to Twitter (www.twitter.com/kukidshp and www.twitter.com/kathydavisku), and have recently arrived at my Blog (http://caring4kukids.blogspot.com/).

My first few months on Facebook were rather quiet. I had a few followers (mostly family and friends) but nothing significant. Then I decided to place an ad on the sidebar of Facebook. I limited myself to one ad to $30.00 for a month, and Facebook determined the demographics of who was following me and, thus, who should be able to see my ad. Within 1 week, my followers increased from 200 to over 2000 and represented countries all over the globe. However, that number has not increased significantly over the past year and my followers on Facebook are not very good about responding to posts that I place with the intent of stimulating conversation. So, I placed another ad, with the same limits. This time, there was virtually no change in my Facebook followers over the course of the month.

A couple of years ago, my son-in-law sent me an invitation to join him on LinkedIn, a site where professionals can connect to discuss professional issues, look for a job, etc. I am now connected to many people, but I do not interact, directly, with them. What has proven to be of interest to me on LinkedIn is the Groups. Groups reflect common interests and enable LinkedIn participants to come together and discuss topics of mutual interest. For example, in the American Academy of Hospice and Palliative Medicine Group, Diane M. recently posted the question, “Do you find that practitioners are still reluctant to speak to their patients about end of life issues”? Any group member may comment and, sometimes, lively discussions ensue.

Twitter, I must say, has become one of my favorite social media sites. That is because I learn so much while communicating with others on Twitter. I can go on Twitter and tweet, “Can anyone recommend a good article on parents’ perceptions of pediatric palliative care?” and, in a matter of minutes, have multiple references. If I find a resource, article, newspaper piece, etc., that I believe others in the field of pediatric hospice and palliative care will be interested, I can tweet the link and send it out to hundreds of people. Each day, some of my tweets (I try to do one per hour between 8 a.m. and 5 p.m.) are included in Twitter Newspapers with names like Pediatrics Daily, The KC-Business Daily, and the SPED Daily Digest. When my posts are published in one of these online “newspapers,” I know that many more people are receiving my message. Another advantage of Twitter is that I "meet" people from around the country who are interested in pediatric hospice and palliative care. Then, when I attend national hospice and palliative care conferences, we can meet in person and continue the dialogue.

My New Year’s resolution was to begin a Blog, and I have done it. Of course, my Blog should have preceded my other social media activities but it did not do that. That is the beauty of social media—there are loose rules, but you can always do it the way that suits you. My Blog is about our pediatric palliative care program, the KU Kids Healing Place and is called Caring4KUKids. I already realize, two weeks into blogging that I should have called my Blog KUKidsHealingPlace thus being easier for people to find if they were searching for our program. I like blogging. It is a rather cathartic experience. I can talk about what I do without talking about to or with whom I am doing it.

I seriously hope to see some of you soon on Twitter—I will tweet away with you. Or, if you visit on Facebook, I will happily be your friend. On LinkedIn, I would be delighted to connect with you. And, of course, you are welcome to come by my Blog any time. Please leave a comment, and I will respond with an answer!
What Should You Say Online?

Perhaps the best place to start in the discussion of what to say on social media sights is in regard to what not to say. Many healthcare professionals are concerned about what to say on a blog, on Facebook or on Twitter. Often, there is concern about protected patient health information and how that “fits in” with social media. The answer is simple—it does not fit in at all.

On any social media site—even if you are a pediatric hospice and palliative care doctor and believe that you are in a group that is composed only of pediatric hospice and palliative care doctors—you should not discuss any specific patient issue. Social media sites are not the venue to do this. If you need to talk about it go offline to do so. A good rule of thumb is “If you cannot say it on the elevator at the hospital, you cannot say it on any social media platform.” Any information that even hints of a specific patient must be avoided completely. There are several tiers of truth to this.

First, everyone would agree that you would never mention a specific patient. “Today we admitted Johnny, a 7-year-old with severe cardiomyopathy to the University of ABC Hospital. This poor little guy is really sick, and we are hoping he will make it” would be readily recognized as a posting that shares protected health information. Even without his last name, Johnny’s school principal or the parent of a cub scout in Johnny’s troop may recognize Johnny from this description.

