



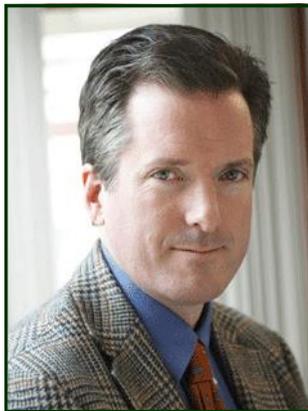
Newsletter

July 2017

From the Chair

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Philadelphia, PA

Section on Hospice and Palliative Medicine



Crawling Out from Under the Bus

We huddled in the hallway, our palliative care team nurse practitioner, social worker, and myself. The door to the patient's room was closed. The 7-year-old boy had been hospitalized for viral pneumonia thus far for two weeks, but looking at his record, I could see that he was more or less on the mend. The BiPAP settings were being weaned down, his FiO2 requirement had declined, his respiratory rate was returning to baseline. And all this

despite his having a rare form of dwarfism. Even more remarkably, given his various health issues, this was the first time he had been hospitalized — ever.

Yet here we were, poised to knock on the door to introduce ourselves, knowing that the family had already been told by the attending physician that he was consulting the palliative care team, and that when the attending physician had requested the palliative care consult he had told us he was frustrated with the family and asked us to "get a DNR."

Now, I am tempted to devote the rest of this essay to how I never — as in NEVER — accept that request. As soon as words to the effect of "get a DNR order" are uttered, I interrupt and say something like: "Can we stop for a moment right there? I can tell you are worried about whether the patient has a survivable condition, and while I respect your opinion and your concern, I simply can never enter a room with an agenda other than to get to know the patient and the family and see



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how I can help. I will be happy to go meet them, as you are requesting, and then we'll see what grows out of that meeting, but I will not go in trying to get a DNR. Okay?"

But I'm going to turn away from that temptation, and instead look at the other side of the door, so to speak: how do we handle situations where the patient or family has formed a negative opinion about palliative care in general or our palliative care team in particular?

The reasons why this negative impression has taken shape vary, and are important since they influence my response. Sometimes, I myself played a key role in "stepping in it" with something I said, or how I acted, or a decision I made. I would like to believe that I don't do this too often — but I do make mistakes. The key in these instances, as soon as I recognize the mistake, is to apologize, in a very specific manner. For example: "I want to let you know that I am sorry. When we were talking earlier today and I said [insert something very specific here], I wasn't thinking about how that could be interpreted, and I apologize for saying that." I then wait. Just because I have offered an apology does not mean that the family — even if they accept my apology — will want to do further business with me. I need to see how they want to proceed. If they respond to my apology in a way that offers the possibility of us continuing to work together, I will likely reiterate my sincere regrets and my intention to work to help their child and them. If they are unwilling to proceed with me, however, I will point out that I made the mistake and take full responsibility for the error, and that I hope they can continue to work with other members of our team. If they express misgivings about continuing to collaborate with the team even if I withdraw, then I or some other member of the team will offer that we will be very willing to reengage if and whenever they decide to do so.

Other times, the negative impression was due to an action or inaction not by me but by some



other member of the palliative care team. Again, this doesn't come up often, but we all make missteps from time to time. When a parent says, "well, we haven't had a good experience with your team [or with some other palliative care team]", I first say that I am sorry to hear that, and ask then whether they can tell me more about what happened. When they have had the chance to fully say what bothered or upset or angered them, I then will say something to the effect of: "I wasn't there, but I do want, on behalf of those who were there, to offer my apology for what happened. It is never my intention, and I think this is true of all my colleagues in palliative care, to upset patients or parents. Yet that is what happened, and I apologize for that." As above, patients or parents may or may not want to move forward after this exchange — that is up to them. I have seen, though, over the years that an honest and open discussion about what went wrong and then a sincere apology goes a long way toward rebuilding a collaborative relationship.

Those two situations are different, though, then when someone outside of the palliative care team has said or done something that puts palliative care in a bad light — or even worse, a false light — in the mind of the patient or parents. This was the situation that I sensed we were about to encounter, huddled out in the hallway before entering the room.

