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Dealing with the Final Passage

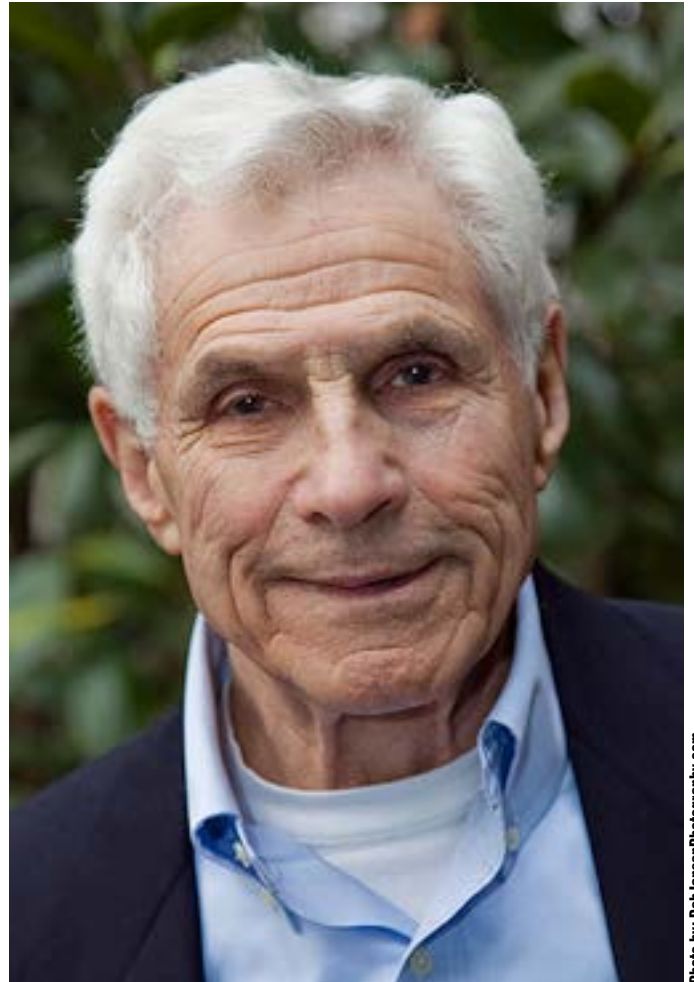
By Sheldon B. Cohen, M.D.

Dealing with fatal illnesses and death is an experience we all try to avoid. Humor is one of the techniques we use. I could write a book of jokes about dying. Woody Allen put it most graphically, “I don’t mind dying. I just don’t want to be there when it takes place!” Of course, this topic is not really a laughing matter. Having to deal with this painful topic in the summer of 2009 when my beloved wife of fifty-four years died, I’ve tried to take to heart one of her adages, “When life gives you lemons, make lemonade.” This issue is lemonade, concocted by a number of thoughtful, compassionate people.

We are fortunate to have a varied, distinguished, and capable group of authors who are addressing the end-of-life issues from a wide variety of perspectives. For this issue, I wear two hats: one is putting together and organizing the contributions of a variety of physicians and others, and the second how and why I got involved in this endeavor in the first place.

Richard Cohen, a brilliant, retired orthopedist, sets the tone for the issue, putting the rest of the articles in perspective. Richard is a good friend and a brother physician (though there are no blood ties between us!). He has thought long and hard about the end-of-life (EOL) care and brings us up-to-date about developments in recent decades, geographically and policy-wise. He notes that an advanced directive is of no value if it’s in a locked desk drawer or a safety deposit box! I repeatedly see this in my practice when I ask patients if they have one, and get the response, “It’s at my attorney’s,” or something like that. It reminds me of the woman who walked into her physician’s office pregnant and was asked why the birth control tablets did not work. She said, “Oh, they’re in my medicine cabinet!” Richard points out that the physician’s order for life-sustaining treatment is a positive document, not one that says DNR (Don’t Let Them Die)!

Boyd Eaton, retired radiologist and author of volumes about the lives of ancient people and a look at many of our forebears, gives us a beautiful background, going back and forth from looking at hunter-gatherers to those who lived 10,000-15,000 years ago. He has helped me understand the roles of Zoroaster and enlightened me about some of the historical relationships my own forebears. He gives us a look



Sheldon B. Cohen, M.D.

Photo by: DebiJansenPhotography.com

at Egyptian, Greek, and Roman views of the afterlife (up to date with the world’s major religions today: Christianity and Islam) and lets us know “no matter what one’s final conclusion, both past and present provide examples showing that others—somewhere, sometime—have come to similar convictions. No one is alone.”

Dirk Huttenbach, whom I’ve known for many years, is an outstanding child psychiatrist. He has put together a beautiful, extremely graphic, program, producing videos with patients that convey even better than the printed words of the impact we would all like to have on our loved ones. Dirk vividly describes his mother’s demise. She made it crystal clear

that she did not want to go to a hospital or nursing home and also badgered her personal physician. He described his experiences with his mother's death. "She died in her own bed in her own home, able to look at pictures of her loved ones placed all around her." Dirk's thinking was molded by experiences with a patient and an aunt, who were given unneeded, degrading treatment because they did not provide an advanced directive as his mother had. Out of his experiences, he conceived the idea of taking videos of patients so that they could express all of their wishes in "living color" so that families and caretakers could have not an iota of doubt about their desires. I was so impressed with this procedure that I arranged to have Dirk interview me so that I would have, in addition to the written instructions, graphic reminders to my family as to my wishes.

Dr. Alison Krause, one of the few trained palliative care physicians, speaks to us from the trenches, where she helps patients spend the last portion of their lives in much more comfortable situations than if they had gotten aggressive care. Dr. Krause practiced internal medicine for a number of years but took on a hospice assignment, in addition to her practice. She has 11 years in palliative care. She learned about palliative care, spent one year at UAB getting training, and then 3.5 years in Lexington, KY. She then spent 5.5 years with Wellstar (where she knew Richard Cohen and my Internist son, Steven). Most recently, she was lured away by Northside Hospital, starting a palliative care program. She currently is doing inpatient consultation with a nurse practitioner, and hopefully, will be expanding to outpatient work. She notes that patients who receive early palliative care live nearly three months longer than those who receive standard cancer treatment. Quality of life and depression are much better. She talks about how you talk with patients and with their families, and gives many pearls that can help us. She quotes Atul Gawnd, who noted, "We only die once." His thesis, as well as Dr. Krause's, do it as well as possible because you don't get another chance.

Melissa Duong, who appears with her extended family, gives us a perspective of someone who is beginning her career after graduating from Emory University and earning a Master of Public Health at Georgia State. She also wears several hats, being the person who has solicited and put together the various contributions, typing and editing them. In addition to giving us references as to the way other cultures handle (or avoid) end-of-life issues, she has discussed reactions of her own family, who, like the references cited, do not want to discuss it and have done nothing about the issue. I have tried to badger Melissa into getting her own Durable Power of Attorney for Health Matters, despite her youth, letting her know that one will never know when it might come in handy!

Laura Waddle, a pediatrician who specializes in children's hospice, gives us a poignant case from her experience. She tells

us what she has learned about dealing with families and how it is especially important with children to involve all of the family. She notes that, for some children, hospice is a second home, and therefore, it is a preference of children and family for many of them to pass away in the hospital (more so than adults who would generally prefer to die at home). She notes how the "little things" are so important, including birthday celebrations, going outside, etc. Some years ago, a woman with breast cancer who was dying, and her family set up a program for the families of people with cancer, letting them go on trips and vacations that they never could have afforded otherwise (Jack & Jill Foudataion/J&JF.org).

Brilliant, comedic Neil Shulman gives us a different take on end-of-life issues. Essentially, he says, "Let's don't take ourselves too seriously." This resonates very much with me, as it is a technique I have used with terminal patients. Patients and I will share humorous books and articles that get us both laughing about what's going on in their lives and in their last days. Two erudite authors, Norman Cousins and Art Buchwald, used humor to both ward off disease and make their last days memorable. Cousins, upon being given a grim diagnosis, decided he wasn't ready to die, did research, and began entertaining himself with funny movies and other material. He fooled his doctors, got well, and subsequently, was invited to be a lecturer at UCLA Medical School, where he taught physicians something about the use of humor in medicine (Cousins, 2005). Art Buchwald was sent to Hospice, supposedly to die, but he began inviting friends to his room and regaled them so much with humorous material that he walked away from Hospice and lived happily for a number of months (Buchwald, 2006). I'm sure that readers may have used humor in their own practices. I often tell my patients that they are doomed to have a psychiatrist who is a member of the BJS (Bad Joke Society), but also let them know that it would be a miserable fate to have a shrink without a sense of humor. We're supposed to leave the audience laughing. That's why I closed with Neil's contribution.

Missing is the paper I had hoped to receive from a dear friend, Lee Blum. Just before the deadline, I received a note from Lee that she would not be able to send her synopsis of her lifetime of dealing with a wide variety of clients because she was occupied with the very real illness of her own husband. Lee and Mel are two of those rare individuals whom we meet, as Dot and I did a number of years ago, with instant bonding and contact over the years (most by email and post). ■

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A Wish for Advance Care Planning & End-of-Life Care

By Richard W. Cohen, M.D.

So, do you have an advanced directive? Do you have a POLST? Do you know about the “Critical Conditions Planning Guide”? Having a conversation with a patient about how they wish to live their lives at the end of their life is an important part of your job as a physician. Do you honor a patient’s advanced directive? Do you know when you are at risk or when you are protected?

When I started in the “business” of medicine half a century ago, end-of-life (EOL) was different. Oh, death will always be the same. Here in Georgia, you have died when either your brain or your heart stops functioning. But what’s changed is how we handle and support a patient at the end of their life – this subsection of medicine has grown and matured. It seems to me that we have raised the dignity of life to a more respected and honored level.

Today we are partners with our patients and their families. This change is important, fundamental and one of the greatest changes that I have seen in medicine in my lifetime. It is as important as open-heart surgery, curing cancer, overhauling a painful hip with a total hip replacement or discovering a new cure for a disease; they are of equal rank to me.

I have learned to advocate for those at the end of their lives, and I hope you will as well; it is part of our job description. Physicians were born to be nurturers, and the advances in the science of medicine should not take away our humanity.

Managing EOL care is about developing and managing resources. This began to change about 25 to 30 years ago with the development of ethics committees.

Ethics committees were originally intended to deal with ethical issues relating to nurses, physicians and patients. Very quickly, however, they morphed into committees that focused on the world of EOL and patient advocacy. They work not as decision makers, but as facilitators and advocates to ensure that a patient’s rights and desires are known, understood and honored by all responsible.

Thirty years ago in cities like Portland, Ore., and La Crosse, Wis., the advanced directive movement got its start. Twenty years ago, Georgia Health Decisions (GHD) was asked to perform a series of focus groups with people across the state and from all walks of life. GHD wanted to know their thoughts and fears about their health care. Results



showed that a patient’s No. 1 concern was “how (and not when) I am going to die.”

With this information, GHD developed “Critical Conditions Guide and Directive for Final Health Care,” the first planning guide combined with an advanced directive in the state. It was piloted in seven communities in Georgia and after a year of success was extended statewide. The “Critical Conditions Guide” is now the document of choice in 80 percent of the hospital beds in Georgia.

In Georgia, the advanced directive process took another step forward when the state passed a new advanced directive law of 2007. This law combined the “Living Will” and the “Durable Power of Attorney” laws and brought the various issues and documents into one that addresses all of the EOL issues. It expressly states the patient’s wishes for care at the end of their life. It names and empowers their Health Care Advocate (HCA) and requests that their HCA honor and represent the patient’s wishes, as expressed, and function in the same way as the patient would have if they had been able to do so. The law provides “Good Samaritan” protections for health care workers, same as when helping an individual injured on the street. It also acknowledges that any advanced directive – in any form or from any other state – is to be honored by the health care team.