The next statement to be avoided is something like, “We admitted a very sick 7-year-old boy to our pediatric unit today. It is believed that he has cardiomyopathy and it is not known if he is going to survive.” Although no names were used in this description, again, it may be easy for those who know the child to identify him.

Rather than references to a specific patient, consider posting information that is available to anyone. For example, a link to a current, well researched article on cardiomyopathy is very appropriate. If you feel that you must comment on your day at work, a simple “What a day!” will suffice.

The Big Four: Blogs, Twitter, Facebook and LinkedIn

New social media sites are being developed all the time. This provides a variety of options for people with different interests, hobbies, or professions. However, do not be intimidated by the wide range of social media options. Rather, think about beginning with some or all of the “big four”: a blog, Twitter, Facebook and LinkedIn. Once you have mastered those, you may decide that you want to branch out to one or more of the other social media applications.

The Blog

A Weblog, or blog, is often touted as the place to start your social media presence. It is a great idea to start a blog, as it can bring a lot of attention your way. Blogging is really very easy.

First, decide what you want to blog about. Pick a great blog topic that you know about—something about which you have experience, credibility, and passion. What is a topic that you know a lot about that other people may want to know more about?

The name of your blog will be very important, also. Try to choose a name that has a word or words that people may search for when seeking information on the topic. Words like “palliative,” “children,” or “pediatrics” may be good choices to include in your blog name.
Now you are ready to find a blog service, or the place where your blog will be hosted online. There are several options for free blogging services, such as WordPress.com, Blogger.com, or MSN Spaces. These services provide additional information about the mechanics of starting a Blog on their site. It is so simple, that you will have your blog up and running in a matter of a few minutes; however long it takes to write your first Blog entry.

There are several sites that will help you develop your blog with the necessary elements to ensure that your blog is one that people find, enjoy reading, and come back to often. Check out some of the following sites:


Twitter

Twitter allows you to say whatever you want, for free—in 140 characters. One realizes just how few characters that is when trying to send a message, or "tweet." To get started with Twitter, simply visit [www.twitter.com](http://www.twitter.com) and set up an account. You will first establish your user name. If you want your friends and colleagues to find you, you should use your real name. If you create a different name, try to create something with as few characters as possible. That will be beneficial when others "retweet" your messages, including your username.

On the Twitter site, you will find instructions on how to develop your site. You will have "followers" who choose to follow you and receive your tweets. You can also identify those Twitter users who you want to follow. On the Twitter site (be sure to log in) search for friends in the search box, or go to their Twitter page and press “Add” in the “Actions” box. Their messages will come through to your Twitter site. These may be people you know or people who are tweeting about a topic of interest to you. You can follow famous people, television stations, athletic teams, etc. However, many professionals choose to follow other professionals in the same field in order to share information.

Tweets can be sent from your computer or your mobile phone. You may send an original tweet that you create yourself, you may "retweet" what someone else has already tweeted, you may send a direct message to another Twitter user, you may mark a certain tweet as a favorite, or you may reply to someone who has tweeted. So many choices of how to tweet!

There are thousands of tweets occurring at any given time throughout the day, so it is important to be able to find the tweets of interest to you. Under “Who To Follow” on the Twitter homepage, you can "View Suggestions," "Browse Interests," or "Find Friends." In the “Who To Follow” search box, enter terms of interest such as "pediatric palliative care" or "end-of-life." Twitter will provide suggestions of others who are talking about those topics.

Once you have settled into Twitter and other social media applications, you may want to check out a site like HootSuite, TweetDeck, Threadsy, or Seesmic. These are examples of social media dashboards that make it easier to manage all of your applications. On these sites, you can schedule your tweets in advance, or connect with others with interests similar to yours by using hashtags. For example, any tweet with reference to pediatric palliative care should include the hashtag #PedPC. By placing the # sign in front of PedPC, all tweets with that hashtag will come to your inbox. Dashboards are very handy, but take some time and study before one can use them easily. It is certainly worth the effort, though, when you are managing all of your social media applications from one site.
Facebook

Facebook was developed as a site to connect college friends. It enabled students to share pictures and to update one another on what they were doing. Facebook continues to be a valuable way for families and friends to connect with one another. It also has some applications for business use. For example, a Facebook Page enables a business or program to create a space where they can interact with fans and get to know customers. Facebook Ads can reach just the people who you want to reach, by identifying who (age, gender, etc.) is "liking" your Facebook page.

