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I am so glad that August is behind us. The rain was dampening my outdoor activities, although my garden loved it. My vegetables are prolific! However, the slugs are prolific, too. I hate slugs. Fortunately, I harvested my lettuce before the slugs did. I canned green beans for the first time and made pickles for the second time last week. As the days get shorter, it becomes cooler and the sun shines less and less. Harvest time is over. All the bounty from the garden is put up; what is the plan for the winter?

My hope is that all my readers are starting to make a plan to get out and enjoy winter. Now is the time to start getting in the habit of being active. My favorite suggestions? Try walking after work, going to the gym, getting a group started to run together on days off or to bike ride before the snow falls, and maybe even start yoga or Pilates on a daily basis. If you start now, your routine will be set, and you will look forward to the activity and carry on throughout the winter. Walk with cleats on, bike with fat tires, cross-country ski on the trails, and go to your yoga class that you started in the fall. Let me know what you do for activities in the winter! Just email me at jane@aknurse.org; I would love to hear from all of you!

In this issue, we have explored nursing of the dying patient. We as nurses deal with death, I think, more than any other profession. Whether we choose to be a critical care nurse or a hospice nurse or a pediatric nurse, death is always there. We try so hard to beat it, to keep that person alive for another day or week or year, but sometimes it is not meant to be. Many times, we have to transition to comfort care, even in the middle of the acute trauma, because we know it is futile. Often, we have worked so hard over many weeks, dealing with family holding out hope for their loved one to get better, but to no avail. The emotional rollercoaster can be overwhelming; nothing can really prepare you for this. It just takes time and experience in dealing with death.

For me, as an ICU nurse for over 30 years, death is a permanent, forever-gone end to life that I experience all too often. The struggle is over, the fight is over, the pain is gone, and I stay there with them, so they don’t die alone. Sometimes just knowing you made a difference in that end-of-life adventure is worth being a nurse.

Jane Erickson, ADN, RN, CCRN
President, Alaska Nurses Association

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May 12, 2017 will be a day that I will never forget. I had heard many other nurses describe a patient dying, and I had known patients that had died, but I had never before been present when my own patient died.

It was not unexpected or sudden that this child was going to die, yet the whole day felt rushed. When I heard the family had decided to withdraw care, I felt a glimmer of excitement. I know that is a terrible thing to say, but for that brief moment I thought, “This isn’t something I’ve had happen before, and I want to experience it while on orientation.” Then it hit me: “Wait, someone’s child is dying. All hope of them surviving is gone.” My mind rapidly shifted from excitement to a feeling of loss.

Everything felt hurried but slow at the same time. I had no idea about all the paperwork that needs to be done when a child dies. Is the patient going to the medical examiner or straight to the funeral home? A funeral home needs to be chosen by the family. Is the patient a candidate for organ donation? In this case, the patient was not. Also, we needed to get the father’s consent and he was in jail. What if the father wanted to continue with care? I couldn’t even imagine how I would feel if that were the case. I’m glad the dad could see his son before he died. He wanted to be there so badly, and it breaks my heart that he could not be there when his son died. The paperwork seemed to drag on and on, but felt it frenzied at the same time. Once completed, it was time for the family to decide when they wanted to withdraw care.

How do you ask a family when they are ready? No one is ever “ready” to say goodbye to a child. No parent can say, “Yes, I am ready for you to remove the breathing tube that is keeping my child alive.” No, “ready” is not something one can be, but no other word is better. The family said at 11:00 am they would be “ready.”

Just after 11:00 am, I entered my patient’s room, accompanied by my preceptor, an RT, a child life specialist, a social worker, and an OCS worker. Priests had been in and out of the room to bless the baby. The doctor explained what he was going to do. I was instructed to be the recorder of the endotracheal tube being pulled and to record the time of death. I turned off the monitor and disconnected the TPN. “I need to flush the line and use a sterile cap,” I thought for a brief moment, “But, wait… I’m not reconnecting.” I turned the pump off and disconnected, the foreignness of not capping the line underscoring the somber event of which I was part. My preceptor removed the leads and pulse ox, and I handed her a towel to wrap the endotracheal tube and NG tube.

At 11:10 am, the doctor removed the breathing tube. I wrote the time down and watched the baby go from pale pink to a grey-blue color. I will never forget that image of the color changing so quickly. The mother brought him up to her face and began to cry. I have never heard such sorrow in my life, and that is when tears came streaming down my face. I was so glad to be wearing a mask. The family began to sing to the baby and he went so peacefully. At 11:16 am the doctor listened to the baby’s chest and he was gone.

Time seemed to stand still as the family comforted each other and a box of tissues was passed around. Staff members slowly left the room until it was just my preceptor and I left. I couldn’t move. All I could do was watch this mother hold her baby and cry. After what seemed like an eternity, we stepped out of the room to give the family more privacy with the baby. I would have stood there by the IV pole all day if that was what the family wanted, but the family needed time alone.

As soon as I left my patient’s room, I realized I needed to be outside. I told my preceptor that I needed a quick walk, and I went. I could hear people asking if I was okay as I walked away, and all I could do was shake my head. No, I wasn’t okay. I needed just a moment alone to let it all go. In a blur, I rushed to the parking garage, walking as fast as possible. I remember reaching outside and the sun was shining and I finally felt like I could breathe. I let myself cry hard and didn’t care if anyone saw me.

As I walked back in the unit, the charge nurse found me and hugged me and cried with me. She said I was a good nurse for caring and that it is never easy to lose a patient. I know she said more to me, but that’s all I remember. When I returned to my patient’s room, my preceptor was assisting the family in giving the patient a bath. I jumped in to help, thinking this might be my only chance to say goodbye. As I helped bathe him, there was a moment it was just me washing the baby. I leaned down and said thank you and told him that his papa loved him, because his father could not be there when he died.