The issue is how to encourage every member of our community to have a conversation between themselves and their loved ones that ends in the completion of an advanced directive, or what is also known as Advance Care Planning. In Georgia, the best numbers I have heard are in the low 20 percent of individuals who enter a hospital have an advanced directive.

The best in the country may be La Crosse, Wis., with more than 97 percent of the community over the age of 50 having an advanced directive.

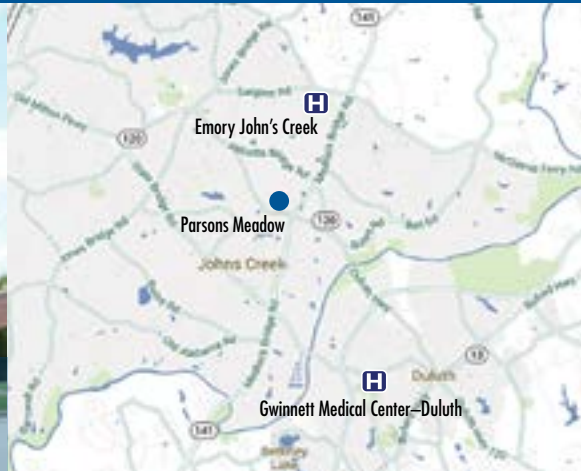
The first issue is getting a person to sit down in a calm, comfortable place with the time to learn and then make decisions about the care they desire at the end of their life. Once the document is completed, it is very important that they have a discussion with their family to explain their decisions and to enlist their support, so that in a time of crisis everyone will be moving in the same direction and will support and honor the patient’s decisions.

It is also important that their advance directive become a part of their physician’s EMR, so that it is available when needed and not in the bottom of a locked desk drawer or safety deposit box. It is only a “living” document when it is readily available.

An advance directive should be a part of every patient’s health care plan, and we should be as comfortable about

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asking and discussing end-of-life wishes as asking, “Do you have any allergies?”

It is not up to the health care professional to make the choices, but to honor the choices made. It would be a great service to our patients if every primary care physician would encourage and provide information on advanced directives to each of their patients. This would go a long way to improving the quality of care of our patients at the end of their lives.

Additionally, there are many specialists who are on the front line as well, such as pulmonologists, cardiologists, nephrologists and oncologists who could do the same in their offices. I would suggest that even surgeons should encourage their patients to have an advanced directive. The message would be clear to the patient that this is a serious surgery, and all issues need to be covered. The goal is for all patients to have an advance care plan/advanced directive and that their physician and the hospital should have it on file so that on any admission to the hospital, the document can be located in the computer. The closest that we have to a registry in Georgia is those hospitals who are on EPIC.

The question next is how to make the advanced directive a “living” document — one that can be used in short order and in any situation when a patient is unable to make decisions for themselves. The answer is a “POLST,” a Physician Order for Life Sustaining Treatment.

Leadership in the development of this document again came 15 years ago from Oregon and has moved into more than 16 states in the country, including Georgia. The POLST is a one-page physician’s order that summarizes the patient’s wishes as expressed in their advanced directive. It is a document that “activates” a patient’s advance directive when appropriate and meets certain medical criteria. It is intended to be the first page of the patient’s chart and provides all health care providers with a quick understanding of the patient’s wishes.

One of the POLST’s goals is to be transferable with the patient from one setting to another, such as to and from the hospital, home, assistant living and long-term care. Since it is an order of a physician, it should be followed by everyone, including nurses, physicians and EMTs.

The POLST will make it easier for the patient to have their wishes known and for the health care team to honor those wishes. This will help relieve a great deal of the tension that occurs in every hospital on how to provide care to a patient at the end of their life.

In July 2012, the Georgia Department of Public Health created a universal POLST form for the state of Georgia. However, there are still several issues that need to be clarified legislatively. Since its creation, there is now a collaborative of more than 35 key organizations that have come together

under the Georgia POLST Collaborative. It is the aim of the collaborative to educate people across the state about the POLST and to support its usage in all hospitals, long-term care facilities, skilled nursing facilities (SNFs) and assistant living facilities or other similar places.

The last piece in this puzzle is the advent of the specialty of palliative care. As gerontology was developing, some saw the need to better understand and assist patients in the issues of EOL. Leaders arose, programs were developed, and now there is a limited supply of physicians who carry on this vital work.

Most large hospitals now have a palliative care team that is led by a boarded palliative care physician. If your hospital has one, you are blessed. Their role is to assist the patient, family and health care team to develop a plan of care for the end of one’s life and to advocate for the patient, their wishes and the plan of care. They also work with the health care team to assure that a patient’s wishes are honored.

If the patient is at the end of their life, they will assist in the choosing of the best plan of care. Often this plan of care will be a “comfort care plan,” which provides an active treatment plan instead of abandoning a patient at their time of need. The “order-set” is changed from one of saving a life to one of allowing a patient to die naturally – “AND” (Allow Natural Death), the replacement for the term “DNR” (Do Not Resuscitate, a negative use of words).

The palliative care physician is unusually gifted in this arena, and he or she understands the issues of pain control and respiratory distress and the like, so that a patient may be in a state of peace. They are also particularly sensitive to the health care team’s distress.

I hope that I have answered the questions that I proposed and that all of you who have read this article have an advanced directive; we need to be an example to our patients. ■

This article is the sole responsibility of its author and does not represent any view or opinions of WellStar Health System.



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The History of Afterlife

By Boyd Eaton, M.D.

Traditional religions offer well-defined expectations about death and afterlife – salvation, paradise, hell and reincarnation. In contrast, an increasing number of contemporary thinkers maintain that existence after death, if any, is beyond human comprehension and that specific, faith-based assumptions regarding its nature are chimeras.

Of course, the existence of an afterlife in some form is not amenable to disproof, so there can be no dogmatism one way or the other regarding this issue. However, like Deists, many current intellectuals tend to be doubters. This article surveys the status of the afterlife concept now and throughout past human experience.

A Long, Long Time Ago

So what did the early, behaviorally modern humans from 50,000 years ago believe about the afterlife? The spectacular cave and rock wall paintings found in Europe, Africa and Australia strongly suggest that Late Paleolithic humans were

nature worshippers and that animals were of great importance in their lives. However, for insights into beliefs about afterlife, interviews with recent foragers have been the most instructive sources of information. Most scholars maintain that foragers studied in the last century were the best available, if imperfect, analogues for Stone Agers living 50,000 to 10,000 years ago.

Between 1870 and 1884, Kabbo, a San Bushman forager, told amateur anthropologists Lucy Lloyd and Wilhelm Bleek of San beliefs concerning afterlife: When people die, they become spirits who go into a great hole in the ground where they enter a subterranean realm inhabited by monsters and “angry things.”

San views on what happens after death resemble those of many other hunter-gatherers. The Tlingit of the Northwest Pacific coast believed the souls of the dead enter a spirit world and dwell near the heat of a great bonfire in the house of that world. When an Australian Aborigine dies, the soul rejoins the spirit world, the “Dreaming.” The essence of each person

exists eternally, both before and after life in the Dreamtime as “...our ancestors who are always with us.”

Many hunter-gatherers had little or no conception of an afterlife. Anthropologists James Woodburn, who studies the Hadza of Tanzania, and Kim Hill, who works with the Aché of Paraguay, agree that neither group exhibits any clear evidence of belief in life after death. Typically, hunter-gatherers are “immediate return” societies – they consume their food within a day or two of obtaining it. They make relatively little provision for future needs, trusting that their well-honed subsistence skills will take care of tomorrow.

It may be that this form of social organization, which focuses on the present, makes the group less likely to develop religious beliefs regarding an afterlife. Elaborate formulations regarding life after death are more a hallmark of the “delayed return” cultures that appeared after the emergence of agriculture.

In any event, belief in a paradisiacal afterlife affording mansions, virgins and similar unaccustomed benefits was rare (more likely unknown) and “recent” if the broad spectrum of societies extant during the past 10,000 years be considered. (Let alone the entire 50,000+ year span of behaviorally modern human existence.)

Neither Australian Aborigine hunter-gatherers nor Brazilian Kalapalo horticulturists harbor any notion of rewards and punishments in an afterlife.

Streets of Gold

Sometime before 600 B.C., Zoroaster, the ancient Persian prophet, composed his five gathas — scriptural poems or hymns that proclaimed monotheism. (Around 1335 B.C., Akhenaten had attempted to introduce monotheism in Egypt, but his beliefs were discredited, abandoned and forgotten shortly after his death.) Zoroaster also described paradise, “the luminous mansions of the sky” as an abode that awaited the souls of the blessed – individuals who had lived rightly during their earthly existence. Persons whose deeds during life merited reward were to be resurrected in physical bodies both immortal and eternally youthful. Zoroaster’s teaching appears to be the first description of what is now called heaven.

The earliest Tanakh (Old Testament) texts say little or nothing regarding an afterlife. However, the Judean captivity in Babylon (597-538 B.C.) was a watershed moment that produced major cultural changes: a new calendar was adopted, and the original alphabet morphed into the classic Hebrew script. Because the Temple had been destroyed, the Torah became the bedrock foundation of ongoing Judaism. Even after the Persians conquered Babylon, allowed the exiles to return home and largely financed the Temple’s reconstruction, many Jews remained (by choice) in Mesopotamia while others

took up residence in Egypt. Scholars consider this period the Diaspora’s beginning, and these changes, taken altogether, have been characterized as transforming the Hebrews into the Jews.

While in Babylon and throughout the 200 years Judea was under Persian control (537- 332 B.C.), Jews were commonly in contact with Persians who practiced Zoroastrianism. It was during this phase of Jewish experience that such concepts as an immortal soul and resurrection make their first Biblical appearance. Before this cultural interaction, the Hebrews believed that after death the soul went to a dark, subterranean region they called Sheol. It abided there for a brief time, then faded completely from existence. No distinction was made between the just and the unjust –afterlife was the same for all.

This belief was similar to that of other ancient Semites. These groups, including Akkadians, Chaldeans, Ugarites, Canaanites and others, practiced what may be termed a “this world” religion with no concept of salvation. Psalm 6:5 expresses the original Hebrew view: “...in death there is

no remembrance of you (God): in Sheol who will give you (God) praise?”

In contrast, Zoroastrianism held that after death, individual souls are judged and their subsequent fate determined by

the balance of good and evil deeds, thoughts and words during their earthly existence. Such views gradually diffused into Jewish consciousness and became prominent during the Hellenistic period (332- 164 B.C.) when Judea was under Seleucid (Syrian-Greek) rule. Between 175 and 164 B.C.,

Antiochus IV attempted to accelerate Hellenization. He installed his own puppet as High Priest, pillaged the Temple, had altars to Greek gods erected in the Temple at which animals unclean by Jewish law were sacrificed, and banned Jewish religious practices including Temple sacrifices, Sabbath celebration and circumcision. It was during this time of national tribulation that the Book of Daniel was composed. It is the earliest Biblical text to speak clearly and unequivocally about the resurrection of the dead. Daniel 12:2: “Multitudes who sleep in the dust of the earth will awake: some to everlasting life, others to shame and everlasting contempt.” *Time* magazine (Aug. 12, 2002) called this assertion, “...an act of incredible theologicalchutzpah.”

Christianity and Islam, both derivatives of Judaism, adopted and greatly emphasized immortality of the soul, ongoing consciousness and personal identity, ultimate judgment and an afterlife that could be either heavenly or hellish depending upon one’s behavior during life on Earth. Each made these central elements of their faith. Such features were immensely attractive to the downtrodden masses whose belief in a delightful postmortem existence helped them endure the

Zoroaster described paradise as “luminous mansions of the sky” that awaited souls of the blessed

misery of their mortal circumstances, promising Paradise if they followed Biblical or Qur’anic precepts about how to conduct their lives.