Although Facebook may enhance some business activities, it is not the most applicable social media application to allow those interested in pediatric hospice and palliative care to connect with one another. Because people are used to sharing information on Facebook, great care must be taken on Facebook to ensure that protected health information is not shared. There have been some situations in healthcare where such information has been posted and problems ensued.

LinkedIn

LinkedIn is a great place for people to connect professionally. You join the site and establish a rather in-depth professional profile, complete with one’s curriculum vitae. You may define your purpose for being on LinkedIn: job inquiries; business deals, getting back in touch, expertise requests, reference requests, etc.

A feature of LinkedIn that provides opportunity for professional growth is the Groups function. You may join groups that are areas of interest to you. Groups include disease specific organizations, hospice and palliative care organizations, university alumni organizations, professional women's organizations and so forth. After joining a group, you may engage in discussions, post questions, respond to others, and a host of activities in the LinkedIn Groups section.

For persons who are seeking employment, LinkedIn may prove to be invaluable. There are job postings, as well as opportunities to post one’s CV and to investigate to determine if jobs of interest are available. You may also ask those with whom you have worked to provide job references or recommendations for you that appear on your LinkedIn page.

Come On In, the Water is Fine!

The main thing to remember about social media is that it provides terrific opportunities for individuals interested in pediatric hospice and palliative care. Through various applications, you can talk to colleagues, share research ideas, look for a new job, find the data that helps you complete your grant proposal, learn new techniques in providing care, share the latest findings in the field, and much more. Social media not only offers these opportunities, but is highly enjoyable. It is a good time to try out social media. Yes, the water is fine! Even if you do not choose to dive in headfirst, at least try sticking in one toe!
USING SOCIAL MEDIA RESPONSIBLY TO PROVIDE EDUCATION ABOUT PEDIATRIC PALLIATIVE CARE

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Social media is now integrated into nearly everyone’s daily lives. As a result, organizations not participating in some type of social media, such as blogs, Facebook, Twitter, etc., are missing a great opportunity for education. With so much medical information (and misinformation) out there online and in social media, it is crucial for pediatric palliative care programs to help the public discern that information and resources shared are correct and helpful.

At the Haslinger Family Pediatric Palliative Care Center at Akron Children’s Hospital, we created a Facebook page for our program in 2009 (www.facebook.com/haslingerpalliativecare), and soon after, created a Twitter account (@haslingerppc). Through this endeavor, we’ve discovered some methods to avoid pitfalls along the way, and we’d like to share some tips and resources that may help other pediatric palliative care programs either begin or improve their own social media accounts. On Twitter, we are one of the few pediatric palliative care programs that are active. We welcome networking with you!

Only start what you can keep up with – and make sure the right person is managing your accounts

Rarely do programs have people with extra time on their hands to devote to keeping up with social media accounts. It can be done, however, with a minimal amount of time, but it helps if the responsible person that can create and manage your program’s accounts is currently utilizing social media in some capacity. The right person will show excitement and enthusiasm about this opportunity, resulting in a better product. Set a realistic goal—3 posts a week, 1 post a day, whatever is manageable for you. As a side note, while it may seem cumbersome at first, the more frequently you update, the more content there is for search engines.

Keep your organization’s public relations/communications department informed

Even if they are unable to offer a lot of direct help, Public Relations/Communications departments need to be aware that you have created a social media presence and may be able to offer advice. They may have some staff assigned just to working on social media, so they will be valuable resources. Many of our PR staff is following our accounts, often making suggestions of related things we might want to post.