The family dressed him and wrapped him in a crocheted white blanket. The family was also able to take pictures with him, so I stepped out to give them privacy. The rest

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of the day was a blur of charting and paperwork. When the medical examiner came to take the body, the mother had left the room briefly to go eat. The ME was going to take the body without her there. This really bothered me. How dare he take this child before the mother was able to say goodbye one last time? I understand this is something this person does every day and he has a schedule to keep and is very busy, but it seemed heartless that he wouldn’t wait 10 minutes for the mom. She hadn’t eaten all day because her child had died and she had been holding him. Thankfully, she showed up just in time.

Once the ME left, the family gathered their belongings and we said our goodbyes. I told them I was sorry that there was nothing more we could do and the mom looked at me and said, “You tried everything you could.” The family thanked the staff for all their hard work and said they were very grateful for us. I looked to my preceptor and asked, “Now what?” We discharged the patient from the computer and called the monitor studio. I saw my educator and she told me to go home. I thanked my preceptor for everything and received multiple hugs from coworkers. I have never felt so much love and support from an amazing group of people. I know that I would not be able to do this job without them.

I got home and just started crying in my car. My fiancé came out and gave me a hug. I walked in the house and sat on the floor, hugged my dogs, and let them lick my face. My fiancé and I went for a bike ride, and that is exactly what I needed to clear my mind. Being outdoors is very important for me during a time like this. It re-centers me and humbles me. Also, writing everything down is important and gives me a chance to process everything and I feel like I am able to move on. I will always remember this day, but I will look back and be grateful for everything I learned. This experience has helped me become a better nurse and a better person.
Thousands of delegates, including five from the Alaska Nurses Association, took part in the July 13-16 AFT convention in Pittsburgh, focusing on how member engagement will chart a course for our union and our democracy. Delegates debated and passed dozens of resolutions on issues such as elections, labor and the economy, and strategic planning for the future of our union.

A number of resolutions were related to healthcare, including ones about workplace violence, creating a rapid response team for disaster relief, healthcare inequalities, the opioid epidemic and support for the Affordable Care Act.

During the convention, the nurses and health professionals who traveled to Puerto Rico and the U.S. Virgin Islands to provide disaster relief and recovery following Hurricane Maria were honored with the AFT's Heroes award.

Delegates were reminded to reflect on their power as union members during the healthcare divisional meeting. The delegates heard from Donna Kelly-Williams, president of the Massachusetts Nurses Association, who talked about her union’s campaign to put safe staffing limits on the state ballot for 2018.

The opioid crisis was on the menu at a joint breakfast that brought members from three AFT divisions together to learn more about ways to address the issue.

The convention also featured speeches from Hillary Clinton, Sens. Bernie Sanders and Elizabeth Warren, AFT members running for office, survivors of gun violence in schools, and more. The four-day event wrapped up with delegates overwhelmingly re-electing President Randi Weingarten, Secretary-Treasurer Lorretta Johnson and Executive Vice President Mary Cathryn Ricker.
The American Academy of Pediatrics recently issued a landmark statement and technical report, warning that certain chemicals found in food packaging and foods may harm the health of children by interfering with their hormones, growth and development.

The chemicals of greatest concern cited in the report and based on the latest scientific evidence include:

- **Phthalates**—chemicals used to soften plastics and make them more flexible, including in plastic food wrap and in food manufacturing equipment such as tubing. Health concerns include: harm to the reproductive development of boys, contributor to childhood obesity, and linked with cardiovascular disease.

- **Bisphenols (such as bisphenol-A)**—chemical additives used in the linings of food cans and as hardeners in polycarbonate plastic food and beverage containers. Health concerns include: neurodevelopmental harm, impairment of immune system, alterations in timing of puberty, decreased fertility, estrogenic and obesogenic.

- **Per- and polyfluorinated substances (PFAS)**—chemicals used to “grease-proof” cardboard and paper food packaging, such as fast food wrappers, microwave popcorn bags, pizza and other take-out boxes. Health concerns include: immune system suppression, thyroid disruption, decreased birth weight, and impairment of fertility.

- **Perchlorate**—used in plastic food packaging to reduce static. Health concerns include: disrupts thyroid function, impairs brain development.
• **Nitrates/nitrites**—added to foods, especially processed meats, as preservatives and color enhancers. Health concerns include: interference with thyroid function, decrease in delivery of oxygen, and linked with gastrointestinal and nervous system cancers.

• **Artificial food colors**—added to many children’s food products. Health concerns include: may worsen attention deficit/hyperactivity disorder (ADHD).

Children experience greater vulnerability to the effects of these chemicals because they are more highly exposed compared with adults and are undergoing rapid growth and development. Harmful exposures may have lifelong consequences.

The report points to the inadequacy of current laws administered by the Food and Drug Administration (FDA) and calls for stringent testing and regulation that protects the health of children. In the United States, more than 10,000 chemical additives are allowed for use in packaging, preservation, or processing of foods. This is a result of serious weaknesses in the regulatory system that operates on presumption rather than proof of safety. We need urgent and collective action to change public policy. States are taking the lead to protect public health because action at the federal level has been stymied. As an example, Washington State passed a law in 2018 which bans toxic per- and polyfluorinated substances (PFAS) in paper food packaging.

**Here are some simple health-protective steps from the American Academy of Pediatrics that you can use to advise your patients:**

• Avoid microwaving foods or beverages in plastic containers, including infant formula and pumped breast milk. Avoid putting plastic containers in the dishwasher. Heat can cause leaching of phthalates and BPA from plastics.

• Replace plastic containers where possible with glass and stainless steel.

• Avoid plastic containers labeled with recycling codes “3” (phthalates), “6” (styrene), and “7” (bisphenols), unless labeled as “biobased” or “greenware,” indicating that they are made from corn and don’t contain bisphenols.

• Whenever possible, choose fresh or frozen fruits and vegetables rather than canned. Avoid processed meats, especially during pregnancy.

• Wash hands prior to food handling and wash all produce that cannot be peeled.
When I was approached by a coworker to write about end-of-life issues, instantly I was eager to accept the challenge because I love writing, even more so when it is something I am passionate about. As I attempted to put pen to paper, I began to realize just how difficult the subject of death and dying is. It's a difficult subject for me to interpret because emotion is expressed by feeling, rather than words.