This arrangement also appealed to the ruling classes, who promptly assumed the role of interpreting, judging and enforcing adherence to scriptural injunctions. Paul’s epistle to the Romans (13:1,2) “Let every person be subject to the governing bodies for ... those authorities that exist have been instituted by God. Therefore whoever resists authority resists what God has appointed, and those who resist will incur judgment,” was especially well received by aristocrats. Similarly, I Peter 2:18, “Slaves, accept the authority of your masters ...” was a precept popular with slave owners. It is these aspects of the salvation (and damnation) doctrine that lead former Episcopal bishop John Shelby Spong to argue that, “It is unproductive to construe the idea of reward/punishment in afterlife as a way to compensate for injustice in this.” Theologian Marcus Borg concurs, “Christianity’s ... emphasis on an afterlife [is one of its] worst contributions to religion.”

The salvation doctrine (and its counterpart, damnation) addressed multiple human emotions:

Mourning – reunion with deceased loved ones.

Fear of the unknown – what happens after death?

Envy of this world’s elites – those saved were to have their own mansions and streets of gold.


Desire for revenge – most elites would be cast into the fires of hell. (Think: the rich, heaven, a camel and the eye of a needle [Matthew 19:23-4]).

Salvation also appealed on a higher, less self-centered plane. For this period’s destitute majority, life seemed pointless, painful and unfulfilling – devoid of goodness, truth and beauty. Hence the concept of salvation, a new beginning on a level playing field, meant more than just material comforts. It offered validation, justification and celebration of existence’s potential. At the subconscious level, it offered a return to the mental ideal –

genetically established in the remote past – of what life should be like.

The Afterlife in Other Cultures

Is belief in afterlife essential, a necessary constituent for religious validity? Followers of Christianity (33 percent) and Islam (21 percent) now constitute a majority of the world’s population, so it is natural to assume that their shared emphasis on immortality, judgment and life after death (with contrasting celestial or infernal consequences for an individual’s ongoing, conscious personality) are intrinsic aspects of human spirituality. This is decidedly not



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so – not historically, numerically, conceptually nor in the broad sense theologically.

Certain allegiance religions did provide visions of an afterlife. Egyptian Pharaohs could look forward to joining the realm of the Gods, while those lower down the social scale would continue their earthly roles and the pursuits of their mortal existence in a perfected postmortem Egypt. Valhalla was reserved for warrior heroes who while there prepared to aid Odin in his ultimate battle against the forces of evil – Ragnarok. However, these beliefs were exceptions, not the rule.

Hunter-gatherer afterlife beliefs recorded by anthropologists in various parts of the world – and which may be considered broadly representative of what ancestral humans thought regarding post-mortem existence – did not entail a paradisiacal prospect similar to what Zoroastrianism introduced and which is now a defining aspect of both Christianity and Islam. Spiritual and physical pleasures - lofty mansions, delicious food and drink, golden streets (and, for deserving Moslem males, virginal houris) constitute an enticing prospect. However, our Stone Age predecessors were too grounded in reality to anticipate any such unlikely post-mortem delights. They were intimately familiar with the natural world's cycle of life and death, and this inescapable, morally acceptable emersion in biological reality made it unnecessary to fabricate a future world too good to be true.

Devout Hindus and Buddhists believe reincarnation in human (or other) form proceeds in an endless cycle. One's actions in life determine the nature of being into which the soul transmigrates, but, in each incarnation, there is no conscious recollection (nor detailed anticipation) of existence in prior or future life. When the soul finally exists in a person whose actions and thoughts are so exemplary that they merit release, Hindus become united with the Supreme and Universal Soul, thereby losing their individual nature and consciousness. Exemplary Buddhists achieve Nirvana, the perfect peaceful nothingness that accompanies the end of identity.

Both Confucius and Lao Tzu held that the existence of afterlife, if any, was beyond understanding, and that humans should conduct their earthly lives so as to optimize social amity, not in expectation of reward or punishment in an afterlife. For them, death was merely the transformation from being to non-being, to be neither feared nor desired.

The ancient Romans believed that souls of the dead drank water from the river Lethe, which produced complete forgetfulness of one's prior life. Existence continued, but the surviving entity would be only a shade with no memory of worldly experience.

Classical Greeks pictured the underworld, ruled by Hades (Zeus's younger brother), as neither a place of ecstasy nor of torture, Open to all, it resembled a troubled dream, full of misty, gloomy shadows and without sunlight or hope – a

joyless abode where the soul fades slowly into nothingness. In Homer's *Odyssey* (11:488-91) Achilles' shade speaks to visiting, still mortal, Odysseus:

**“O shining Odysseus, never try to console me for dying
I would rather follow the plow as thrall to another man,
one with no land allotted to him and not much to live on,
than be a king over all the perished dead.”**

In the Sumerian epic of Gilgamesh, the underworld is a wretched place where dead mortals exist in darkness and dust, an existence bleak as that in Hades.

Bishop Spong argues that through death, life is interconnected, illuminated and transformed from the mere present to the eternal. Li Po, Saladin, Jeanne d'Arc, Lincoln and Mother Teresa live on, not as metaphysical entities, but as memories respected, recalled and revered by the many generations who have succeeded their earthly existence. Similarly, the grandmother who read nursery tales and soothed the fears of her grandchildren lives in their enduring love and memories. There she remains more real than as pictured in an illusory golden mansion.

Dietrich Bonhoeffer expressed the same sentiment; for him the memory of someone dear to us preserves an authentic relationship, a connectedness, “...a precious gift deep within, a hidden treasure of which one can always be certain.” Today's secular humanists do not exclude the possibility of afterlife because the concept can neither be substantiated nor refuted. However, the more educated, sophisticated segments of society across the world are increasingly aligned with the views of Spong and Bonhoeffer rather than with those of Calvin or St. Paul.

Each of us comes to her or his own conclusions about afterlife; thoughts on this subject are natural for humans everywhere. Our ethnic culture, our specific faith tradition and our exposure to educational influences all affect our ultimate persuasion. No single opinion can be called “right” or “wrong.” It is helpful, however, to appreciate the perceptions of others because the range of beliefs is broad. No matter what one's final conclusion, both past and present provide examples showing that others – somewhere, sometime – have come to similar convictions. No one is alone. ■

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Pediatric Hospice

By Laura Waddle, M.D.

“We found a mass in her liver... it looks like metastatic cancer.”

As a pediatric resident, I received this call one night from a radiologist regarding a two-year-old patient our team had admitted earlier that day with a limp and refusal to bear weight. It was her second trip to the emergency department in a few days.

The first time the plain films of her hips and legs hadn't shown anything concerning, so she was sent home to continue supportive care. When she returned still refusing to walk, she was admitted for further workup and imaging. The radiologist told me they had found a fracture in her femur, which made sense to me. But he said it also looked like she had a “lesion” at the site of the fracture. He explained that based on the abnormality, they had continued the scans upwards to include her abdomen and had found what looked like a large tumor in her liver.

The likelihood that this small child had a pathologic fracture of her femur secondary to a metastatic cancer was something that none of us had seriously considered while admitting her. A call like this can be surprising even in an adult patient, but in a two-year-old child who, as far as any of us knew, was healthy, this was shocking.

The mom and grandmother were waiting for me in her room to find out the results of the scan. I don't remember

how I went about breaking this news, although I suspect it did not follow the “breaking bad news” protocols I now know so well. I only remember that I sat down to talk, watching this little girl sleeping peacefully, knowing I needed to actually say the word “cancer” no matter how much I didn't want to say this scary word that would change their lives forever. When I told the mom and grandmother that the scans were very concerning for cancer, I will never forget the grandmother looking at me and saying, disbelieving, “Children can get cancer?”

Children can get cancer. And so many other things that can limit their lives, although do not limit the meaning or impact of their lives. It isn't fair, and it doesn't make sense. But statistically, more than 50,000 children from birth through age 19 die in the United States each year. The majority of these deaths occur in infants from birth to age one year, with most of these deaths occurring in the first week of life. Pediatric hospice programs seek to reach out to these children and families, sometimes even before birth in prenatally diagnosed disease, to help prepare for whatever comes next, whether it is better or worse than expected.

As it turns out, realistic expectations for our children are incredibly difficult to determine. As important as it is making decisions and planning for the future, prognostication is complicated in children. Death in childhood is a relatively rare occurrence in this country, thank goodness, and the

syndromes, congenital abnormalities and diseases from which children die are often rare. When we are dealing with diseases whose known population is in the hundreds worldwide — if even that — we make our best guess based on trajectory, available treatment options and family’s goals and go from there.

Even when we are involved prenatally with a family expecting a baby with a genetic diagnosis of Trisomy 18 or Trisomy 13, relatively “common” diagnoses on our team, the range we see prognostically is wide. We generally don’t know what to expect until the baby is born. Some of these babies die within a day of birth and never get to go home, while others thrive despite limitations and are discharged from our service after more than a year. While our expectations for quantity of life are often uncertain, our expectations for quality of life in hospice are clear.

How does pediatric hospice differ from adult hospice? In practicing both, I find that while there are some important differences, there are more similarities. A prognosis of six months or less if the disease takes its normal course still applies for pediatric hospice eligibility. Determining the goals of care is vital, as these goals drive the plan. We still focus on impeccable symptom management and provide support for the entire family unit, including two years of bereavement support. Pediatric hospice teams include nurses, social workers, chaplains and physicians, all ideally with special training in pediatrics.

However, as any pediatrician will tell you, children are not just small adults and pediatric hospice is punctuated by many aspects that also make it unique. Pediatric hospice covers children from birth (and even prenatally in some programs) until age 21. In some cases, we serve children beyond the age of 21 who have chronic conditions of childhood that are mostly managed by pediatricians.



Children develop and process the world surrounding them vastly differently as they age. The five year old and the 15 year old on our team will understand their disease and prognosis at different levels and need different things than patients of a similar age difference on the adult side. The four-year-old child who asks “What happens when I die?” may be asking for very different information and for different reasons than the 12 year old or 20 year old who asks the exact same question. It is the pediatric team’s job to determine what answers the child is really seeking, and let them continue to guide the conversation.

Similarly, the child’s ability to be meaningfully involved in determining the course of their care is greatly influenced by their developmental stage. But what does this mean legally and ethically in the pediatric population? The 13 year old may have much more ability to make informed decisions about what care they do and do not want than a 5 year old, but no more legal right.

These gray areas of autonomy exist in adult medicine as well, but they are further complicated



in pediatrics. What should happen when the child wants one thing and the parents want another? In addition, many of our patients have two legal decision makers, their parents, who do not always agree on what they feel is best for their child. Not to mention there are a great number of subspecialists who typically remain very involved in the child's care throughout the course of their disease.

Beyond these more philosophical concerns, there are other practical differences between adult and pediatric hospice. In pediatrics there are few long-term care facilities available, and this is typically not an option families seek out. Also, many pediatric patients and their families have spent so much time in their hospital that it is a second home to them. Often they feel more comfortable and safe there than their own home. Dying at home is not, therefore, always preferred by parents or children as it is for most of our adult patients. We are also more likely to utilize medical technologies such as feeding tubes, home ventilators, tracheostomies, ports and other equipment in our pediatric patients.

The use of such artificial "life-sustaining" technology may seem at odds with traditional hospice philosophy. And until recently, parents and guardians have faced deciding between pursuing curative-intent treatment for their child's underlying disease, or receiving hospice services while foregoing further disease-modifying therapy.

In 2010, President Obama signed the "Patient Protection and Affordable Care Act," which changed this. This act, which is also referred to as "Concurrent Care for Children," requires all state Medicaid programs to pay for curative treatment of the underlying disease as well as hospice services for children ages 21 and younger who qualify. Although it doesn't fix everything, this law reduces a significant barrier to pediatric hospice services and opens up this resource to many more families.

The family of my two year old with newly diagnosed metastatic liver cancer met with many specialists and learned about her treatment options, limited as they were. There was no possibility of a cure. In the end, after much soul searching, they took her home with hospice.