ALWAYS make sure you are aware of privacy concerns and potential HIPAA (Health Insurance Portability and Accountability Act) regulations

You’re sharing a link to a public article about one of your program’s patients, but does the article mention the child was a patient at your hospital? Does it mention palliative care? These are situations in which you can avoid issues by how you word your post: always stick to facts mentioned in the article. If it doesn’t say John was a patient at your hospital, write something like “Here’s a great article about John, a teen with cystic fibrosis.” When in doubt, if you really want to share a tie to the patient that isn’t directly
mentioned in the article, contact the family and get permission, and have them sign an authorization for release form. Most families that are willing to talk to the media will not mind at all, and it covers anyone else who might think there’s an issue.

**Read through everything you share**

Someone you follow on Twitter has the link to what sounds like a great article. Before retweeting that post, click on the link to ensure that it works and that you’ve at least skimmed the whole article. Sometimes the title can sound good, or it seems like something you want to share at the beginning. Because many palliative care articles are focused on adult care, an article may not be appropriate to share for the pediatric palliative care audience. An article with suggestions for alleviating caregiver stress may sound good, but you may read it and find it’s narrowly focused on caregivers of the elderly. Use your best judgment, as some information is transferable to pediatrics or may focus on some aspect that you want to highlight, but you need to read the entire article to make that decision.

**Finding help with this endeavor**

First and foremost it’s important to find mentors who are more advanced than you are at this craft. Most folks are more than willing to share and give advice. A good mentor will also encourage you, scold you, and hold you accountable. Some mentors may be in the pediatric palliative care field or have expertise in social media, or both! Generally, pediatric palliative care professionals use social media because they want to collaborate and share information. Use them! There is a #hpm “Tweetchat” every Wednesday at 9 p.m. EST. You simply go to tweetchat.com with your Twitter login and password, and type in #hpm to join the chat. More information is available at [http://www.gobemore.org/whyhpm](http://www.gobemore.org/whyhpm).

One particular “virtual” mentor can be through the blog by Laura Christianson, Blogging Bistro, at [http://www.bloggingbistro.com/](http://www.bloggingbistro.com/). The blog is an exhaustive resource alone. Followers can also receive regular social media tips via email through a free subscription.

Staff members managing your blog, Facebook, and/or Twitter sites will find a lot of resources you may or may not know about otherwise—these can also be great for people who are already involved in your program. It’s important to educate Facebook users with personal accounts that simply linking to (i.e., indicating that you “Like”) an organizational page does not give others access to personal accounts. If patients or parents see the staff member also follows a particular page and sends staff a friend request, please advise that professional boundaries encourage the declining or ignoring of those requests. An organizational page can give staff the opportunity to interact with parents and patients through social media while maintaining professional boundaries. Twitter can be more challenging, but if staff prefer, they can change their settings to approve followers of their account.

**Whom to follow**

We specify Twitter, but most of our suggestions are also on Facebook. You should be able to find them with a quick search. When using Twitter, be sure to make use of “hashtags”—these help categorize posts so Twitter users can identify content easily. For your posts, you’ll want to include #hpm (hospice and palliative medicine), #palliative (palliative care), and #pedpc (pediatric palliative care), but there are many others, and more are created by users all the time. A good resource is [http://www.foxpractice.com/healthcare-hashtags/](http://www.foxpractice.com/healthcare-hashtags/), which features a fairly comprehensive listing of healthcare-related hashtags.
Here are some suggestions to get you started.

**Your hospital/organization’s main accounts**
Make sure to follow other accounts your hospital or organization has. See what they are posting, see what you can reshare or retweet, or ways you can contribute in the future to generate more education and interest in your program. If your hospital has a blog, there will most likely be related stories your followers will be interested in. Encourage staff members who have an interest to write a blog post related to palliative care. We recently had staff members who attended a pediatric palliative care conference in South Korea write blog entries about their trip.

**Other local similar or complementary organizations**
Follow local hospices, hospitals, home care agencies, your local Ronald McDonald House, and other agencies you collaborate with, or that feature good content you can retweet or share.

**National hospice and palliative care organizations and professionals**
These organizations and professionals share a lot of good articles and resources. Most are adult-focused (which is why we are encouraging everyone to get out there for pediatrics), but there are some about pediatrics, and some general palliative care topics that will overlap with your audience.