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Specifically, I was worried that the mother would not want to talk with us because she would have the notion, based on comments from the attending physician, that we were there to talk her into a DNR order. Yet that was not my intention. So, I wondered out loud to my teammates, how could I engage her in a preliminary dialogue about what our team really intended to do, and then — having provided her with accurate information — give her the opportunity to either engage us or tell us to go away?

We knocked and entered. The nurse practitioner crossed the room to the mother, said hello, gave her name, and stated that we were part of the palliative care team. Immediately the mother responded: “Oh, no, you’re just here to talk about the DNR and I don’t want to talk about that or talk with you.” By this point I had drawn up next to the mother. I needed to validate and affirm her position and clarify my intention. I said: “I totally, absolutely, 100% agree with you. I also don’t want to talk about any DNR. I think your son is getting better. What I do want to do is see whether there is anything I and our team can do to

help your son continue to get better and go home, and anything we can do to help you. Would it be okay if we talked for maybe five minutes about what we might be able to do that would be helpful, and then you can decide whether you want us to stay or go? Would you be willing to do that?” She said yes, and in the course of the ensuing conversation we identified several ways we could help out — including calling a halt to further repeated discussions about resuscitation status. And our team remained a part of his care team thereafter. And interestingly, after discussing the consultation, the attending physician wasn’t upset, but instead was pleased that we were going to be able to help the child and mother on a few different fronts.

We all make mistakes. Confronting serious illness raises the stakes and the stress-level for patients and families, and for clinicians. Wittingly or unwittingly, things will be said or behaviors will occur that will upset people. Learning how to apologize, make amends, and rebuild damaged relationships is a core part of what we are called to do.



Pediatricians Advocate to Protect Children's Health Care Coverage

By Devin Miller, AAP Advocate and Public Affairs Assistant
Washington, D.C.

Since the U.S. House of Representatives introduced health care legislation earlier this year that would reverse the progress made on children's health care coverage and fundamentally change Medicaid, the Academy and pediatricians have been working relentlessly at every step of the way to speak up for children.

In late June and after weeks of negotiations behind closed doors, the U.S. Senate released its health care legislation, the Better Care Reconciliation Act (BCRA), and the Academy immediately responded with strong opposition.

"The U.S. Senate's health care legislation, at last unveiled today, fails to meet children's needs," said AAP President Fernando Stein, MD, FAAP, in a press statement. "The bill fails children by dismantling the Medicaid program, capping its funding, ending its expansion and allowing its benefits to be scaled back. The bill fails all children by leaving more families uninsured, or without insurance they can afford or that meets their basic needs."

At the time of this article's deadline, the fate of the Senate bill was still uncertain.

Portions of the bill are especially relevant to members of the AAP Section on Hospice and Palliative Medicine and the patients they see every day with complex health conditions. The bill includes misleading 'protections' for children by proposing to exempt them from certain Medicaid cuts. Yet, a 'carve out' for some children determined to be 'disabled' does not work if Medicaid is stripped of overall funding, which will force states to chip away coverage in other ways. For example, states could decide to not cover children living in poverty who do not have complex health conditions, or to scale back the benefits that children and their families rely on. While the bill claims to 'carve out' children so they would not be impacted, this is a meaningless distinction since the cuts to the overall program are so severe. The cuts will impact all children who rely on Medicaid.

In addition, if under the Senate bill private insurance companies were able to re-instate lifetime limits on health coverage, children with complex

health conditions could hit those limits early on and families could be faced with staggering medical debt.

The Academy mobilized its full membership for two days of action in June to protect Medicaid and oppose the Senate bill. This proactive effort was kicked off with an emergency conference call to AAP chapter, committee, council and section leaders, giving them the tools and latest information necessary to engage their fellow colleagues and networks.

On both days of action, pediatricians made hundreds of calls and emails to their U.S. senators and sent thousands of tweets using #KeepKidsCovered and #DontCapMyCare. According to one Senate office, the phones were "ringing off the hook" with pediatricians calling in. These efforts were coordinated with other child health organizations as well as pediatric residency programs across the country.