Pediatric hospice is about working aggressively for the best quality of life – however a family defines this for their child. It isn't that families who choose hospice are "giving up" – it is that their goals are to do whatever it takes to give their children good, comfortable days. They pursue time to make family memories, to cuddle, to live, to laugh, and yes, to cry.

At some point, the hospitalizations and tests won't change the likely outcome for their child, but they do take up the time and space that may be used to create other memories. Hospice is about living in the moment and enjoying today. Our team has helped to arrange all sorts of things for patients and their families to remember – a first-ever family vacation to the beach, a trip to Hawaii, even a trip out of state on

continuous life-sustaining IV medications for a patient who wants to visit friends.

And in between all the big celebrations, we celebrate the little things. We celebrate birthdays, even if they aren't at the one-year mark. We celebrate a walk outside in the sun, a baby taking a bottle, siblings all curled up on the same bed together. On a journey that can be so isolating, our team seeks first and foremost to be present with families and to walk with them. We may not have the power to cure, but for today we can be present. ■



Laura Waddle, M.D. completed her fellowship training in Hospice and Palliative Care at Emory University. Prior to her fellowship, she did a combined residency in internal medicine and pediatrics. She serves as the pediatric hospice medical director for the dedicated pediatric team at Visiting Nurse Health System. In addition, she works as a palliative care physician at the Atlanta VA caring for veterans and teaching medical students and residents about palliative care and hospice.



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Conversations Matter

By Alison E. Krause, M.D., M.A., FAAHPM

Everyone dies. Despite all our medical efforts to avoid this reality, there comes a time when medicine cannot cure. A widely held assumption is that the more treatments patients receive, the better their healthcare. Unfortunately, studies have shown that this theory is incorrect. In advanced illnesses, aggressive medical treatments are commonly associated with poorer quality of life and little or no extension of life.¹

There are a few predictable patterns for the trajectories of serious illness. In an article published by the Journal of the American Medical Association (JAMA), four distinct trajectories of dying were presented.² Dementia is typical of a prolonged illness with a slow decline. Metastatic cancer is an illness that usually results in a sharp decline. Heart failure and chronic pulmonary disease have intermittent dips without a full recovery to baseline until death. Finally, a small percent of patients die suddenly and unexpectedly.

Whatever the trajectory, our entire society – doctors, patients and families – are not handling the end of life well. So how can we help our patients when they approach the end of their life?

Palliative Medicine

I practice palliative medicine, a specialty of medicine that focuses on reducing symptoms, managing pain and addressing goals of care. Although it is sometimes mistakenly considered synonymous with hospice care, palliative care is appropriate for patients with chronic illnesses at a variety of disease stages, including, but not limited to, end of life.

A landmark study published in *The New England Journal of Medicine* in 2010 involved patients with metastatic lung cancer.³ It showed that those who had received early palliative

care had less aggressive care at the end of life, but lived nearly three months longer (12 months vs. nine months) than those who had received standard cancer treatment. The quality of life and rates of depression for those in the palliative-care program were also significantly better. It makes sense that if palliative care treats pain and other symptoms, as well as supports their emotional and spiritual concerns, people with advanced cancer will feel a bit better and survive longer.

Communication

My training included how to have conversations with patients and families regarding their end of life goals. These conversations matter. Most of us want to die at home, but, unfortunately, the majority will die in hospitals. Having these difficult conversations improves the chances that patients will not be burdened with futile and extraordinary treatments at the end of life. When communication fails, everyone suffers. Most people already know the reality and truth when it comes to the end of their life. My experience has been that it takes only a short conversation for patients, families and clinicians to acknowledge “the elephant in the middle of the room” and make the tough decisions.

Yet, we avoid talking about dying as if the discussion itself will make death more likely.

Why?

Most doctors have not been trained to have these conversations, and that makes us feel uncomfortable. We don’t want to give bad news because we don’t want to strip our patients of hope. It’s easier to avoid the conversation and focus on aggressive medical treatments. Most patients want us to be honest. Instead of saying ‘Let’s try another round of chemotherapy,’ patients may want us to sit down, listen and

help them cope with the reality of their situation with an honest conversation. Most patients want the honest truth.

Models for Difficult Conversations

End-of-life discussions have always been a part of practicing good medicine. There are three common scenarios for having these conversations, ⁽¹⁾ those that are held when patients are diagnosed with a chronic illness, ⁽²⁾ those that occur as an illness progresses, often when a patient is hospitalized, and ⁽³⁾ those that occur emergently.

What constitutes a discussion of end-of-life care? Ideally, these conversations will occur over time as an outpatient before it's too late. When one is initially diagnosed with having a chronic, life-limiting illness, such as dementia, congestive heart failure, COPD or cancer, a discussion about disease trajectory is appropriate in small amounts over time. Most of us want to be in control of our lives, and this is the appropriate time to bring up an advance directive.

Conversations should focus on the difficulties a patient may face given the illnesses with which they are coping, the decisions that they would make in specific situations and who they would like to appoint as their health care power of attorney. These decisions are a gift to family members, who are often asked to make critical choices for their loved one.

As an illness progresses, the focus should be on goals and outcomes. It's our job to discover our patient's goals and provide advice to help make them happen. During any discussion, it's always helpful to understand a little about the patient's experience, values and goals, and then frame the information about options based on that information. Ask the patient what's important to them. If there were a choice, would they prefer to die at home or in a hospital? How would they want to be treated when their illness becomes terminal? Who would they want to appoint as their health care advocate to speak on their behalf if they were unable?

During these conversations, it's appropriate to ask a patient what they understand about their illness and how much information they'd like to know. Some people want all the details, while others want very little. After eliciting this information, tell them honestly what choices are in their future. If a patient has early dementia, it's appropriate to discuss their wishes regarding placement of a feeding tube when they will likely fail to thrive or develop dysphagia. In other cases, as patients decline from congestive heart failure or COPD and are frequently admitted to the hospital, it's appropriate to bring up the option of hospice with no plans for further readmissions. Often, patients and families don't know of any other option other than admission to the hospital.

An example of an emergent conversation might be a terminally ill cancer patient who is in the Emergency Department in respiratory distress. The patient and family need to decide whether to intubate or to shift the goals of care to comfort. Think through the words you'll use during the conversation and realize that how you frame the prognosis or present the proposed intervention may influence a person's decision.

In the above example, give permission for the patient and family to make a decision for comfort measures, which may be more medically appropriate. It's important in these conversations to explain what comfort measures are, that they are medical care and that there will be no suffering. Suffering is the one thing that both patients and families fear, and this fear may influence their decision.

The same goes for code status. If you know that the likely outcome of a code would be death, then the words we use are important. Keeping the patient comfortable and allowing a natural death are gentler ways of saying 'do not resuscitate.' Just because we can do something doesn't mean we have to do it.

Families suffer when asked to make difficult decisions for a loved one. Initiating these conversations with the patient early in the disease process provides important information regarding what someone values and the choices they would make if capable. If you are uncomfortable with having these conversations, that's when consulting a palliative care specialist can help.

We only die once.⁴ Most of us would not choose to suffer in our final days. We have the opportunity to help make this happen by openly and honestly communicating. Let's not take the "easy" way out by avoiding these difficult discussions and focusing only on treatments. What would it be like if doctors routinely had effective end-of-life conversations and met our patients on a personal level?

Let's not lose a wonderful opportunity to help our patients by communicating. It gives our patients the opportunity to achieve what is most important to them ... time with their family, time to say "goodbye" and to say "I love you." ■

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Personal Stories to Personal Video

Video Backup for Advance Directive

By Dirk E. Huttenbach, M.D.

My mother, Berte Huttenbach, died on June 6, 1992, at home, in her own bed. She had a massive stroke. She was 82 years of age. I was her healthcare agent, appointed by her, many years before.

She died in Springfield, Penn, outside Philadelphia. I live in Sandy Springs, Ga. My sister lives in Germany. My mother had been in failing health following a minor stroke nine months earlier, in September 1991. She had a live-in caretaker, a good Christian lady, for those nine months, who looked after her very well.

Time and time again, my mother had reminded me that in the event of her having a major cardiac event or a major stroke, she absolutely did not want to go to a hospital or a nursing home. She reminded me. She badgered me. Constantly. She badgered her personal physician, too.

On June 6, 1992, around 10:00 a.m., after reading her morning newspaper, she had a major stroke. She was unconscious and could not speak. Her right side was paralyzed.

Her caregiver informed me by telephone. With a clear conscience, I could instruct her caretaker to move my mother from her living room chair to her bed in her bedroom. I told her caretaker to keep my mother comfortable. I would fly to Philadelphia as soon as possible and make further decisions.

My mother died before I made it to her house. She died in her own bed, in her own home, able to look at pictures of her loved ones placed all around her.

I was very grateful that she was able to die in peace, in comfortable, familiar surroundings, with a compassionate and competent caretaker looking after her.

My mother and I had already said goodbye a number of times before. My sister and I had discussed this possible scenario many times already. My sister and I were in full



Berte Huttenbach 1909 - 1992

agreement in regards to this choice. I have heard, seen and experienced many other situations, however, where the end of life did not play out so well.

During my junior medical school clerkship at the Syracuse, NY Veterans Administration Hospital 50 years ago, I was assigned to look after an aging U.S. World War I veteran. I was only 25 years old at the time. I was to follow my patient's progress over six weeks. He was chronically ill, but mentally alert. He strongly told me two or three times: 'Don't have me become a vegetable like so many of these

other fellows on our unit!” I agreed. What else could I say? What did I know?

Two weeks later, while making ward rounds with the attending resident, I noticed that my patient had stopped breathing. I rushed over. I checked his heartbeat: No heartbeat!

I panicked. I started pounding his chest. Lo and behold, he came back to life, except, he now was “a vegetable.” He remained in that state for the remainder of my clerkship rotation. I felt terrible. I felt I had violated his wishes. I did violate his wishes. I had to look at him daily, for four more long weeks. I am not proud of what I did.

A dear aunt of mine died in a nursing home, years later after a severe stroke. She was in her 80s. She remained in a vegetative state for the year or two following the stroke. A once vibrant, engaging, cultured woman, she became a shriveled up breathing corpse, staring into space, equipped with IV’s, a nasogastric tube, a catheter and a diaper. She no longer was able to communicate with anyone. She was unable to complain of any pain or suffering.

To my knowledge, there was no Advance Directive or Living Will. There was disagreement among immediate family members. My mother knew her well. She thought all this was terrible. My mother absolutely did not want this to happen to her. I am pleased and proud that this did not happen to her.

A time comes for all of us when we need to allow God (or Mother Nature, for non-believers) to take over. At that time, I believe medicine should shift from aggressive, futile medical care to comfort care, i.e., palliative care and/or hospice care, which is now much more available. Modern medicine can postpone death, but it cannot prevent death. Too much aggressive medicine can cause pain and suffering. Comfort care, in contrast, provides comfort.

Having an Advance Directive to express your wishes regarding End-Of-Life medical care is so important. The more people who know what you want, the more likely you will get the care that you want. It is very, very important not to leave your loved ones guessing and/or in conflict with each other over what you might or might not have wanted. A clear message from you, via a written legal Advance Directive, can make life so much better and easier for you, your loved ones, your physician(s) and your nurses.

An important part of your Advance Directive is to appoint a health care agent, who can and will speak for you when you can no longer speak for yourself. Your health care agent should be very informed regarding your wishes. He or she

needs to carry out your wishes, even if family members or medical personnel raise questions or disagree. It is therefore also very important for you to keep your immediate family, your medical doctors and your nurses well informed. You do not want significant others to disagree with your Advance Directive wishes or with your health care agent.

There are people who want their physician(s) to prolong the lives of their dying relatives as long as possible. They want the physician “to do everything.” They want to do this out of love, out of religious beliefs, but sometimes out of denial or guilt. Their hopes and wishes need to be respected, but they should also have the opportunity to hear from physicians and nurses. They need to hear that “everything in medicine” is not necessarily “the best of medicine.”