Suggested Twitter follows:
- Center to Advance Palliative Care @CAPCpalliative
- National Hospice and Palliative Care Organization @NHPCO_news
- American Academy of Hospice & Palliative Medicine @AAHPM
- Hospice & Palliative Medicine Blog @Pallimed
- Children’s Hospice & Palliative Care Coalition @CHPCC
- KU Kids Healing Place (University of Kansas) @KUKidsHP
- Stephen Liben, MD (PPC physician, Montreal Children’s) @BuddhishMD
- Stacy Remke, LICSW (PPC SW, Children’s of Minnesota) @StacyRemke
- Diane Meier, MD (Director, CAPC) @DianeEMeier
- Christian Sinclair, MD (Kansas City Hospice & Palliative Care) @ctsinclair

**National organizations related to pediatrics, general healthcare, and bereavement**
For example, KevinMD is a physician who blogs and features lots of different guest bloggers about every healthcare topic under the sun—many articles are related to palliative care, end-of-life care, and other related topics.

Suggested Twitter follows:
- KevinMD.com—blog of Dr. Kevin Pho @KevinMD
- Martha Tousley, Bereavement Counselor, Phoenix, AZ @GriefHealing
- The Compassionate Friends @TCFofUSA
- New York Times Health News @nytimeshealth
- Disability News @disabilityscoop
- American Academy of Pediatrics @AAPNews

**How to get followers/fans**
There are two primary reasons people get involved in social media: for entertainment and to gain knowledge. It’s important that your social media outlet is a cross-section of both. Cross-promotion on the
organization’s main social media accounts will be very helpful in finding users specifically interested in your program, as well as in educating about pediatric palliative care in general. According to Laura Christianson of Blogging Bistro, LLC, it takes six weeks of regular blogging, Facebooking, or Tweeting to establish a habit. It takes from 6 months to 2 years to build a loyal following. Social media marketing is a marathon—not a sprint. We don’t have thousands following our social media accounts, but really it’s quality, not quantity.

Make sure to have your social media account information available to your audience—add it to your email signature, have it on information you give out to patients, families, referral sources, anyone who has an interest. If you are doing presentations in the community or at national conferences, include a slide with your program’s social media information. Create that slide and distribute it among your staff to add to their presentations.

Suggestions for posts

In addition to looking at what other organizations and professionals are sharing, make sure you are also sharing stories about your program and staff, as well as original content. Original content (not just recaps of other articles or verbatim duplicates of other articles) keeps readers coming back for more. Also, think about what key words you want to make certain are in your article repeatedly so the piece will show up in a Google search. Ask yourself, “What would I Google to find this article?” Also, a good rule of thumb is, “Short sentences get read.”

If you have a donor bringing in blankets, make sure to get a photo to post. If a family sends you photos of their child, ask for permission to post a photo. Did a staff member or your program receive an award? Make sure to share that information, and a link to information about the award, if it’s available. Make sure you are sharing information about events and educational sessions that are available. You can create an event on Facebook, or you can also just put the information in a post. By the way, according to a book by John Medina, Brain Rules, people remember about 10% of presented information. Add a picture/photo and they remember 65%. Links are often used on Facebook and Twitter; however, if you are posting an article with hyperlinks in a blog, it’s important that it is set to open in another window. That way your readers do not have to hit the “back” button to return. This avoids “tangents” that lead readers away from, rather than back to, your site.

Parting message

If you’re new to using social media, we know it can seem like overwhelmingly new territory. Remember it’s a learning process—the more you use it, the easier it will get, and the more useful it will be in producing your desired outcomes. Be patient—slow and steady wins the race. Use the resources and tools available, include collaboration with others. Conversations are happening—make sure you are involved!
READER’S CORNER

*Keep Fighting, Stop Struggling: The Miles Levin Story*

By Miles Alpern Levin
Foreword by Bob Woodruff
Commentary by Jon Levin
(Bookstand Publishing, 2011)

Reviewed By:
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Miles Levin was in 10th Grade when he was first diagnosed with Rhabdomyosarcoma, a cancer that seemingly came out of nowhere to turn the lives of Miles and his Mom, Dad, and younger sister upside down. In the early days of Miles’ diagnosis, his Dad stumbled onto a CarePages kiosk in the lobby area of the pediatric floor where Miles was being cared for. He first thought it was a video or arcade game for the kids, but soon learned it was a dedicated station to www.CarePages.com. After reading more about it and understanding how it could be a convenient way for the family to communicate with all the family/friends wanting updates on Mile’s condition, his Dad created a page for him, which Miles soon claimed as his own.