“Grief is not a disease or pathology to be cured. Grief is the tangible evidence that we’ve cared and loved someone.”

–Anonymous

Everyone is affected by death, it’s unavoidable. It’s simple and yet complex. Death has a finality to it which forces you to briefly remember what is important. Life continues to move forward for everyone else, while, for a moment that feels like eternity, life becomes motionless, confusing and unfinished for those left behind.

Nurses are passively given permission to be involved in an intimate part of someone’s life. As a nurse, my job is to protect and nurture my patient and their family, to ensure they have a solidified understanding of what their medical picture looks like, to provide a platform to which questions can be asked and to help ensure their voices and values are being heard.

I started my career as an RN in an oncology clinic. It was incredibly overwhelming learning everything new. I then had to look past all the equipment and see patients as people. As time went on and I became confident in my practice, conversation became easier. I learned people didn’t want to focus on their disease and they don’t want to feel pitied. When I transferred to the Critical Care Unit (CCU) a few years later, I was able to that simple, yet valuable, knowledge with me. A place where intimate conversations seemed almost non-existent to me but held greater importance in the immediate sense. The added equipment was intimidating, but I tried to never let it affect my ability to create a rapport with my patients or their family.
Difficult questions, conversations and situations are unavoidable, especially in the CCU. As a nurse, you naturally want the best possible outcome for your patients. Sometimes the best outcome means allowing a patient’s journey to come to a close. I hadn't realized the impact or the importance of advocating until I came across a patient who not only changed my life, but changed the direction of my nursing career. My newly learned critical care skills, combined with my timid confidence, made approaching the intensivists with my unsettling feelings difficult. At the same time, sitting idle and continuing to provide care to a patient who made his wishes clear was even more distressing.

It was the end of May. I was assigned to take care of JR. He had a seizure disorder which resulted in him falling and leaving him with multiple brain injuries over time, with this last episode being the worst. Because of his head injury, he had a hard time expressing his thoughts, which made him more anxious and tearful. He would forget things almost immediately, so he repeated the same question multiple times. This became frustrating for him very quickly, so I decided to just sit with him. Once he was no longer anxious, he shared his life before seizures, about his dream of being a firefighter, his dogs, his thoughts on politics, his hatred for the “damn Yankees” (his dad’s favorite), and his favorite team: the LA Dodgers.

I learned he and his dad were best friends. They took care of one another, as they could never live independently. When one got sick, the other stressed and vice versa. It was impossible for one to see life without the other.

I worked with JR for several days, encouraging him to remember who I was and why he was in the hospital. By the end of the week he was getting up into a chair and eating again. He had improved enough to be transferred out of the ICU. As JR was progressing forward, his uncle became our next ICU patient.

When it came time for JR to transfer, his uncle seemed to be stable. Only a few days later, his uncle had a heart attack and passed away. Around the same time, JR aspirates while eating and develops respiratory failure. This time while he’s in the ICU, he requires life support.

JR’s dad is not only grieving the loss of his brother and must prepare his funeral, but is now being told his son is back in the ICU on life support and has developed severe respiratory failure. He is unable to be removed from the ventilator, forcing the family to have to make the difficult decision whether or not to have a tracheostomy, a tube providing an airway to the lungs, placed. They agreed on placement with the hope of JR recovering and returning home. The heartache becomes too much for JR’s dad, and he too is admitted to the hospital for heart complications.

After being discharged, he came to the unit to visit with his son. It was painful to watch the two clutch onto one another, each carrying hope for the other. We tried to explain to the family that JR may not recover and maybe it would be best to allow him to pass away peacefully. His dad was clearly upset and was not ready to make this decision.

Another day passes. JR remains on life support and lightly sedated. Our conversation has become one-sided, as he can no longer talk. I share with him game updates and turn on every Dodger game I can. I mistakenly put on a Yankee game and teasingly asked, “Why didn’t you tell me the Yankees were playing?!”

I removed JR’s restraints, as I didn’t see them necessary at the time. The doctor asked me to lighten his sedation to see if he would become more interactive. I briefly went to check on my other patient, only to be called back to JR’s room by his alarming vent. When I got to him, he had removed the circuit from his neck and removed the only IV access I had to make sure he was comfortable. He was crying and thrashing his head, which only worsened when I asked to place a new IV. His heart rate was nearing the 180’s, causing me to panic. I was finally able to calm him enough to explain he needed an IV, so I could keep him comfortable. After he settled, I had to restrain his hands for his own protection. I ensured he was comfortable, and just sat with him and cried. I told him I was so sorry, and I promised I would once again encourage his family to allow him to go peacefully.

That night after work I went to my favorite bar and had a shot of Fireball whisky. I wanted a shot that wasn’t so terrible I couldn’t stand it, but still something that tasted
like the hell I had created. When I returned the next day, I told JR I had a shot of Fireball just for him. He raised one eyebrow which proved he heard me. I told him I never wanted anything like that to happen to him or anyone ever again. I told the doctors I refuse to lighten sedation again until the family was there to witness the consequences. When his family arrived, I again lightened his sedation and he began to cry, as he was fully aware of his reality. His family said they would take a few days, maybe a few weeks, to talk things over as a family before deciding what to do with JR’s life.

After his family left, I again lightly sedated him and cried with him once again. I again said how sorry I was but explained the importance of his family seeing what he had already shown me. Feeling as though my encounter with his family bore no fruit, and feeling like I had exhausted all my options, I took my concern to the ethics committee for help.

June 17, 2017 was the last time I saw JR. As the end of my shift neared I choked back tears and, very heavy-heartedly, held his hand and said, “I have tried everything I can to get you what you want,” and explained that I had submitted a letter on his behalf. I also told him, “I hope I don’t see you again, but if I do, I hope you are feeling better. I vow to be a Dodgers fan, except when they play the Cubs.”