I believe that the best that medicine can offer at the end of life is comfort care, i.e., palliative and/or hospice care, as directed via one’s Advance Directive. Increasingly, I hope and believe, this is becoming the accepted standard of care. It makes for much less pain, suffering and conflict at a time that is difficult already.

Because of my own experiences, and because of hearing and reading stories from and about so many other people, patients and parents of patients, I felt a need to become more

involved, even though my regular job is being a child and adolescent psychiatrist.

I served on the Kennestone Hospital Ethics Committee for a number of years under Richard Cohen, M.D. I joined the citizen organization Compassion and Choices (C&C), which promotes comfort care at the end of life. I have served on the Board of Directors of the C&C Georgia Chapter for about eight years. Our Georgia C&C chapter’s main mission is to educate the Georgia public on the need to prepare their Advance Directive sooner, not later.

I have advocated for Patient Proposed Physician Orders (PPPO) to facilitate that initial discussion between patients and their physician(s). This idea was approved and supported by the Cobb County Medical Society and is available via the Cobb County Medical Society website at www.cobbdctors.org. I have also advocated for Advance Directives at Medical Association of Georgia House of Delegates meetings.

I now offer the opportunity for people to back up their legal written Advance Directive with a personal video recording, described more fully later in this article.

I signed my own first Advance Directive in April 2005, about a week after the death of Terry Schiavo. I had prepared it earlier but had not signed it until then. I, like many others,

An important part of your Advance Directive is to appoint a health care agent, who can and will speak for you when you can no longer speak for yourself.

procrastinated, even though I strongly believed in the cause of Advance Directives.

I recently revised my Advance Directive to have it conform to the State of Georgia recommended Advance Directive format, created by the Georgia Legislature in 2007 as part of HB-24. This was beautiful, much-needed bipartisan legislation sponsored by Representatives Steve “Thunder” Tumlin (38th District), Mike Keown (173rd District), Allen Freeman (140th District), Mary Margaret Oliver (82nd District), and Katie Dempsey (13th District), and signed by Governor Sonny Purdue. Anyone can download this model Advance Directive, fill it out, and use it for their own Advance Directive.

I gave my updated (paper) Advance Directive to my son and health care agent, Eric, 40, over Thanksgiving 2013. He prepared electronic copies, which he then emailed to me, my wife, his brother and his two sisters. He pointed out that having my Advance Directive in electronic form makes it available on his smartphone. This way, he told me, he can access my Advance Directive anytime he wants to or needs to. I thought that was very smart. It makes my Advance Directive much more available to those who need to know.

How do you keep your loved ones well informed?

1. Talk to them. Talk to them repeatedly about your wishes. Have that conversation. My mother did so. I have done so with my wife, my children and my personal physician.

2. Prepare your own legal written Advance Directive, which includes appointing your health care agent. It is wise to appoint a back-up health care agent. Give a copy of your Advance Directive to your health care agent. Give copies to your immediate family, other loved ones, as well as your personal physician. Do it or have it done electronically also. Give it to anyone who should be informed about you. Hospitals are now starting to keep that kind of information in their records regarding you, which is very good.

Review your Advance Directive, preferably every five years. Your circumstances and/or preferences may change over time.

3. To express your views even more strongly and clearly, you can have a digital video recording made of you discussing your Advance Directive with a knowledgeable professional, such as myself. The idea of making this available grew in my mind over the years, subsequent to my mother’s death. The idea also grew as I grew older myself. I felt it was important to have one’s expressed wishes to be as clear, as available and as people-friendly as possible.

Having an Advance Directive video backup can make it easier to have a constructive discussion with those you want to inform. “A picture is worth a thousand words.” It is also helpful to have these video comments available, in addition to your legal written Advance Directive, if you are no longer able to speak on your own. This can be very supportive to your health care agent, especially if he/she has to face people who question or disagree with your wishes.

It is good for your loved ones to hear and see your words come out of your mouth while you are still mentally competent. You will support and back up your legal written Advance Directive with your own words on your personal video. Even though your written legal Advance Directive conveys your wishes already, your wishes expressed by you on a personal video will feel more personal and may better convince those who need to know and respect your wishes.

Admittedly, a personal video makes for added expense. Obtaining the Georgia Advance Directive for Healthcare format can be done for free, via a download from www.aging.dhr.georgia.gov. A personal video is more personal, however. You can direct comments to loved ones. Video clients have done so already.

Information about the Advance Directive Personal Video is available at www.advancedirectivesvideo.com, which includes three demonstration videos. The individuals featured have graciously and joyously given consent to allow their interviews to be used to inform the public.

In conclusion, most importantly:

1. Start that conversation with your loved ones and your physician.
2. Prepare your written legal Advance Directive. Do it sooner rather than later. Do not wait until it is too late.
3. Be nice to yourself, your loved ones, your physician and your nurses. Do not leave them guessing at a time when they need to know what you want. Make yourself as clear as possible.



Dirk E. Huttenbach, M.D., DLFAPA, lives in Sandy Springs and has been in private psychiatric practice in Cobb County since 1972. He is Board Certified in general and child psychiatry. He belongs to the Cobb County Medical Society, MAG, AMA, APA and the Georgia Psychiatric Physicians' Association (GPPA). He is

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Death is a Certainty: What Will You Leave Behind?

By Dick Yarbrough

There are only three things certain in this world: Death, taxes and a robocall offering you a great deal on a timeshare in Colorado just as you sit down to dinner. (Okay, I made the last one up because we would rather talk about that kind of thing than we would facing up to death and taxes.)

Death is democratic. It will get us all no matter what our standing, and as smart as we are, we can't be certain when our time is coming. But we can be certain that we have made things as easy for those we left behind as possible, and that includes being sure they have to pay as little taxes as possible.

I recently sat through a thorough review of my Last Will and Testament with my wife and adult children. It is not the most fun thing I have done, but it was one of the most important. I encouraged questions, comments and suggestions from my family. We talked about Durable

Power of Attorney and burial vs. cremation. We covered all the bases. When I am gone, I don't want there to be any questions about "Dad meant this" or "Dad wanted it handle this way." Speak now or forever hold your peace. If you have been through a similar exercise, good for you. If not, I would suggest you do so sooner rather than later.

It was a surreal and sobering experience, listening to our attorney read out loud the words that will be attributed to me when I am no longer here to speak them for myself. Alas, I sound a lot more articulate in my will than I do in my columns.

Much of what will be said in my name when I am gone is as foreign to me as Swahili slang. It is designed to satisfy the legal hoops one must jump through in order to leave one's heirs what one rightfully worked one's buns off to earn.

I love my country and the great state of Georgia, but I don't love them enough to give them one penny they don't deserve. They certainly didn't earn it. I did.

During my career, the government seemed to take great delight in making it difficult for me to do my job because of burdensome laws and weird regulations. If the politicians and bureaucrats got their hands on my money posthumously, they would probably spend it trying to create more burdensome laws and weird regulations.

As I listened to the therefores and wherefores, I suddenly had a staggering sense of my own mortality. I realized that I have lived more days than I have ahead of me. I am not just in the September of my years; I am



edging towards the first week of December. Fortunately, I've got the financial part – such as it is – figured out, but what about the rest of it?

I don't normally do business with friends, because that is a sure way to lose a friend. My one exception has been my attorney. Not only has he hectored me into getting my will updated, but he has given me some additional food for thought that I pass along based on his experiences in estate planning.

First, we tend to spend more time getting our financial house in order than we do in deciding who gets what in our physical house when we are gone. Some of the biggest disputes he has seen didn't involve dollars; it was who got momma's diamond ring or the family china or dad's pocket watch.

His advice: Make a list of those personal items you want to leave to someone. If possible, tell them ahead of time. No surprises. Even better, ask for preferences. My attorney has seen heretofore loving families end up in court suing each other over what would have been consider trivialities in an earlier time. ("Your kids never love each other as much as you think they do," he says.)

Even more important than the money and the family china is the legacy we leave behind. I attended the funeral recently of a 91-year-old friend. Our church was filled to overflowing by those of us wanting to pay tribute to this good man. He was a successful executive with a *Fortune 500* company, but his career was scarcely mentioned during the memorial service. Rather, everyone talked about his innate kindness; how he made everyone feel special, no matter their station; how his smile lit up a room when he walked in.

I sat and wondered what would be said about me, assuming I could get up enough of a crowd to listen. My mentor, the late Jasper Dorsey, who was vice president of Southern Bell Telephone Company, taught me a lot about being a manager, but he taught me also about life, including the obligation we have to leave this a better world than we found it. I haven't always done that.

In my younger days, I knew that I could always clean up tomorrow what I messed up today. Today, I can't be sure there will be another tomorrow. I have only this day to try my best to be my best. Sometimes, my best won't be very good, but it should not be from a lack of trying.

Billy Payne, chairman of the Augusta National Golf Club, is one of the special people to pass through my life. He was the visionary who had the idea to bring the Olympic Games to Atlanta. A lot of people scoffed at that idea, including me. That was before I got to know him. The man walks his talk. Working with him during the 1996 Centennial Olympic Games was a great experience and a lesson in the pursuit of excellence.

Payne was a scholar-athlete at the University of Georgia when that term meant something. He was an "A" student and never played in a football game for UGA in which he didn't start. Watching him perform each week was his father, Porter Payne, himself an outstanding football player for the Bulldogs in the mid-'40s and good enough to be drafted by the New York Giants.

Billy tells of talking with his father after each game and asking his dad to assess how well he had played that day. Porter Payne's answer was always the same, "It doesn't matter what I think. The question is what do you think? Did you do the best you could do?" The younger Payne would have to admit that perhaps he could have done something a little better and would vow the next week to improve.

Every week, the same conversation between father and son, the same answer and the same resolve to do better in the next game. His father didn't have to push Billy Payne to be the best he could be. He was teaching his son to do it himself.

Maybe this is a good time for us to look in the mirror and ask ourselves if we have done the best we can do today. Have we made the effort? Or will we put things off until tomorrow while we strain at gnats today? I now know that tomorrow may never come. This is the only day guaranteed to us. It is a precious gift. Don't waste it.

We've got a lot to do before death comes knocking on our door. Be sure you are up-to-the-minute with your estate planning. Our intrepid public servants in Washington and Atlanta have a way of changing the rules on us when we least expect it. That is why you need a good estate attorney to keep up with those changes. I check my will yearly for updates.

Also remember to take the time to make a list of personal items and who gets what. That is a more important task than we sometimes realize. Little things mean a lot.

Finally, and most importantly, remember that your ultimate legacy won't be defined by your net worth but whether or not this is a better world because you passed through it. I don't know about you, but I am still a work in progress. ■



Dick Yarbrough is the most widely syndicated newspaper columnist in Georgia. He is also a retired vice president of BellSouth Corporation and was a managing director of the 1996 Centennial Olympic Games.

A Lucky Curmudgeon

By Sheldon B. Cohen, MD

I have been a fortunate man, in both my personal and professional lives. By all rights, this should have been written by my beloved wife of 54, very, very short, years. Unfortunately, she died much, much too young, but left me a rich legacy of warm memories. One of Dot's many talents was her exquisite ability to understand and work with people. Our practices were intertwined, and though, I was the senior with more academic credits, she taught me so much about life. As part of her inherent leadership, she helped guide Visiting Nurse and Hospice Atlanta for many years, often being the "go to" person for people in the organization and those who sought comfort.

It is said that it takes a village to raise a child, but I have learned that it takes an entire country to sustain an aging, bereft octogenarian. Fortunately, many people have come to my rescue: first and foremost, my three loving, supportive children, Andrea, Bruce, and Steve; friends, old and new, have been there when I needed them; professional colleagues have pitched in; and my patients have been most understanding. One of the cornerstones of my practice has been to try to help patients realize their potentials, but I also find that in every therapeutic session with patients, I learn something.