In addition, more than 70 pediatricians posted videos online sharing the importance of Medicaid to their patients and urging their senators to oppose any funding cuts to the program. A video from Elizabeth Meade, MD, FAAP, caught the attention of a local news reporter, which then led to a broadcast segment on a Washington state television station about the health care bill and its harms to children.



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During the window of Senate-focused advocacy, nearly 30 op-eds, letters to the editors and blogs were published by pediatricians, highlighting how children and families in their state rely on Medicaid and would be impacted by any efforts to cut or cap Medicaid funding.

Dr. Stein called the advocacy efforts pediatricians were undertaking, “unprecedented.” Local and national news outlets also picked up on this work. The Academy’s opposition to the Senate bill and pediatrician advocacy efforts were covered extensively by print, online, television and radio news networks. Pediatricians joined conference calls and press events with their senators, spoke with reporters and even invited them to their own clinics to offer an expert health perspective on the legislation’s harmful consequences for children and families.

Initially, the Senate was aiming to vote on its bill before the Fourth of July recess, but decided to delay the vote until after the week-long hiatus. This decision was a testament to the work of those advocating against the bill and its policies, including the Academy and pediatricians. During the recess, the AAP urged its members to pursue in-state advocacy tactics and to continue to build on this mo-

mentum when lawmakers returned to Washington. Similarly, the Academy engaged directly with its chapters in target states.

Throughout the health care debate, the Academy is responding as the leading voice for children and empowering its members to deliver these messages, whether that means reacting to breaking news, proactively influencing legislators or weighing in at strategic legislative moments.

As a member of the Section on Hospice and Palliative Medicine, there are several ways for you know the latest news in Washington. To receive timely advocacy action alerts and a weekly Federal Legislative Update every Friday that Congress is in session as part of our Key Contact Network, please email kids1st@aap.org with your name and your preferred email to receive the communications. As part of the Key Contact Network, you will stay up-to-date on the newest developments in the health care debate.

In addition, the Academy’s federal advocacy website, federaladvocacy.aap.org, provides more information on the AAP’s federal policy priorities with opportunities to contact your members of Congress and take action.

Fellow's Column

PALLIATIVE CARE FINDING

Life is What Happens When You've Got Other Plans

By Kathryn Harmoney
Iowa City, Iowa

When I was a little girl, I asked my mother if I could marry my grandfather. She chuckled, but didn't say much else. As I aged, I figured out that maybe, that wasn't such a good idea. I never lost admiration for my grandfather, though. Even with life's ups and downs, he seemed to live life fully. He had a cabin in the mountains, went deep sea fishing off the Alaska coast nearly annually until his mid-eighties, and would strike up a conversation with anyone. There was no stranger to him; not illness, not death even.

As he approached his death, there was no question of how he would die. It would be on his own terms, where he wanted it. If he could have dictated the time, he might have done that too. Nevertheless, even as he experienced worsening heart failure, he maintained that he wanted to remain at home, surrounded by his friends, family, memories, and his dog. He had a large extended family to help care for him, so he could stay in the house that he had built years earlier. He could pass away peacefully at home.

After his death, we had a memorial. We held it in the little town in which he lived, in the Grange Hall. It was an older building that had no gas or electric heat. The only heat was from a wood-burning stove in the corner. In that bitter January winter, the stove brought the temperature inside up to only 17 degrees. Despite this, we spent hours telling stories, laughing, and crying. All of this seemed so natural to me that it never occurred to me that there was another way to die. Even after matriculation into medical school, the way our family approached death seemed normal. It wasn't until my geriatrics unit that I realized that my grandfather's death was no longer typical. I discovered how many people die in the hospital, often without discussion of what matters most to them in life, and in dying. Certainly, there are instances when such conversations are not possible, such as a sudden accident or illness. There were times, however, when such conversations could have been had. I recall a young patient that I met in medical school. She was suffering from end-stage pancreatic cancer. Although she continued to seek out treatment

options to prolong life, it soon became clear to the team that we could no longer meet that goal of care, and her time would be short no matter what treatment we gave her. A discussion needed to be had to address the change in her condition and prognosis, but no one initiated this conversation with the patient or her family until mere days before her death. She died in the hospital. She was able to have her loved ones surrounding her, but I have no idea if that is the location of death she would have chosen for herself.