Throughout Miles’ cancer treatments, he chronicled what this journey was like for him in a very intimate and personal way with the readers of his CarePages webpage, creating quite a national and international following. It became an open forum diary as Miles sorted out what he was facing with a much broader audience. And while it initially started as a communication vehicle to take some of the burden off of his family, over the next two years of Miles’ life, it became so much more. It was how Miles chose to journal about this experience and what the cancer was teaching him, but more importantly, about life, and how to have a better appreciation for it—the good and the bad parts. Miles was carried through his cancer experience by this public journaling and the support he received from those who read it. In turn, the readers often felt they learned and gained as much (or more) from Miles as he did from them.

*Keep Fighting, Stop Struggling: The Miles Levin Story* gives readers a perspective on the power of social media networks like CarePages when children and young adults are seriously ill and/or dying. The benefits realized by Miles’ use of the CarePages webpage, for him and his family, and the supportive response he got from those who read his posts far transcends anything they would have ever imagined. In this online community, Miles found a web-based home that buoyed him in his darkest moments, and celebrated with him when he triumphed. And when he was too sick to post himself, his Mom did in his place, which, after reading the book, seemingly was very cathartic for her as well during his illness and into her grief and bereavement.

Through the use of actual excerpts from Miles’ posts on his CarePages webpage, and with commentary from his Dad, Jon Levin, *Keep Fighting, Stop Struggling: The Miles Levin Story* takes you inside Miles’ journey as if you had walked it with him as it happened. Importantly, it underscores the importance of supportive tools like online community/web-based social media pages like CarePages, CaringBridge, Facebook, and a litany of others, for the pediatric palliative/hospice care families who choose to avail themselves of them, despite some of the issues and caveats with their use.

*Keep Fighting, Stop Struggling: The Miles Levin Story* is available on Amazon.com or via the website: www.levinstory.com.
PRACTICAL POINTERS
HOW TO GRACEFULLY DECLINE A FACEBOOK REQUEST

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It’s so hard to say no, especially to a Facebook request! Helpful tips for turning down requests.

In your role as pediatric palliative care provider you’ve likely been asked, “Will you be my friend . . . on Facebook?” or “How come you didn’t respond to my friend request?”

Are you prepared to answer these questions when your 15-year-old patient asks you to be her friend or the mother of the “cutest” 2-year-old patient lets you know she has new pictures to share on FB if you just “friend” her? What can you say instead of just “ignoring” such requests.

Patients and families want honest and accurate information about their child’s condition and they also appreciate honest communication about other aspects of their care, communication, and relationship with their healthcare providers. We are their healthcare providers and this relationship is one that intrinsically brings un-equal power dynamics. We are not friends of the families to whom we provide care and support, even though we become especially close.

The British Medical Association made a statement last year that “doctors should not accept Facebook requests from patients.” (See “Using Social Media: Practical and Ethical Guidance for Doctors and Medical Students,” available at http://www.bma.org.uk/images/socialmediaguidancemay2011_tcm41-206859.pdf) The BMA outlined the potential dangers of breaching confidentiality, damaging their professionalism, and risking the general doctor-patient relationship. It was also suggested that physicians should be extremely conservative in their Facebook privacy settings.

So how might you effectively and compassionately decline a patient/family request to be a Facebook Friend?

“My Facebook page is for personal use only” is an extremely effective response.

“It’s always great to hear from you, but I’ve decided to use Facebook for contact with family and close friends only” is another effective response.

If your organization has specific policies related to social media, and more are creating these policies, use the policy and procedure excuse. “I appreciate your request, but my organization doesn’t allow me to be Facebook friends with patients and families.”