I find myself attempting to prepare for the final voyage, which leads I know not where or when, with the best

preparations that one can make. I prepared my Durable Power of Attorney for Health Matters while Dot was still alive, and it befalls my children to see that my wishes are carried out. To make them even clearer, I enlisted the aid of my colleague, Dirk Huttenbach, who

describes, in detail in another article, the marvelous device that he has developed that allows me to put my thoughts in live video, which can be seen by those who need it at the appropriate time.

In my psychiatric practice, I query each patient about their own Durable Power of Attorney for Health Matters. Some have made good preparations; others have one "somewhere." I emphasize that it is not helpful to have it sitting in an attorney's office, a safe deposit box, but that all of those significantly involved in their lives (life partner, children, and each of their physicians) should have a copy in hand. Ironically, when I found myself rushing to go to the hospital, I could not locate my own Durable Power of Attorney. Fortunately, a call to my internist had a copy sent to the orthopedist who was revising my hip, and we all felt much better. Too often I have seen people end up in hospitals without this significant piece of paper. In that case, many physicians feel that they must do everything to keep a specter of life going. The last days are then spent sans reason, with tubes in every orifice, needles in available blood vessels, and breathing kept going by ventilation.

The country that keeps me going is filled with wonderful, diverse citizens. In my practice, I've had a succession of dedicated, able, very bright students who needed to earn a few bucks. They have been able to do many of the technical things, at which I am an inept novice. This missive is being transcribed by Melissa, who is tops. She keeps the office moving, and I've persuaded her to make her own contribution to this special issue from the standpoint of a young person whose career is at a very nascent point.

The chores of my household are borne by two people who Dot recruited long ago. My friend, Lamar, does the heavy lifting and leaves each week with an admonition to keep moving. Mary, my housekeeper, always is willing to go the extra mile to see that my wardrobe is up-to-date and that all the other chores are handled with dispatch, despite her own physical woes. Bruce found my landscaper, Billy who also

"Sunset Syndrome"

Diagnosis:

- Misplaceditis
- Did-I-do-ititis
- Slow-downitis
- Flooritis
- Don't-Fall-Downitis

checks up on my well being. I could go on and on about all of my friends and acquaintances, but suffice it to say that they know whom they are, and I just hope I have been able to properly acknowledge what they have done for me.

Just as I expect honesty from my patients (none are deliberately dishonest), many moons may go by before they reveal to me some hidden aspect of their life that they have been too uncomfortable or ashamed to talk about, even with their “shrink.” I try to be as transparent as possible about any aspect of my life that will affect them. I do not discuss irrelevant details, nor try to utilize patients as my own therapist. I have shared with them from the get-go my wife’s illness and her death, and they know that this is something that I’ve attempted to deal with.

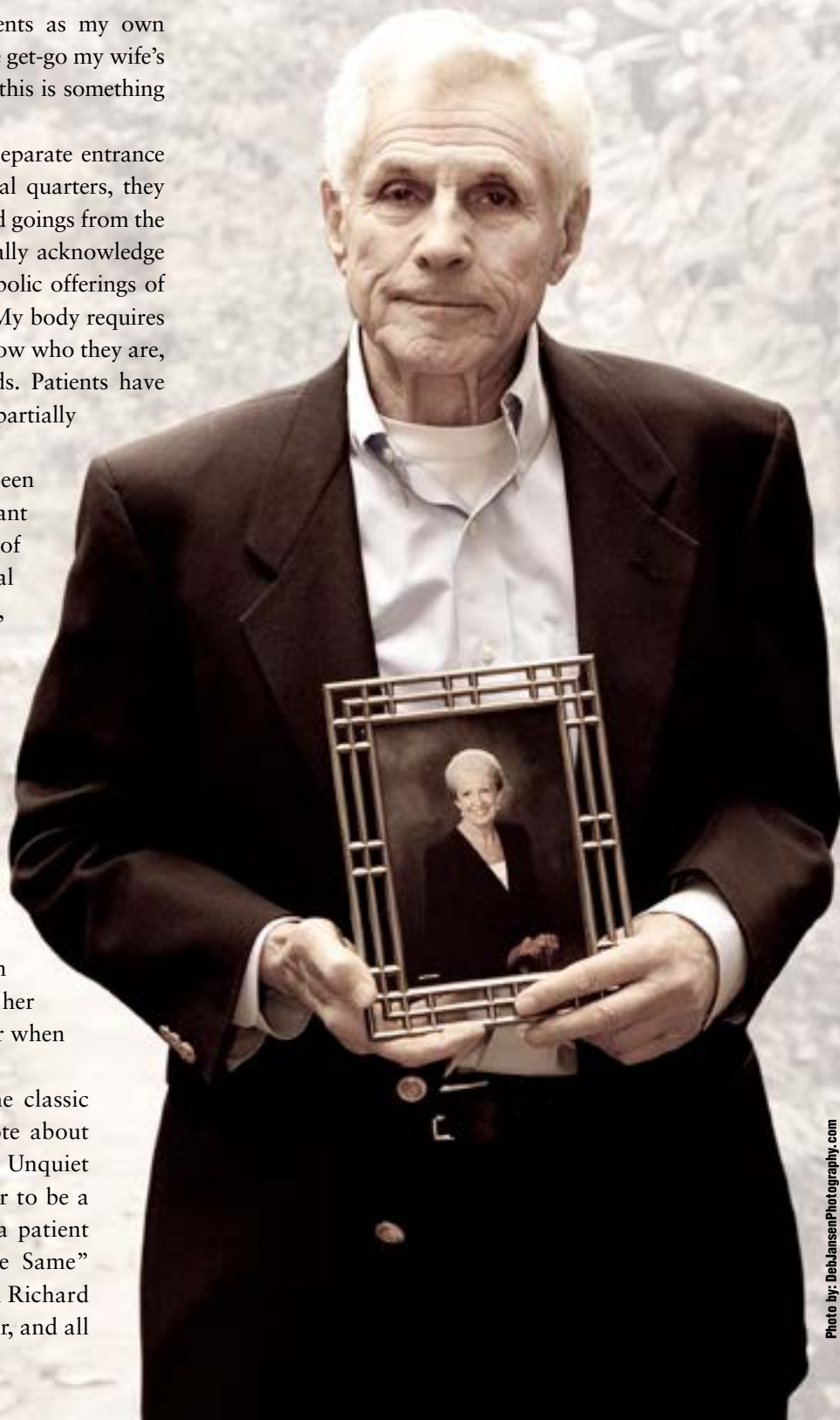
Since my office is in my home, with a separate entrance and physically separated from my personal quarters, they surmise many things about the comings and goings from the other entrance of my domicile. I continually acknowledge and thank them for their wishes and symbolic offerings of care, usually an example of culinary art. My body requires the services of a host of physicians who know who they are, some of whom have become good friends. Patients have tolerated very well the times I’ve been partially incapacitated and offer assistance.

The written word has always been important to me. Two memoirs by brilliant writers describe the lives and the deaths of their spouses. The first, “A Year of Magical Thinking,” by Joan Didion, is a beautifully, painfully crafted story of a woman whose husband suddenly died while they were caring for their gravely ill adult daughter (Didion, 2007). I found myself in Didion’s husband’s shoes when he made the decision for the couple to take a trip, as I did a month before my wife became gravely ill. We both must have acted on unconscious needs. It turned out to be a wonderful time for Dot and me. These are memories I treasure. Didion has a follow-up of the attempts to save her daughter’s life and what it was like for her when she was left alone, without any family.

Kay Redfield Jamison, coauthor of the classic text on bipolar disorder, previously wrote about her struggle with bipolar disorder, “An Unquiet Mind” (Jamison, 1997), which I consider to be a classic of the thoughts and feelings of a patient with mental illness. “Nothing was the Same” (Jamison, 2011), the story of her life with Richard Wyatt, a brilliant schizophrenic researcher, and all

that they did to try to save his life can make all of us more appreciative of what we have.

When one is a hammer, everything appears to be a nail. I am daily coming across writings of those who have dealt with the prospect of death. Jeffrey M. Piehler, a retired thoracic surgeon, realized after 11 years of dealing with prostate cancer, he had no viable (no pun intended) options and decided to build his own coffin: “Ashes to Ashes, But First a Nice Pine Box” (Piehler, 2014). This



produced empathic responses by two people, one of whose sisters began building pine boxes for the family. The first one turned out so well that her mother had shelves installed and used it as a bookcase in the months before her death!

We all know what happened when the Affordable Care Act attempted to insert language that allowed families and patients to discuss end-of-life discussions. It was called the “Death Panel.” As a follow-up with this, there was “Invitation to a Dialogue: End-of-Life Talks” (Spring, 2012).

At this writing, I consider myself to be healed and hearty, telling any and all that, “From the shape I’m in, I’m in pretty good shape.” I never say “I understand how you feel,” but I tell people that their thoughts and actions are so similar to what was going on with me.

“How Doctors Die,” (Murray, 2013) sent to me by my friend Susan Ullmann, beautifully talks about how death for physicians is the same but different than the rest of mere mortals! A young resident, Paul Kalanithi, wrote about how he dealt with his own cancer diagnosis: “How long have I got left?” (Kalanithi, 2014). Bill Keller engendered several letters to the Editor when he discussed some of the awful things that happened to people whose families had no voice in their fate. William Breitbart is one of “over a handful of psychiatrists in North America who devoted their professional lives to helping dying patients.” Another article about Dr. Elizabeth Kingsley in hospice care is also called “Please get this one out.”

In the last few years I have scribbled down a number of brilliant thoughts. In one, I attempted to be humorous, talking about the “Sunset Syndrome,” and diagnoses that I came up with: Misplaceditis; Did-I-do-ititis; Slow-downitis; Flooritis; Don’t-Fall-Downitis.

I also wrote about “dealing with death’s daily devastating detritus.” I raised several pragmatic issues, dealing with mail and phone calls that continue to come in for Dot and trying to deal with all of the “stuff” that she left. It doesn’t help that we were both packrats. One humorous moment came when I was going through one of her files and came across a number of unopened mail items. Most of them could be discarded because vendors have sent subsequent bills and the others were not relevant. I decided it was like my taking a number of items, which she purchased that I had no use for, back to a store that had a liberal return policy. After the second or third time I came, having explained why I was returning them, the woman handling the returns smiled and said, “I think your wife got all of these things to give you something to do!”

A poignant piece by Joan Marans Dim, “My Husband’s Things,” brought a smile to my face, as it did to hers, when she talked about her husband buying things in multiples: “10 staplers, 20 rolls of packing tape, enough mouthwash and cotton balls to take me through the next millennium” (Dim, 2014). I wonder if he was also a devotee of Costco.

Every day, I find some further piece about someone who has lost a loved one.

When I originally talked about this special issue with Barry Silverman, I was consciously thinking about the pragmatic aspects to see how this could help others. I had not realized what a therapeutic endeavor it would be for me. ■

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Sheldon B. Cohen, M.D. is a graduate from Medical College of Georgia. He did graduate work at Charity Hospital, Menninger School of Psychiatry, and Tulane Department of Psychiatry. Also at Tulane he trained as a psycho-analyst. He served on the psychiatric faculties at Tulane and Emory. He has been active at a number of medical associations, both locally and nationally. He is a past editor of *American Journal Clinical Hypnosis*. As an expert in tobacco addiction, he has written and lectured, widely. Dr. Cohen served nine years on the Medical Association of Atlanta board and twice was the recipient of the Distinguished Service Award. Dr. Cohen practices psychiatry in Atlanta.



Cultural Issues Affecting Care

With changing U.S. demographics, awareness and advocacy for culturally sensitive healthcare issues is growing

By Melissa Duong, MPH

Not everything is black and white. In fact, advance directives come in many different colors: red, brown, yellow, gray, blue, green. That is, there are cultural facets that affect end-of-life planning for some families.

In essence, the document itself should be simple enough to complete: asking and answering questions that pertain to complications that may arise at the end of one's life. However, coaxing an elderly adult to sit down and talk about these issues may actually be the greater obstacle.