During the summer between my first and second year, I spent time working with a palliative care group in Boston, studying family meetings. The meetings all took place in the hospital, and the patient was nearly always days away from death. I saw families grapple with decisions to extubate, decisions to escalate care, and many other things. Nearly all of the patients seen by the palliative care team died in the hospital. Usually, the patient's surrogate decision maker was put in the position of deciding the patient's code status. Often, the patient was unable to participate in the family meeting, because they were sedated, intubated, or obtunded. I became convinced that it wasn't necessary for patients to have this sort of end of life experience.

My journey in medicine took me into the world of pediatrics, and I was fortunate enough to attend residency in the state of New Mexico. In that hospital, I took care of patients with any number of ill-



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nesses, from many walks of life. Fortunately, most of our patients did well. For the ones who didn't, however, I saw many of the same issues that I had noted in medical school and in my research in palliative care. Families struggled with how to care for their child, if they should forgo treatment with a high degree of uncertainty, or if they should be more aggressive in treatment to give their child every possible chance at survival. The doctors and nurses I knew in residency tried to be mindful of a family's values while caring for their child. The discussions regarding goals of care occurred more often than not, but they still occurred late in the patient's disease course.

As I entered the world of pediatric hematology-oncology fellowship, the issues of life and death discussions intensified. I continued to question why some people, like my grandfather, had a peaceful death, while others would seemingly suffer, their families distraught with trying to make health care decisions. I reasoned that some people might want to go out 'guns blazing,' but surely not everyone. So when do we have that conversation? I began to awaken to the idea that offering to have this discussion with patients and their families sooner (and as often as needed) might help the transition between life and death, for everyone.

My decision to pursue palliative care as part of my future career, even during my fellowship, has not been an easy one. I've cared for children and their families when our medical treatments are able to cure their disease, or give them a longer life of good quality. I've also cared for children and their families when they approach the end of treatment options and the end of life, and I have seen them struggle with how to approach death on their own terms. I find the disease processes in hematology-oncology fascinating, and also feel called to help families navigate the journey when we cannot cure, and when quality rather than quantity becomes the thing we can impact most. I see a future where I marry the two, practicing in a field Justin Baker likes to call "Palliative Oncology," helping children and their families to live life fully, and not face the strange-
death
ness of
alone.



CARE AT THE OPPOSITE ENDS OF LIFE

By Carla Steckman— *New York*



Pediatric palliative care doctors and obstetricians operate at different ends of the same spectrum. As a parent who has experience with both sets of providers - those ushering a life

into the world and those guiding one out - I find many similarities.

My third child, Talia, is twenty-two months old and I am watching her die slowly from Tay Sachs disease. My husband and I engaged palliative care immediately upon diagnosis. Now, an unknown number of months before Talia's death, I have the space to reflect on how both types of doctors provided me with a similar set of tools to prepare my family and me for the unknown.

First Trimester

My earliest appointments with my OB were fraught with anxiety. I had a new being inside me and I questioned every decision regarding my body and lifestyle. I felt that it was essential for me to build a relationship with my doctor so I could entrust him with my child's safe passage into the world.

I felt both powerful and incredibly powerless as my doctor provided me with the first views of this tiny free floating embryo and I marveled at the magic of life. I noticed how the doctors spoke in measured tones when counseling me about test results. I listened carefully about how to best care for myself, and by extension, for my unborn baby. Healthy mother, healthy baby, I was frequently told. I left each appointment feeling empowered by the new information. After Talia was born, as we hunted for the causes of why she missed milestones and had abnormal reflexes, I prepared for life with a severely disabled child. The absolute powerlessness I felt was almost unbearable when she was diagnosed with Tay Sachs, meaning inevitable death. My husband

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and I immediately engaged palliative care and that feeling dissipated somewhat after our first meeting.