When I came back to work several days later I, was terrified I would walk into the same situation I had left. Instead, I learned that a few days after our last family meeting, JR’s dad was again suffering from a broken heart, which left him on life support in the ICU, in the very room where JR and I had first met. The family had agreed neither one wanted to live without the other. The staff arranged for father and son to be placed in adjoining rooms, where family could be at both bedside together. They were both transitioned to comfort care; first the father, followed by his son. Father and son became CCU’s first two palliative care patients. JR and his dad passed away peacefully surrounded by family within four hours of one another.

As I promised, I faithfully watched every Dodger game, even ordered a customized jersey: Junior #15. Although this is the catcher’s number, it was also JR’s birthday, January 15th, and so for me #15 was a way to remember him. Every victory was followed by a shot of Fireball to honor his life and love for the team. They won 104 games that year, a Major League best record. With that many wins I felt I should own stock in Fireball.

As the season started to wind down, as fate would have it, for the second year in a row, the Cubs faced the Dodgers in the division finals. Because I wanted to honor JR’s life, I painfully rooted against my Cubbies in hopes of the Dodgers making it to the World Series.

Baseball had become my life; baseball came before nearly everything. I drug my kids around with me to watch every game they would tolerate, pushing my superstitious behavior on them. The World Series was incredible, but also heartbreaking; a brutal seven games. Game seven left me devastated. With the Dodgers defeated, my fairytale ending was gone. I wanted so badly to take a road trip to JR’s hometown and celebrate the win. When it didn’t happen I almost felt as though I’d let him down. So, I pushed my trip off for a few more days.

JR was alive because baseball was alive. Now that baseball was over, the harsh reality set in that JR was gone. The Sunday following the final game, I took the two-and-a-half hour trip. I created my own memorial for him, made up of a small bouquet of balloons, a dozen blue flowers, a card for JR and for the one who discovers my
memorial, a baseball that I labeled “Dodgers 2017” and – of course – a shot of Fireball.

In JR’s card I wrote:

As I promised I supported the Dodgers 100% this year (even when they took out the Cubs in the NLCS). Unfortunately, as with life, there was no fairytale ending. But like you, the Dodgers put up one hell of a fight. An amazing series. You may never understand the impact you made on my life, not just as a nurse. But I will spend the rest of my career honoring the foundation we have laid.

For the finder of my memorial:

Although the impact JR has had on my life is unknown, my hope is, this memorial will stay alive each time this ball is put into play. Every nurse has that one patient, JR was mine.

A good friend of mine, who has encouraged and helped feed my love for baseball, has supported and shared my journey with me. He told me the devils themselves, Brent Strom and Ralph Dickenson, were coming to Anchorage to coach the local kids. These were the pitching and hitting coaches of the Houston Astros who beat the Dodgers in the World Series. On the final day of the training I wanted to symbolically relive the series, so I wore my Dodger jersey. Naturally I was called out. Strom shared pictures of the trophy and their unique celebrations. But he also told me that the greatest Dodger of all time, Sandy Koufax, was his best friend. He went on to tell me the Dodgers are a great organization, a great young team and they’ll be back next year, and he also wished luck on my Cubbies next year.

For me, JR wasn’t just a patient, and baseball was no longer just baseball. Because of JR, my advocacy allowed me to help many other patients, but he also helped me advance into my palliative care role I practice today. He deepened my love, or some would say obsession, for baseball. In an effort to keep him alive I began researching baseball; anything and everything I could possibly think of, I researched it.

I realized recently my baseball obsession wasn’t just about JR. In an ironic way, baseball has become cathartic for me. Baseball is something I look forward to after a long day; I don’t have to think about my patients or their struggling family members. I can sit and watch a game, honor my friend, and enjoy a live game of chess on the grass.

For many, death is the elephant in the room, which no one wants to address. Being a part of a medical team, we walk a fine line trying to maintain professionalism and staying emotionally disconnected. When you work with incredibly sick people all the time, it’s a sad truth that your feelings become calloused, like you’re “dead from the heart up” as Patch Adams puts it.

As a nurse you see death across a spectrum, we often term them as good, brutal, painful, sudden or peaceful, among others. As a bedside nurse it is difficult to gain a subjective viewpoint when you are struggling with the discord of your own personal beliefs and those of the family. JR gave me some insight on the different views of medicine and the views of family. But it wasn’t until I started doing palliative care, that I really felt a paradigm shift. My perspectives on my patients now go beyond the bedside. There are still some situations I come across and struggle with deeply, but I have learned I can accept the wishes of families if they have a well-informed decision. Families have been with my patients for far longer than my few days in the CCU. I have little connection with them, besides the care I give. With little emotional connection, it’s easy to say this is what I would do and move on. But to expect families to feel the same is unfair and emotionally insensitive.

As Dr. Byock says, it feels like you’re “winning a lottery ticket from hell” when you have to have raw discussions with nearly complete strangers. Although these discussions are often uncomfortable for many, they provide more value than what is seen on the surface. Families are suffering from inevitable grief. By broaching the subject, the family is being given permission to express their thoughts and values. They can feel confident in building a plan of care with the medical team which will honor their family member. Often, you can see the relief in their body language. And although the values of the family still may not align with your own, allowing the family to voice their understanding and their values empowers them to trust in the care that is being provided.

As I mentioned earlier, JR was one patient who changed my life and the direction of my career. Our paths intersected early in my profession, and although the experience was one I deeply struggled with both personally and professionally, it helped me to honor and celebrate his life but also his death. He also helped me realize I have a deeper depth than I ever thought possible. He had a profound effect on my life, which I will likely continue to honor for the rest of my life. Even though JR’s life and death and the 2017 World Series had a modified fairytale ending, he has been my greatest story.