Growing up in a Catholic Vietnamese family, I have noticed that my parents are more concerned about what happens *after* death than *at the time of* death. They would rather talk about their desire to be cremated or buried than if they should be resuscitated when the time comes. This makes bringing up the subject of advance directives especially challenging for Asian American households.

In a chart review of 400 medical records of patients who have had palliative care consultations, 45 percent of whites signed an advance directive, whereas only 32 percent of nonwhites signed one (Zaide et al., 2013). The disparity in end-of-life preparation found in this study between whites and nonwhites provides a glimpse of the barriers that many ethnic groups face in end-of-life decisions and care.

One cannot truly understand the obstacles for end-of-life care without first examining the underlying cultural barriers that plague Asian Americans. Cultural barriers affect one's attitude towards seeking care. Most first-generation Asian Americans, especially the elderly, view suffering and illness as a natural and inevitable part of life (Kim & Keefe, 2010). Thus, there is a certain discomfort

when talking about personal wishes for dealing with illnesses, particularly at the end of life.

Asian elders may attribute the etiology of illnesses to supernatural causes, such as an imbalance of yin and yang, an obstruction of chi, or a curse or punishment by evil spirits (Uba, 1992). This cultural emphasis on stoicism encourages the acceptance of suffering based on the principle that one's length of life is predetermined and medical care for physical pain or illness is futile (Uba, 1992). This cultural belief decreases Asian patients' likelihood to seek medical care promptly, if at all.

Moreover, Asian cultural values do not emphasize end-of-life care or the decision-making process associated with it. In a study of 26 elderly Koreans (aged 65 and over), none had signed an advance directive. A central theme among the participants was that advance directives were unnecessary if they still felt healthy. Notably, more than 50 percent of the participants said that they would rely on their family members to make end-of-life decisions for them when the time comes (Ko & Berkman, 2012).

This family-centered decision-making process was found in other studies (Kwak & Salmon, 2007), where some participants even said that their advance directives may be null or void because family members will know to make the best decisions for them.

Relying on other family members to make these end-of-life decisions is also common in other ethnic groups. In a study of 1,193 enrollees of the Program of All-inclusive Care for the Elderly (PACE), 33 percent of blacks, 15 percent of Asians, and 15 percent of Hispanics had an "alternative decision-maker" (typically, a child or spouse) for end-of-life issues.

This greatly contrasted the 8 percent of whites who had an alternative decision-maker (Hornung et al., 1998).

To complicate the matter, many Asian caregivers, who are usually the children of those who are nearing the end of life, feel that it is the physician's place to initiate the discussion of advance directives and wishes for end-of-life care (Kwak & Salmon, 2007). Physicians are highly regarded among Asian cultures, and thus their words of advice are taken much more seriously.

Cultural competence is becoming more important in the healthcare field as the United States population is changing and its majority is shifting more towards minority groups. There needs to be more awareness and advocacy for culturally sensitive healthcare issues.

For example, patient confidentiality may become an obstacle during end-of-life care when the patient expects their family members to make decisions for them. Physicians should be aware of the challenges and differences of perspective when working with ethnic groups and prepare to discuss these issues upfront to alleviate the unnecessary hardship that may otherwise transpire. ■

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Ms. Melissa Duong received her Bachelor in Chemistry from Emory University (2011) and her master's of Public Health from the School of Public Health at Georgia State University (2013). Because of her immigrant background, Ms. Duong has always been passionately interested in using health policy to increase access to healthcare and alleviate health inequities among refugee, immigrant and minority populations. She is currently working as a policy analyst at the Government Accountability Office.

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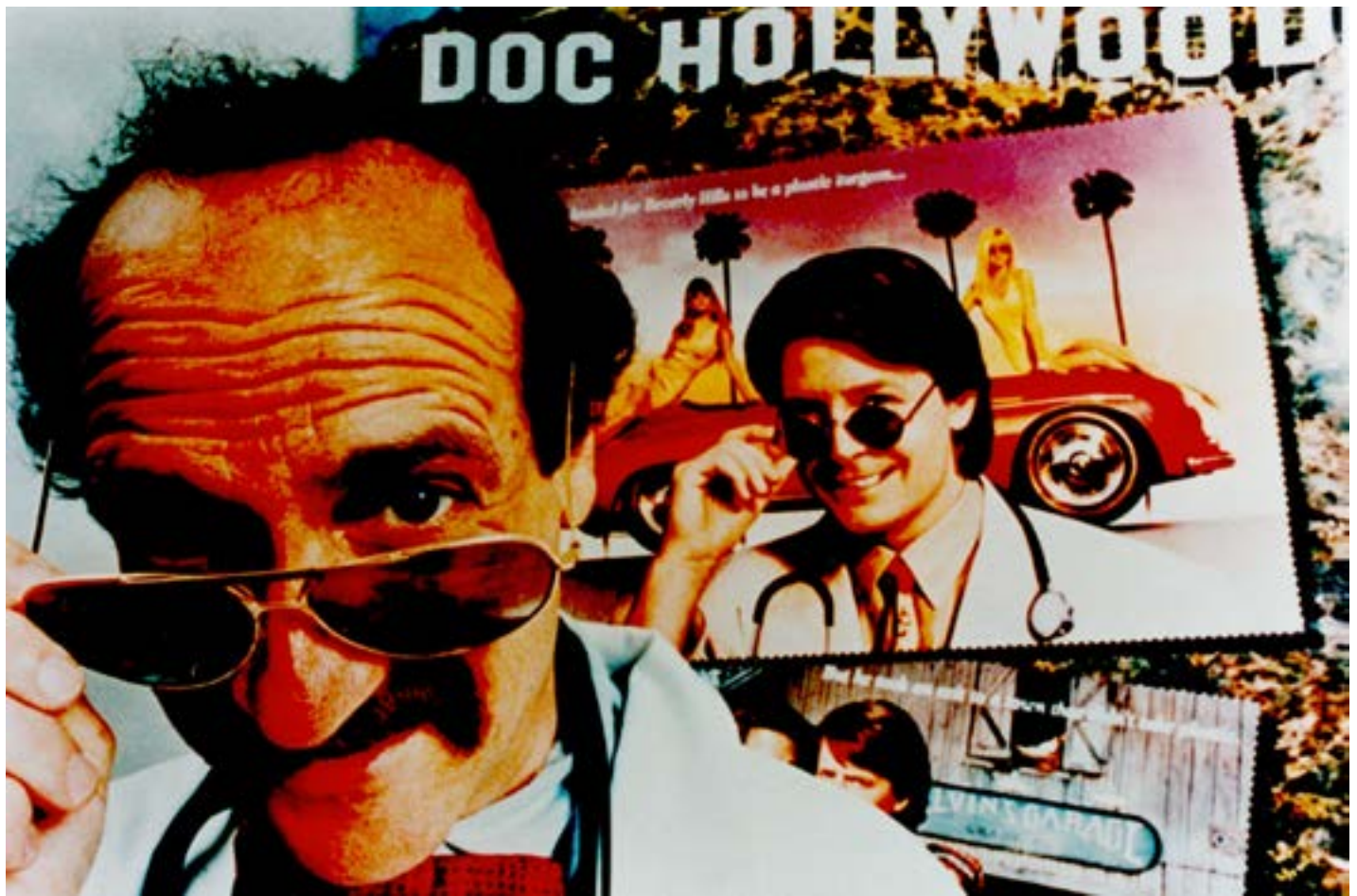


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Humor in Palliative Care

A Positive Vehicle for Enhancing Patient Care

By Neil Shulman, M.D.

I am a total klutz. When I eat, I miss my mouth. When I dance, I step on toes.

But I have saved more lives than any doctor in America ... by not becoming a surgeon.

A friend of mine is a malpractice attorney. He begged me to go into surgery. He said that he would split everything he made suing me, and I would become a billionaire within a year.

Thanks to 60+ years of stumbles and bumbles, I have discovered that laughter is great medicine, especially when you make fun of yourself ... since then you don't have to worry about offending anybody.

I have had the opportunity to speak to many groups of doctors and individual doctors about the appropriate use of humor as a positive vehicle for communication, regardless of how good or how bad the patient's prognosis is.

I wrote my first humorous novel, *Finally, I'm a Doctor*, during the time I was going through medical school. Learning medicine is a very serious, very intense experience, which creates an extreme need for humor as a coping mechanism.

Actually, there are many very funny situations that come up. For example, there's the phenomenon of medical students thinking they are coming down with every new disease they study. The medical world is associated with such stress and fear, I think that culturally we have a great need to demystify medical training and the practice of medicine, both to practitioners and to patients.

While moonlighting in rural emergency rooms in the southern United States as a young doctor, several things occurred to me. One was the recognition that rural America was enormously underserved and in dire need of more physicians to set up practice.

The other was that small town medical practices were bursting with funny and unique experiences and characters. I had stumbled upon a treasure trove of medical humor in the foothills of the Appalachians. As a result, I got busy writing a book, which eventually led to an opportunity to associate produce the Warner Brothers blockbuster comedy movie *Doc Hollywood* starring Michael J. Fox. It's a story about a young city doctor fresh out of residency

Humor is a vehicle to distract and uplift patients from the physical pain, mental anguish, fear and depression that can so easily take over.

on a road trip out to California to become a rich plastic surgeon who gets stuck in a rural southern town. Warner Brothers executives are now interested in producing a Broadway musical as a spin-off based on the book and movie.

Ever since the 1991 release of *Doc Hollywood*, I have performed stand-up comedy centered on the practice of medicine at a range of events, from performances with Rosalynn Carter to salute caregivers and events for the United Nations in Cypress to fundraisers with Jane Fonda and Miss America. I have even performed with the real Patch Adams when I became president of his non-profit organization, which itself has accelerated its global influence since Robin Williams starred in the entertaining movie based on Patch's life, especially his time in medical school.

I even ended up using humor to highlight my own desperate plight to find a wife when I produced and acted in the movie *Who Nose?* (see “who nose movie” on YouTube). In reality, I ended up marrying the woman who acted in the movie.

In every performance or presentation, I emphasize the need for humor in order for us to keep a healthy mindset in life and to cope with illness. I also encourage everyone to learn how to laugh at themselves, beginning with sharing the most embarrassing moments as a doctor. I also use book “giveaways” to entice people to come onstage and tell about their most embarrassing stories.

I have done this for general audiences at conventions, fundraisers and special events, as well as for audiences of medical students and hospital staff for Grand Rounds, med school graduations, CME courses, etc. I've also developed

variations on this theme for populations on both ends of the spectrum, from the beginning of life to the end of life.

For many years and in many locations across the U.S. and in other countries, I've performed my “What's in a Doctor's Bag?” show based on my book by the same name to demystify medicine to kids in a goofy and entertaining way at elementary schools, libraries and pediatric wards (YouTube: What's in a Doctors Bag/www.whatsinadoctorsbag.com).

I've performed my “Laughing With Seniors” program for elderly folks at assisted-living facilities, nursing homes and senior centers. This came about after writing a humorous novel, *Second Wind*, about life in one of these facilities. That has now spun off into an award-winning short film. We are hoping to launch a feature movie that will celebrate seniors and ideally put them on a pedestal so that younger people seek their wisdom since they have had a lifetime of experience.