We share extremely intimate relationships with our patients and families in the pediatric palliative care setting and saying no to a Facebook request will support you in a sustaining honest relationship.
RE-INTRODUCING CHIPPS

Dear Readers,

We would like to re-introduce ChiPPS! The Children’s Project on Palliative/Hospice Services is a project of the National Hospice and Palliative Care Organization (NHPCO). ChiPPS was first established in November of 1998 and has been one of the most consistent groups working to advocate for and promote education, standards, and support for pediatric palliative care in the United States. NHPCO has always had a strong commitment to the care of children and their families and continues to uphold that commitment. In fact, many resources such as our quarterly e-Newsletter are available to anyone working or interested in pediatric palliative care at no cost. Check the website for more resources and archives of our past issues at www.nhpco.org/pediatrics.

In this issue we will briefly provide an overview of the different workgroups that are part of ChiPPS. Contact information for the Chairs is included – we welcome new volunteers! In future issues we will be highlighting the individuals ‘behind the scenes,’ our workgroup members and our Leadership Advisory Council. For more information or questions please contact us at: pediatrics@nhpco.org.

ChiPPS Leadership Advisory Council

The Advisory Council is comprised of the chairs and primary members of each workgroup. The Leadership Advisory Council oversees and guides the work of ChiPPS in keeping with our strategic plan and mission.

Chair persons: Sarah Friebert, MD, sfriebert@chmca.org, and Mary Kay Tyler, RN, MSN, PNP, mktyler@hospicewr.org.

Quality and Standards Workgroup

The Quality and Standards Workgroup is charged with reviewing and revising the Standards of Care, as well as developing implementation tools for hospices and medical institutions who care or may care for children. Education around utilization and implementation is also a role of this committee.

Chair person: Brenda Blunt, MSN, RN, CHPPN, RNC, CCRN, bblunt@gilchristhospice.org.

Education Workgroup

The Education Workgroup provides ideas, speakers and content for NHPCO conferences, audio-conference seminars, and on-line courses with Mount Ida College. This workgroup also reviews pediatric session proposals for NHPCO conferences, and assists with the development of NHPCO’s Pediatric Intensive at NHPCO’s Clinical Team Conference. In particular, this group is working on developing on-site training opportunities based on the recently-completed interdisciplinary 10-module NHPCO pediatric palliative care curriculum. Download this PDF available at nhpco.org/pediatrics with information about the pediatric modules – the first 3 modules of the curriculum are available now. To take advantage of these modules, please visit the NHPCO E-Online learning portal; from this site you are able to purchase the courses, download, and get your continuing education credit!

Chair person: Liz Sumner, RN, lsumner@elizabethhospice.org.
**Communication Workgroup:**

The Communication Workgroup works with NHPCO to update ChiPPS printed and website materials and to develop or review educational resources for pediatric palliative care. Members also monitor and respond to queries on the mynhpco.org listserv for pediatrics.

Chair person: Amy Brin, MSN, MA, ARNP, abrin@hospicebg.org.

**Governance Workgroup:**

The Governance Workgroup’s aim is to focus on guidelines, development, mentorship and succession of the ChiPPS membership.

Chair person: Donna Armstrong, BA, MSW, darmstrong@hospicebg.org.

**E-Newsletter Workgroup:**

The e-Newsletter Workgroup is responsible for the free quarterly newsletter focused on pediatric palliative care. The newsletter has grown from a two-page synopsis of various information bits on pediatric palliative care to a peer-reviewed newsletter with over 3000 subscribers. Topics cover all aspects of pediatric palliative care and represents all members of the interdisciplinary team – physicians, nurses, social workers, chaplains, volunteers, child life specialists, expressive therapists, psychologists and most especially families. The newsletter is a community service by NHPCO and ChiPPS. Chief Editor is Chuck Corr, PhD.

Subscribe at: www.nhpco.org/pediatrics or E-mail requests to pediatrics@nhpco.org. Newsletter Archives can be found at: www.nhpco.org/pediatrics.