“A life is not important except in the impact it has on other lives”

- Jackie Robinson,
Brooklyn Dodgers

Thank you for allowing me to share my journey.
There are some things in life that we can change, and there are others that we can’t. Death and the loss and bereavement that follows are experiences that we may all have at some point in our lives. “In this era of high-technology medicine, people have come to see cutting-edge advances and medical miracles as the norm. Each new advance, however, pushes the boundary between life and death into murky territory where patients are largely bewildered and the goals are less clear.” (Volandes, 2015)

There is a culture that exists in the hospital environment that is very different from the culture that exists outside the hospital. We have seen and experienced life-saving events, as well as unexpected and expected deaths. These events can affect how we view the end-of-life experience.

As nurses and healthcare providers, we cannot predict exactly when or how a patient is going to die. We can only provide the best information, based on our own research, knowledge and experience, about what may happen. Depending on the situation, the time left can vary from hours to days, weeks and sometimes even months. Death might come sooner than we anticipate, or it may come later. The conversation we have about end-of-life with patients and families will impact many peoples’ lives.

“What people need most on this journey is not the promise of the next new technology but rather a guide to help navigate this dark forest in which they will undoubtedly find themselves.” (Volandes, 2015) When we approach families to have an end-of-life discussion, we should be ready for the challenges that may present themselves. Good communication is a tool that can be used to help patients and their families. How we approach end-of-life discussions can negatively or positively affect the conversation and potentially impact the plan of care.

Our conversation with the patient and family should include listening to what the patient and family have to say and answering any questions that they may have. Listening
and being silent are important tools that can help build a trusting relationship with patients and their families. However, there are also things that should be asked and answered. We can do this by asking questions while we are also listening. We need to take time to become familiar with the patient, their family and their support system. How does their family see them, and how do they see themselves? What are the things that are the most important to them, and what things do they still enjoy doing? Do they have fears about their illness, what might happen, or treatments that they may have to endure? Are there important spiritual, religious, philosophical or cultural beliefs that guide their medical decision making? If the choice was better quality of life or living longer, what would the patient choose? Would the patient prefer to die in the hospital or at home? Find out who the important people are in the patient’s life. Make sure that the patient or his family have an opportunity to share and express their thoughts. The patient’s thoughts, wishes and values will guide them in deciding about their goals of care at the end-of-life.

Identifying the Surrogate Decision Maker (SDM) for medical decisions can be critically important for the acute and critically ill patient. If there is no Advance Directive (AD), it is important for the patient to select someone to make decisions for them if they cannot make decisions for themselves. If the patient cannot speak to us and there is no AD and no clear SDM, it can become more challenging. Now is the time to ask the family to place themselves into the shoes of the patient and think about what the patient would want. At this point, the conversation continues until the family can agree on the kind of care that will be provided moving forward.

We need to remember that religious beliefs and values affect the decisions that are made by the patient or family at the end-of-life. These beliefs and values have guided patients and families throughout their lives, and they are not something that we can expect to change. We must learn to respect those beliefs, just as we expect our beliefs to be respected.

The last and most difficult step is for the family to decide how to proceed. Will it be Full Code or Partial/No Code, ventilatory support for the long term, short term, or not at all, tube feedings or not? You will need to explain what it all means and answer more questions. Is it time to stop the aggressive measures that are keeping the patient alive? Reflect on whether we are helping the patient or prolonging the dying process. Decisions and choices will be made and we will need to support the patient and family in the decision that they make. And always keep talking to the family, offering support and explaining what is happening.

Before engaging in conversations about end-of-life, make sure that you have identified you own emotions, and be prepared to disagree with the patient or family’s decision. You must be prepared to address and identify conflict, even if it cannot be resolved. Give the patient and family the time that they need to make their decision based on the information that you have provided and their own beliefs and values. Nurses and healthcare providers all have a role in supporting the family and the patient when they are making decisions about how they want themselves or their family to be cared for at the end of their life. We can impact this experience in a positive way by supporting their decisions and by caring for their family as if they were our own.

“At least two kinds of courage are required in aging and sickness. The first is the courage to confront the reality of mortality – the courage to seek out the truth of what is to be feared and what is to be hoped. Such courage is difficult enough. We have many reasons to shrink from it. But even more daunting is the second kind of courage – the courage to act on the truth we find. The problem is that the wise course is so frequently unclear. When it is hard to know what will happen, it is hard to know what to do. But the challenge is more fundamental than that. One has to decide whether one’s fears or one’s hopes are what should matter most.” (Gawande 2014) The courage patients find to make choices at the end of their life may depend on how those choices are presented.

Remember that “open honest communication fosters trust and informed decision making.” “Nurses are able to address hopes, by not destroying them, and by allowing them to be voiced. Then, if these hopes are not possible, talking about what else they might hope for? Nurses can be available to listen, reflect and connect with patients and families. They can assure patients and families that someone will always be available during the dying process. Nurses play an important role in keeping the conversation going, listening to patient’s and families’ voices, and accurately communicating the information from patients and families to the interdisciplinary team.” (COH & AACN, 2015)

Goals of Care conversations at the end-of-life will have the greatest impact on the patient who is dying, but the impact will also be felt by the family and those of us who care for the patient. “Family members who witness the last days, hours and minutes of their loved one’s life will remember the death for as long as they live. Nurse have a unique role in making sure that patients die with dignity and great peace.”

REFERENCES


COH & AACN. (2015) Module 8: Final Hours, ELNEC Core Curriculum Faculty Outline.


Advocates for a pro-euthanasia position have been working for years to champion the right to die for patients with terminal illness. Best known for this position is Dr. Jack Kevorkian, an American pathologist and euthanasia proponent. He claimed to assist at least 130 patients in ending their lives and helped to set a platform for reform of patients’ rights. Dr. Kevorkian was tried four times for assisting suicides before he was eventually convicted of second-degree murder and delivery of a controlled substance for the televised administration of a lethal injection in the voluntary euthanasia of Thomas Youk, a victim of Lou Gehrig’s disease.

It is first important to know that euthanasia can be separated into multiple categories. A commonly practiced, often legal form is passive euthanasia, which occurs when life-sustaining treatments are withheld. Much more controversy broils over other types of euthanasia, including active euthanasia and assisted suicide. A key distinction between active euthanasia and assisted suicide is that in cases of assisted suicide, the individual receives assistance yet ultimately causes their own death, while with active euthanasia, another person acts to cause the individual’s death.