I feared that the entire discussion would be focused on Talia's death. Instead I found a doctor who spoke of Talia's life and how to ensure it would be free from pain. I learned about the importance of stepping back and creating a philosophy of care and how our decisions would be based around those core principles. We spoke of Talia's daily existence and of what equipment we could choose to maintain her quality of life. Equally important we talked about which interventions we would NOT utilize because it didn't fit with our care plan. At our first appointment, I built a relationship with my doctor that left me feeling stronger and more in control than I had felt in months.

Second trimester

At the OB, the second trimester is marked by the 20 - week ultrasound. I approached these appointments with great excitement. The shock of being pregnant had faded and my fear of miscarriage had dissipated. My husband on the other hand knew that this ultrasound could potentially reveal significant deformities and refused to exhale until after it was accurately read.

Now, in the middle of Talia's decline, the shock of diagnosis has worn off slightly and we watch sadly now as my child continues to grow, but not develop. I desperately wish there was a test that could show me month by month what Talia's decline will be. The uncertainty about timing makes me long for the relative simplicity of a trimester timeline and inevitable due date. My appointments at this stage include advice on how to manage the open timeline and how to keep on living my life while knowing that Talia's death could be weeks or years away. Our doctor helps prepare me mentally for how to survive the process of watching my child die. If I don't take care of myself, I can't properly care for Talia. Healthy mom, healthy baby - sort of.

Third Trimester

At the end of pregnancy, the OB meetings were about our birth plan and the uncertainties around labor itself. I worried I wouldn't know what a contraction felt like (ha!). I worried about pain and being pushed into a C-Section prematurely. While I was never one who obsessed over a natural versus epidural birth plan, I did spend the final trimester imagining every possible scenario and trying to mentally prepare for each. As much as many par-

ents want a "natural birth" for their children, it's the OB's job to try to adhere to their wishes while still keeping the parents focused on the medical realities of delivering a child.



Now I find myself obsessively thinking about our death plan for Talia. I meet with the palliative care doctor to discuss in exacting detail the way I envision my child's death. I worry I won't know what the final decline will look like. I worry about managing Talia's pain, and of my own aching pain. Our doctor runs through potential end of life scenarios with my husband and me as we plot our course through the impossibly choppy waters. I am fixated on helping Talia pass out of this world in a pain-free manner with as few interventions as possible. Yet I have to prepare myself for the fact that, much like Talia's birth, there may be medical realities that I don't anticipate and can't control. I must remain flexible and allow myself to reassess as conditions warrant. As a result of our conversations, I feel empowered to advocate for my wishes for my child in the midst of a system designed to keep her alive regardless of diagnosis.

Families need to feel a sense of control, even when largely powerless. Discussions with good doctors - a form of gentle realism - at both the beginning and end of life, can give us that. Without my palliative care doctor, I wouldn't have believed that the end of life could be as thoughtful and empowering as the beginning.

2017 AAP LEGISLATIVE CONFERENCE

PRESSURE & TIME: A RECIPE FROM CHANGE

By Zach Rossfeld —Columbus, OH

There's a scene in *The Shawshank Redemption* where Morgan Freeman's character, Red, observes that geology is the study of pressure and time. Having recently seen the gorgeous yet austere marble buildings in Washington, D.C., I can tell you that political advocacy can also be considered a function of these same forces: pressure and time.

Through support from the American Academy of Pediatrics (AAP) Section on Hospice and Palliative Medicine, I was thankful to be able to attend the 2017 AAP Legislative Conference, a transformational experience that I highly recommend. Since 1988, the Legislative Conference has convened annually for three days of advocacy training followed by meetings with congressional representatives. The conference programming takes attendees from the very basics of the legislative process to a clear rehearsed 'ask' of legislators. This year, 220 pediatricians from across the country — including Alaska — participated. Two pieces of legislation highlight the extremes of health policy advocacy.

The American Health Care Act of 2017 (AHCA) illustrates the use of pressure in advocacy. The AHCA was introduced in the House of Representatives on March 20th, 2017 and ultimately passed on May 4th, 2017. However, prior to its passage there was a widely publicized week of powerful public opposition that ended with the bill being withdrawn from the floor in anticipation of insufficient votes. Contributing to the bill's withdrawal was the collective, historically loud, opposing voice of the public. This moment of effective advocacy against AHCA was a nearly unprecedented amount of pressure applied in a very brief amount of time.