Chair persons: Christy Torkildson, RN, PHN, MSN, PhDc, torkc@sbcglobal.net and Maureen Horgan, LICSW, Maureen.Horgan@providence.org.

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Another facet of the pediatric focus within NHPCO centers on policy awareness, education, and coordination of public policy initiatives for pediatric palliative care. This contingent works closely with NHPCO’s Policy Committee, which is tasked with the coordination and review of public policy activities of the National Hospice and Palliative Care Organization.

In 2009 ChiPPS initiated a national Pediatric Palliative Care Policy Networking Group. The group is now co-sponsored with the American Association of Pediatrics and has representatives from 43 states. For more information on policy issues please visit the website at www.nhpco.org/pediatrics.
Items of Interest:
In each issue of our ChiPSS 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, and stress and moral distress (identifying stressors and supporting staff). (Please note that you can visit archived issues of this newsletter at www.nhpco.org/pediatrics.) For future issues, we are thinking about addressing subjects such as educational issues, issues involving infants and children, and topics related to involving 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; Maureen Horgan at Maureen.Horgan@providence.org; or Chuck Corr at 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.

3. Practical Pointers. In this issue, we inaugurate a new feature in this newsletter consisting of brief, occasional articles that offer practical tips on some subject related to the overall theme of the issue. For example, in this issue Maureen Horgan offers some tips for professionals on how to decline a Facebook request. As with our Reader’s Corner column, we welcome suggestions for brief, practical articles that fit this feature. Please send all such suggestions to Christy Torkildson at torkc@sbcglobal.net or Maureen Horgan at Maureen.Horgan@providence.org.

4. SAVE THE DATE for NHPCO’s 13th Clinical Team Conference and Pediatric Intensive. Mark your calendars for November 5-7th, 2012 at Walt Disney World Dolphin Hotel in Lake Buena Vista, Florida. In addition to the conference, NHPCO is proud to announce a new educational opportunity: NHPCO’s Pediatric Palliative Care Training (PPCT). This extensive and intensive training will be offered as a two-day (6 hours each day) Preconference Seminar on November 3-4th. Taught by expert interdisciplinary pediatric hospice and palliative care faculty, the PPCT is designed for hospice and palliative care clinical staff (nursing, physicians, social workers, spiritual care professionals, bereavement professionals and related disciplines) who are seeking intensive, interdisciplinary preparation to care for infants and children facing life-threatening conditions and their families. Mirroring NHPCO’s Online Pediatric Palliative Care Training Series, the PPCT has been created by pediatric palliative care experts to ensure the provision of quality, patient/family-centered care to this important population. Watch for
announcements in this newsletter and in other NHPCO publications related to the conference and make plans to attend!

5. Forthcoming Conference—Save the Dates. On April 9-10, 2012, the Northwest Pediatric Palliative Care Symposium will offer a conference on "Providing Pediatric Palliative Care Support Across the Continuum of Care." In addition to break-out sessions covering a wide variety of topics with a focus on best clinical practice and support a family from the start of care into bereavement, on April 9 the keynote speaker will be Dr. Chris Feudtner, who will address the topic, "What Do I Need to Do to Be a Good Parent for My Child? A Key Question for Many Parents of Ill Children." April 10 will be devoted to a Pediatric End-of-Life Nursing Education Consortium (ELNEC) Training for Nurses. More information concerning this conference is available at www.providence.org/hospiceofseattle; find the symposium link under "Events" on the main page. 6.0 hours of CME and CEUs (nursing and social work) have been approved.

6. Another Forthcoming Seattle 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 seattlechildrens.org/pediatric-bioethics-conference or call (206) 884-8355.

7. CureSearch Website now in Spanish. CureSearch for Children’s Cancer has translated the Foundation’s website, 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.

8. Calendar of Events. As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the Web site, www.nhpco.org/pediatrics. Please e-mail Christy Torkildson at torkc@sbcglobal.net to have your pediatric palliative care educational offering listed.

Thank You
We appreciate you taking the 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 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. Staff of NHPCO’s Solutions Center will be happy to help you adjust your communications preferences; contact them at 800-646-6460.

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ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.
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.