Currently, active euthanasia is legal in the Netherlands, Belgium, Colombia, Luxembourg, and Canada. Assisted suicide is legal in Switzerland, Germany, the Netherlands, and in the states of Washington, Oregon, Colorado, Hawaii, Vermont, Washington DC and California, and is de facto legal in Montana.

Should patients have the right to choose? This is a question that most of us have pondered throughout our careers. We see the suffering that can go on for patients and their families with chronic diseases that we know will lead to death, with potentially days, weeks or years of suffering along the way. The march towards death can be acutely horrific for patients who suffer from Multiple Sclerosis (MS), Amyotrophic Lateral Sclerosis (ALS, or Lou Gehrig’s disease), and a host of other diseases that end with aspiration pneumonia, urinary infection or sepsis.

I’m sure many a nurse has wondered, “What if that were to happen to me?” Should someone have the right to decide to end their suffering at their home with their loved ones beside them? I believe it is an option that everyone should be able to have, but that in our current environment, society and law serve as the decision-makers for what should instead be a very personal choice.

In the hospital, we may remove a patient from a ventilator and provide comfort care as indicated by the patient through an advanced directive. Sadly, not everyone has the forethought to plan their end-of-life care with an advanced directive. Having a conversation before a devastating diagnosis or accident occurs is a way to help ease the burden on family members so they will know your wishes from the beginning of your final journey.

Patients may have many years of deterioration to the point of not being able to feed or care for themselves. At what point do we say it is time to stop treatment? Our bodies are very smart, and many complications could be seen as the body’s attempt to potentially avoid excess suffering at the very end. For example, a cancer patient may get a serious pulmonary embolus or other clotting in the body. How many blood thinners should they take? When is the right time to stop them? What about the brain tumor patient getting a neurogenic bladder, who passes away from urosepsis before the tumor can ever cause the patient to lose function on one side of the body – Is this a way of the body saying it is time? I don’t know what the answer is, but I do know after many years of watching loss of function and acute suffering, it may be time to let patients decide when they have enough.
WHEN IS ENOUGH, ENOUGH?
Euthanasia and Patients’ Rights
By Donna Phillips, BSN, RN

LitSite Alaska is an online community promoting literacy, cultural diversity, and well-being throughout Alaska. A gathering place for families, communities, and teachers, LitSite Alaska features narratives illustrating many cultural aspects of life in Alaska. LitSite Alaska contains a special feature called “Narrative and Healing” aimed at health professionals. Narrative and Healing focuses on the therapeutic properties of writing and storytelling, providing examples of how people of all ages face life’s challenges through the art of telling their stories. LitSite Alaska is currently accepting narrative essays from nurses and other healthcare professionals. Please consider submitting your story! To learn more, visit www.litsitealaska.org.
Five Wishes
www.fivewishes.org

Five Wishes is the first living will that talks about your personal, emotional and spiritual needs as well as your medical wishes. You can use Five Wishes to express how you want to be treated if you are seriously ill and unable to speak for yourself, using a document that is easy to understand. All you need to do is check a box, circle a direction, or write a few sentences. The five wishes included in the document are:

- **Wish 1:** The person I want to make healthcare decisions for me when I can’t make them for myself.
- **Wish 2:** My wish for the kind of medical treatment I want or don’t want.
- **Wish 3:** My wish for how comfortable I want to be.
- **Wish 4:** My wish for how I want people to treat me.
- **Wish 5:** My wish for what I want my loved ones to know.

Five Wishes meets the legal requirements for an advance directive in Alaska. Once it is signed and witnessed, your Five Wishes is a legal document. Five Wishes is for adults age 18 and older and is available today in 26 languages.

My Wishes and Voicing My Choices
www.fivewishes.org

Though it is not always easy to think, or talk, about a serious illness with children, it is important that you understand their feelings, thoughts, and wishes should the need ever arise. Voicing My Choices, for adolescents and young adults, and My Wishes, for young children, are tools to help guide the discussion in the event they become seriously ill. Developed with feedback from young people living with serious illness, these tools can help you sensitively discuss advance care planning. Voicing My Choices and My Wishes are written in language for children and young adults and capture how your child wants to be comforted, supported, treated, and remembered by family, friends and caregivers.

Supportive Care Matters
www.supportivecarematters.org

Supportive Care Matters is a public awareness campaign aimed at helping people living with illness or challenged by aging achieve a better quality of life. Supportive care is any kind of care or support that supplements your treatment and helps you live your best life. The Supportive Care Matters website contains useful tools and resources including information how to pay for
treatment and where to find emotional support, tips to manage chronic illness, an action plan for ongoing care, an advance care planning tool, self-care practices, and other tools to help you become an effective advocate for yourself in healthcare decision-making.

Hospice & Palliative Care Nurses Association  
www.advancingexpertcare.org

The Hospice and Palliative Nurses Association is the national professional organization that represents the specialty of palliative nursing, which includes hospice and palliative nurses. HPBA supports the profession through education programs, research initiatives and advocacy. The Hospice and Palliative Credentialing Center offers specialty certification to hospice and palliative nurses, and other members of the interdisciplinary team. It currently offers four certification exams for RNs and APRNs, pediatric palliative nurses, and those dealing with perinatal loss.

End-of-Life Nursing Education Consortium  
www.aacnnursing.org/ELNEC

The End-of-Life Nursing Education Consortium (ELNEC) project provides palliative care training to nursing faculty, CE providers, staff development educators, APRNs, and specialty nurses in pediatrics, oncology, critical care and geriatrics. Once trained, nurses go on to teach this essential information to nurses and nursing students in educational and clinical settings.

Association for Death Education and Counseling  
www.adec.org

The Association for Death Education and Counseling is one of the oldest interdisciplinary organizations in the field of dying, death and bereavement. ADEC provides continuing education courses, webinars, certification in thanatology (the study of death and dying), handbooks, journals, and other resources to its members.