The Palliative Care and Hospice Education and Training Act (PCHETA), first introduced July 19th, 2012, illustrates the impact of advocacy over time in a different way. This piece of legislation was written with the intention of providing grants for Palliative Care and Hospice Education Centers to ensure an adequately trained Hospice and Palliative Medicine (HPM) work force. PCHETA represents a more typical process for a piece of federal legislation: in the last ten years, less than 3% of introduced bills become law and fewer than 6% are ever brought for a vote. PCHETA has been introduced in each successive Congress since 2012 and has steadily garnered more support [Table 1]. In fact, more U.S. Representatives in the 114th Congress have signed onto the bill as a co-sponsor (234) than would be required to pass the bill (218). But the legislative priorities of the federal government have precluded PCHETA from being voted upon. The increasing bi-partisan support over the last five years is proof that steady pressure over time would ensure the bill's passage if it became a priority and PCHETA were brought to the floor for a vote.

These bills offer important insight into our American democratic process and inform how to advocate on behalf of our patients, our field, and ourselves. But, in the context of political advocacy, what is pressure and how does one make good use of time? At the Legislative Conference, I learned that pressure from advocates should be thought of as the combination of data and stories. Elected officials and their staff are well equipped to understand the percentages and dollars presented to them but these are mere numbers on a page without a human story. A first-person narrative complements the bullet points with emotion and truth and impact. Progress requires persuasion on a continuum, from brief

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Table 1. Historical Congressional support for The Palliative Care and Hospice Education and Training Act

| Congress | Years | Number of House Co-sponsors | Number of Senate Co-sponsors |
|-------------------|-----------|-----------------------------|------------------------------|
| 112 th | 2011-2012 | 39 (37-D, 2-R) | 6 (6-D) |
| 113 th | 2013-2014 | 170 (138-D, 32-R) | 24 (23-D, 1-I) |
| 114 th | 2015-2016 | 234 (145-D, 89-R) | 20 (13-D, 6-R, 1-I) |
| 115 th | 2017-2018 | 108‡ (59-D, 49-R) | 7‡ (4-D, 2-R, 1-I) |

D = Democratic Party. R = Republican Party. I = Independent. ‡ = numbers accurate as of June 13, 2017

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(e.g. posting to social media or reflecting on a patient story) to time-intensive (e.g. presenting to colleagues or attending an advocacy workshop). (See Table 2 for further ideas).

Much like any new activity, getting started seems to be the biggest hurdle. And so I encourage you to dedicate five minutes to HPM advocacy today. Identifying your own elected officials and then visiting the Hospice Action Network website to learn more about how to be a hospice advocate might be a good place to begin.

Advocacy is an opportunity. It is an opportunity to grow personally and professionally. It can affect change where there is frustration. It is a path toward doing better. It is the pressuring of lawmakers with data and personal stories. It also requires time. In *The Shawshank Redemption* Red had it right: "That's all it takes really. Pressure. And time."

Table 2. Time-based examples of advocacy efforts

5 minutes or less

- Social media post
- Discussion with a colleague
- Identify a patient story

30 minutes or less

- Draft an e-mail to colleagues or lawmakers
- Phone calls to elected officials
- Background reading

60 minutes or less

- Letter to the Editor or Op-Ed
- Presentation to colleagues
- Attend conference or webinar



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Upcoming Events



September 15-19, 2017 in Chicago, IL
[AAP National Conference & Exhibition](#)

September 16-20, 2017 in San Diego, CA
[National Hospice and Palliative care Organization \(NHPCO\) Interdisciplinary Conference](#)

October 13-14, 2017 in Houston, TX
[21st Annual Interdisciplinary Conference on Supportive Care, Hospice and Palliative Medicine](#)

November 5-10, 2017 & May 7-11, 2018 in Cambridge, MA
[Palliative Care Education and Practice \(PCEP\)](#)

November 9-11, 2017 in Phoenix, AZ
[Center to Advance Palliative Care National Seminar](#)



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