The Conversation Project  
www.theconversationproject.org

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care. The Conversation Project’s most valuable tools are its free conversation starter kits, including a starter kit to help you talk with your loved ones openly and honestly before a medical crisis happens to give everyone a shared understanding about what matters most to you at the end-of-life. The Conversation Project also includes a starter kit for families of people with Alzheimer's Disease or other forms of dementia, and a pediatric conversation starter kit designed to help parents of seriously ill children who want guidance about “having the conversation” with their children.

Hospice Foundation of America  
www.hospicefoundation.org

Hospice Foundation of America educates the public and healthcare professionals about death, dying and grief. HFA brings together the nation’s leading experts to contribute to the content of HFA’s books, web-based tutorials and programs, and videos. Hospice Foundation of America also funds research about hospice care, supports specific hospice and/or grief initiatives (such as children's grief camps), and financially assists hospice providers in times of disaster.

Caregiver Action Network  
www.caregiveraction.org

Caregiver Action Network (CAN) is a non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge. CAN's online family caregiver toolbox includes resources on advance directives, nutrition, understanding Medicare, locating eldercare, finding support groups, how to talk to your doctor, caregiver depression, respite care and much more.
Children’s Hospice International
www.chionline.org

Children’s Hospice International pioneered and promoted the idea that critically ill children should have access to hospice and palliative care along with curative care from the time their life-threatening illness is diagnosed. CHI’s ultimate goal is to so ingrain the hospice concept into pediatrics that it isn’t considered a separate specialty, but rather an integral part of healthcare for children and adolescents. CHI provides education, training and technical assistance to those who care for children with life-threatening conditions and their families.

National Hospice and Palliative Care Organization
www.nhpco.org

The National Hospice and Palliative Care Organization is a membership organization committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones. NHPCO develops public and professional educational programs and materials, convenes meetings on emerging issues, conducts research, monitors Congressional and regulatory activities, and works closely with other organizations that share an interest in end-of-life care.

Perinatal Hospice
www.perinatalhospice.org

Perinatal Hospice is a clearinghouse of information about perinatal hospice and palliative care, including many resources for parents and caregivers, as well as an international list of more than 300 programs. Featured resources for nurses and other caregivers include conferences and training, materials for patients, journal articles and other references, and resources on birth planning and starting a perinatal hospice program. Resources for parents include online forums, information on specific conditions, funeral resources, and information on organ donation, photography and perinatal bereavement.

International End of life Doula Association
www.inelda.org

The International End of Life Doula Association (INELDA) is a nonprofit organization dedicated to bringing deeper meaning and greater comfort to dying people and loved ones in the last days of life. INELDA was founded to foster the use of end-of-life doulas in hospices, hospitals, communities, and directly to dying people through the service of private practitioners. To accomplish these goals, INELDA offers end-of-life doula program development, private and public doula training classes, and a comprehensive doula certification process that establishes a professional-level standard for the field.

Death with Dignity
www.deathwithdignity.org

The Death with Dignity National Center is promotes death with dignity laws based on its model legislation, the Oregon Death with Dignity Act, both to provide an option for dying individuals and to stimulate nationwide improvements in end-of-life care. Its website includes resources and information for patients and families, advocates, researchers and healthcare providers.

Palliative Care Alaska Network
www.anthc.org/palliative-care/palliative-care-alaska-network

The Palliative Care Alaska Network (PCAN) supports palliative care through collaboration and education to empower a comprehensive and dynamic network of individuals, agencies and communities to share tools and resources throughout Alaska. If you are interested in participating in PCAN, joining the network listserv, or serving on any of the workgroups or steering committees, send an email to palliativecare.alaska@outlook.com and include your interest. You can also join the PCAN group on Facebook.

Hospice of Anchorage
www.hospiceofanchorage.org

Hospice of Anchorage is a community agency comprised of an interdisciplinary team – volunteers, nurses, social service coordinators, bereavement coordinators and chaplains – who provide assistance to meet the transition from life through death and to cope with loss and grief. This may be a one-time visit, periodic contact or may grow into an ongoing relationship lasting weeks or months. All services are provided at no cost.

Alaska Hospice and Palliative Care Nurses Association
www.facebook.com/akhpna.net

Join the community on Facebook as the group works towards the establishment of an Alaskan Chapter of the Hospice and Palliative Care Nurses Association.
REMINDER: ALASKA NURSING LICENSE RENEWAL

RNs and APRNs: It’s time to renew your nursing license!
Online license renewal is OPEN for RNs and APRNs and will continue until November 30, 2018.

You must renew your license on or before November 30 in order to continue practice in Alaska. There is no grace period to practice on a lapsed license.

All licenses and authorizations expire on November 30 regardless of when first issued, except new licenses issued within 90 days of the expiration date, which are issued to the next biennium.

Licensees who receive their original license within 12 months of the expiration date pay a full licensing fee upon application, and at their first renewal pay a prorated renewal fee (half of the current license fee).

Hours toward fulfillment of the continuing competency requirements must be completed between 12/1/2016 and 11/30/2018.

Before a license can be renewed, nurses must complete two out of three methods for maintaining continuing competency:

- 30 contact hours of continuing education
- 30 hours of participation in uncompensated professional activities
- 320 hours of nursing employment

Hours toward fulfillment of the continuing competency requirements must be completed between 12/1/2016 and 11/30/2018.

Registered Nurses who received their original license on or after December 1, 2017 are not required to provide proof of continuing competency for their first renewal.

Licensees are subject to a random mandatory audit of continuing competency. If you are selected for the audit, you will be notified in writing and given 30 days to submit proof of continuing competency claimed for the licensing period.

You must truthfully answer the renewal application questions. If you are unsure how to answer the questions, contact the Board of Nursing for assistance prior to submitting your renewal application.

Online license renewal is available at: ProfessionalLicense.Alaska.gov/MYLICENSE

In most cases your license will be renewed immediately. Due to a heavy volume of renewal activities, processing time for renewal applications received by mail may take up to 4-6 weeks.

To use the online license renewal service, you need to register for a MY LICENSE account. You may have already registered using the email sent by the division on May 10.

If you have not registered, follow these simple steps:

1. Visit the MY LICENSE customer home page at: ProfessionalLicense.Alaska.gov/MYLICENSE
2. If you have an existing myAlaska account, enter your account information. If not, please create an account. You will be redirected to the MY LICENSE customer home page.
3. Under Access an Existing License, enter your license number and Web Authorization Code, if one has been provided. This information is on your renewal notice.
4. To renew your license, simply select the license you wish to renew from the Professional Licensing section.
We’re pleased to announce that each issue of The Alaska Nurse will now include a free CE offering!

READ – Enjoy this issue of The Alaska Nurse

LEARN – Discover new information and gain knowledge

EARN – Earn free contact hours when you pass the online post-test

How to Earn Contact Hours:
After you’ve read this issue of The Alaska Nurse, visit AaNA’s online CE center (alaskanurse.litmos.com/online-courses) and find the CE offering for this issue (October/November 2018 - The Alaska Nurse). Add the course to your cart and sign-in or register for a new account. Follow the course instructions to complete the post-test and evaluation. Your CE certificate will be awarded upon successful completion of the course!

The Alaska Nurses Association is an approved provider of continuing nursing education by the Montana Nurses Association, an accredited approver by the American Nurses Credentialing Center’s Commission on Accreditation.
## Calendar of Events

### AaNA

**UPCOMING MEETINGS**

<table>
<thead>
<tr>
<th>Event</th>
<th>Date</th>
<th>Time</th>
<th>Location</th>
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</thead>
<tbody>
<tr>
<td>AaNA Board of Directors Meeting</td>
<td>4th Wednesday each month</td>
<td>4:30-6pm</td>
<td>Anchorage</td>
</tr>
<tr>
<td>AaNA Labor Council Meeting</td>
<td>4th Wednesday each month</td>
<td>6-7pm</td>
<td>Anchorage</td>
</tr>
<tr>
<td>Providence Registered Nurses</td>
<td>3rd Thursday each month</td>
<td>4-6pm</td>
<td>Anchorage</td>
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**Education and Events**

- **6th Annual Trending Topics in Nursing Conference**
  - by the Alaska Nurses Association
  - October 11-13, 2018
  - Anchorage
  - Earn up to 18 contact hours just in time for license renewal!
  - [www.aanaconference.org](http://www.aanaconference.org)

- **AaNA's General Assembly**
  - October 13, 2018
  - Anchorage
  - [www.aanaconference.org](http://www.aanaconference.org)

- **TUESDAY TALKS**
  - (FREE Event)
  - **Increase of Syphilis in Alaska: How Do We Fight This Outbreak?**
    - Presenter: Amy Doogan, BSN, RN
    - Tuesday, October 16, 2018
    - 6pm
    - AaNA Office
    - Anchorage
    - Earn 1.25 contact hours
    - RSVP to dani@aknurse.org
    - www.facebook.com/AlaskaNurses

- **TUESDAY TALKS**
  - (FREE Event)
  - **Successful Implementation of the Dedicated Education Unit**
    - Presenter: Thomas Hendrix, PhD, RN
    - Tuesday, November 20, 2018
    - 6pm
    - AaNA Office
    - Anchorage
    - Earn 1.25 contact hours
    - RSVP to dani@aknurse.org
    - www.facebook.com/AlaskaNurses

### Alaska State Board of Nursing

**UPCOMING MEETINGS**

<table>
<thead>
<tr>
<th>Event</th>
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<th>Time</th>
<th>Location</th>
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<tbody>
<tr>
<td>Anchorage</td>
<td>November 7-9, 2018</td>
<td>Agenda deadline: October 7, 2018</td>
<td>Anchorage</td>
</tr>
</tbody>
</table>

The Alaska Board of Nursing has a listserv that is used to send out the latest information about upcoming meetings, agenda items, regulations being considered and other topics of interest to nurses, employers and the public. To sign up for this free service, visit [www.nursing.alaska.gov](http://www.nursing.alaska.gov).

### Alaska Native Diabetes Conference

- by the ANTHC Diabetes Program
- October 10-12, 2018
- Anchorage
- [www.akcache.org](http://www.akcache.org)

### Hale Borealis 2018

- **Strengthening Whole Community Partnerships to Improve Healthcare Resiliency**
- October 23-25, 2018
- Anchorage
- [www.haleborealis.com](http://www.haleborealis.com)

### 13th Annual School Health & Wellness Institute

- October 29-31, 2018
- Anchorage
- [http://dhss.alaska.gov/akshwi](http://dhss.alaska.gov/akshwi)

### All Alaska Pediatric Symposium

- November 2-3, 2018
- Anchorage
- [www.a2p2.org/pediatric-symposium](http://www.a2p2.org/pediatric-symposium)

### Youth Mental Health First Aid

- November 30, 2018
- Anchorage
- [www.aktclms.org](http://www.aktclms.org)

## Important Reminder:

**2018 is a License Renewal Year!**

**RN & APRN Renewal Deadline:**

- November 30th

Make sure your mailing address is up-to-date with the Board of Nursing! Renewal reminders will be mailed at least 60 days before the expiration date to the last address you provided to the Board. You must renew your license on or before the expiration date to continue practice in Alaska. There is no grace period to practice on a lapsed license.

Remember to visit [www.facebook.com/AlaskaNurses](http://www.facebook.com/AlaskaNurses) for current events and [www.aknurse.org](http://www.aknurse.org) for frequent updates and information on local nursing continuing education opportunities and conferences.

Want to list your event in The Alaska Nurse Calendar of Events and at [www.aknurse.org](http://www.aknurse.org)? Send information to andrea@aknurse.org
Install and test carbon monoxide (CO) alarms at least once a month.

CO is called the “invisible killer” because it’s a colorless, odorless, poisonous gas. Breathing in CO at high levels can be fatal.