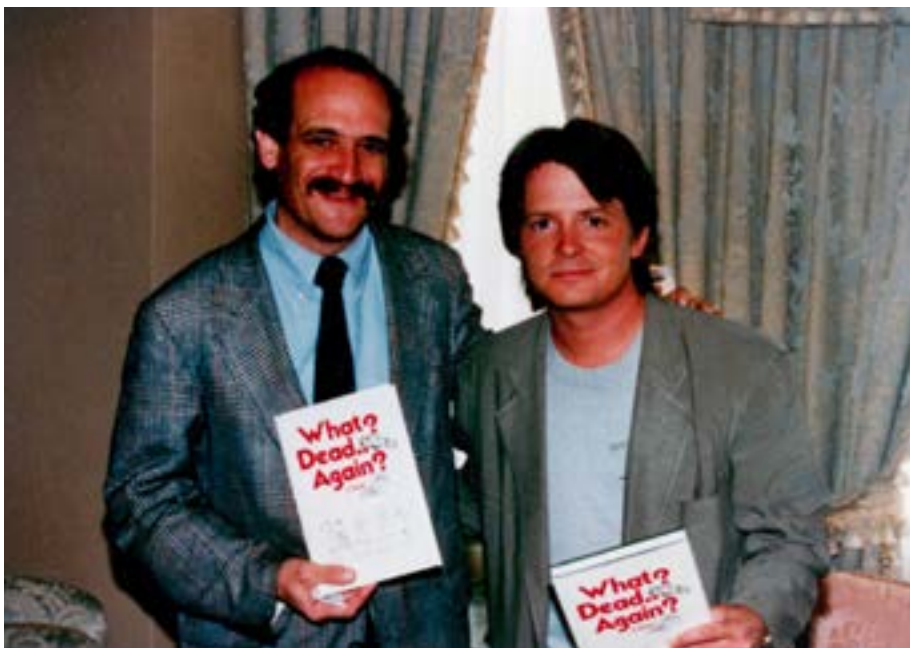
When engaging in palliative care, a sense of humor can become especially valuable in communicating with patients. Since this is an extremely fragile and painful time for any family, one has to be particularly careful that the humor does not have any negative impact on the mental state of the patient or their family members. However, if you take time to get to know the patient and family and are relating to them in a way that conveys your genuine concern and empathy for their situation, your stabs at humor are probably going to be well received.

When my father had terminal cancer and was dying at home, I witnessed an extraordinary positive impact on my father's psychological state when I suggested that he write his own eulogy. I knew that he had a wonderful sense of humor and that he would want to instill a positive upbeat spirit at his own funeral.

He became very engaged in this endeavor and was in great spirits while doing it. When I read his address at the funeral, those attending kept bursting into laughter. I felt that dad was also laughing from above.

We also had a good dose of humor in the family when my mother was suffering from Alzheimer's, and I would fly up to Washington, D.C., to visit her. I would bring her a bunch of flowers and she'd be very happy about this and give me a big hug.

Ten minutes later I would leave and bring her back the same flowers. She would light up again and give me another big hug. I did this multiple times with



the same reaction. Then I announced to Mom and all the other relatives in the room, “Hey, this is one of the positives nobody ever talks about with Alzheimer’s; all I have to do is buy one bunch of flowers and I get credit for 10.” Mom thought this was really funny!

I remember on one occasion addressing a group of patients with terminal prostate cancer, and asking the group if anybody wanted to share a moment of humor he had experienced during the course of his illness. One gentleman immediately offered this to the group: he was reclining on a lawn chair in his backyard one afternoon when it was particularly muggy and buggy, and his wife came rushing outside and exclaimed, “Honey, come inside. It’s too hot, and you’re getting eaten by the mosquitoes.” He responded: “No, no ... It’s payback time. I want the mosquitoes to get infected with prostate cancer.”

Patients might enjoy reading humorous books, watching a humorous video or engaging in humorous banter with old friends. A grandchild might even want to sing a funny song or play an entertaining game with Grandma or Grandpa. I have even given copies of my book *101 Ways You Know If You Are A Nurse* to patients to give to their nurses.

And just how do you know if you’re a nurse, one might ask? Well, some examples are that you use bedpans as chip and dip trays, you check for good veins when shaking somebody’s hand and you’re smart enough not to be a doctor! If your nurse is laughing while you’re in his or her care, it helps in building a positive relationship.

Humor is a vehicle to distract and uplift patients from the physical pain, mental anguish, fear and depression that can so easily take over. A positive cerebral response can stimulate the secretion of endorphins, which could possibly reduce pain and increase happiness.

Happiness is also contagious since it can change the spirit of an entire group. So in creating a moment of happiness for the patient or for one family member, it can lift the spirits of the whole family.

The bottom line is that doctors are so often focused on diagnostics and therapies that they frequently don’t take into consideration this very positive approach for dealing with patients who are in palliative care. Likewise, families of a dying loved one are often so focused on the sorrow and helplessness of losing their beloved that they lose sight of the fact that a person is alive until the moment they breathe their last breath. Even if they are not able to belt out a good guffaw at something, if a patient can be tempted on a regular basis with a little bit of a chuckle or the tiniest smile of appreciation, it can have great effect in enhancing their well-being during their last days of life. ■



Neil Shulman M.D., has authored more than 30 novels, children’s storybooks and consumer health books. He was co-producer of the 1991 movie *Doc Hollywood*, based on one of his books. He has written/produced for CBS, CNN and Disney. Early on, he received more than \$8 million in research grants and co-authored more than 50 scientific papers. Since then, he has focused on medical education, speaking on serious health issues and performing comedy for audiences of all ages (including acting in *Who Nose?* (search “who nose movie” on YouTube).

Physician Orders for Life Sustaining Treatment

Thanks to the efforts of three TSPMG physicians, the Medical Association of Georgia (MAG) passed a critical Palliative Care resolution at the 2013 House of Delegates meeting.

TSPMG’s Anna Skold, MD, joined by colleagues Larry Bartel, MD, and Martha Wilber, MD, sponsored Resolution 114A.13, calling for the statewide implementation of Physician Orders for Life Sustaining Treatment (POLST).

The resolution calls for all Georgia physicians and hospitals to honor a patient’s advanced directives as “a physician order”, rather than merely “patient preferences”. Georgia is the 16th nationally-endorsed POLST program. Continued MAG support through this resolution will help significantly toward statewide implementation of POLST.

“All physicians have a fundamental duty to comply with a patient’s wishes, including and especially at the end of life. The state-wide adoption of the national POLST initiative frees all Georgia doctors and hospitals to honor each patient’s wishes at the end-of-life, regardless of treating institution or treating physician”, said the resolution’s author and sponsor, Dr. Skold, who is board certified in Palliative Care.

“Dr. Skold’s work in this year’s MAG House of Delegates meeting represents the latest example of PMG’s expanding influence in Georgia’s physician community,” said Rob Schreiner, MD, TSPMG Executive Medical Director.

TSPMG physicians accounted for 12 voting delegates at this year’s meeting, the highest number of any prior year. ■

The Heart of the Matter:

Groundbreaking Treatments Improve Life for Patients With Cardiovascular Disease

By Helen K. Kelley



According to the American Heart Association, each year an estimated 380,000 men and women in the United States die as a result of heart disease — making it the leading cause of death among men and women. In fact, approximately 83.6 million Americans are living with some form of cardiovascular disease or after-effects of stroke.

Physicians at the Northside Hospital Heart & Vascular Institute are making it their mission to be at the forefront of finding effective new ways to treat patients with cardiovascular disease, through the use of new technologies, advanced surgical techniques and a robust clinical research program. The Institute offers a comprehensive, integrated network of

preventative, diagnostic and medical services for the heart, veins and arteries.

Minimally-Invasive Interventional Procedures are Easier on Patients

Michael Balk, M.D., Medical Director of Cardiology Services at Northside's Heart & Vascular Institute, says that the public's growing awareness of health issues has led to an increase in recent years of patients being diagnosed with heart disease and cardiac problems like atrial fibrillation, a leading cause of stroke.

“Healthy people — many of whom have seen a friend or family member experience a heart attack — are increasingly interested in detecting heart disease early, before it causes a cardiac event. And as the Baby Boomer population ages, we're seeing a big increase in atrial fibrillation — by 2050, about 12 million people will have it,” he states. “We're always looking for better ways to treat these conditions that are less painful and stressful for the patient.”

One such treatment is transradial cardiac catheterization, a procedure used to diagnose and treat issues such as coronary artery disease, angina and aortic stenosis by accessing the problem area through the patient's wrist. The simple procedure has several advantages over the previous method of going through the patient's groin, including less bleeding, pain and recovery time.

“The transradial procedure is so much better and safer for the patient. They don't have to lie flat for a long period of time as they would if we did the procedure through the groin, and they don't have to endure any clamps. Afterward, they're sitting up in five minutes; they go rest in the lounge, have coffee, and go home later the same day,” says Balk. “So, the advantages are increased

patient comfort, fewer complications, less bleeding and less cost.”

Balk adds that transradial cardiac catheterization is particularly helpful for patients who are morbidly obese, due to difficult access to the groin area.

“We just go in through the wrist, apply a pressure band and then we’re done,” he explains.

Balk estimates that 95 percent of coronary disease cases can be diagnosed and/or treated transradially.

Another minimally-invasive procedure — one making a big difference for high-risk patients with thoracoabdominal aortic aneurysms (TAAA) — is performed by Joseph Ricotta, M.D., Medical Director of Vascular Services at Northside Heart & Vascular Institute. As the only physician in the United States with an investigational device exemption (IDE) from the FDA to create and implant custom-modified endografts to treat TAAA, Dr. Ricotta is able to create these stents in as little as 30 minutes, right in the operating room and therefore can even treat patients in an emergency setting.

“We keep all the necessary supplies and tools to make the endografts on hand and ready in the OR,” he states. “When a patient is admitted for TAAA, we can make a customized graft immediately, which is especially helpful in emergency situations.”

Since the kidney arteries and intestinal arteries all arise from different positions off the aorta, the devices are custom-made to fit the specific anatomy of each patient.

“Angles, curvature and locations can differ from patient to patient,” Ricotta explains. “No two people are the same in terms of their blood vessels and aortic anatomy.”

Since the entire aneurysm is repaired from the inside of the aorta, rather than cutting open the chest and abdomen, patients who receive a custom-modified endograft have a much shorter hospital stay — as little as two days — and a quicker recovery time. A traditional surgical procedure would require at least a week’s hospital stay and has a 10-fold higher mortality and complication rate than his minimally invasive approach.

Northside Hospital vascular surgeons are national and international experts in the field of endovascular therapy. Ricotta estimates that 85-90 percent of all artery blockages can be treated with these mimimally-invasive

Northside Heart & Vascular Institute Services

Cardiology:

- Arrhythmia
- Congenital Heart Defect
- Heart Failure
- Heart Murmur
- Mitral Valve Prolapse
- Pericarditis
- Stroke

Vascular Surgery:

- Aortic Aneurysm
- Carotid Disease
- Peripheral Artery Disease
- Renal & Mesenteric Disease
- Thoracic Outlet Syndrome
- Venous Disease/ Deep Venous Thrombosis
- Stroke

techniques rather than with open surgery. “The advantages that we have as vascular surgeons is that we can treat patients with endovascular techniques but if open surgery is required we can do that as well. This flexibility allows us to individualize treatment to each patient and optimize outcomes”, says Ricotta.

Minimally-invasive procedures like transradial cardiac catheterization and customized fenestrated-branched endografts continue to evolve as advancements are made in technology and surgical techniques are honed.





“As with aortic, carotid and peripheral artery disease, with venous disease we’ve evolved from having to repair veins with open surgery to treating patients with minimally invasive techniques. For example, whereas a patient with varicose veins used to have them surgically removed in the hospital, now we perform the treatment in-office with a catheter. Just a simple needle stick, a few minutes’ time, and the patient walks out of the office,” notes Ricotta. “The foundation of what we do is the same, but the way we do it changes over time. We continue to make improvements — always looking for ways to make the procedures quicker, safer and easier for the patient.”

Research

Currently, the Northside Hospital Heart & Vascular Institute is participating in numerous clinical trials that cover the four main pillars of vascular disease.

One of those trials involves the cutting edge technology of using drug eluting balloons in the treatment of peripheral vascular disease.

Ricotta explains the benefits of these stents for patients with blockages in their legs: “Traditional treatment involves inflating a balloon in the leg, which creates a passageway through the blockage. But sometimes, the blockage can come back, scar tissue can form, or the artery can close back up. Now, we can mount medication on a balloon that keeps the blockage from coming back. The balloon creates a channel to open up the artery and then, the medicine leeches off the balloon to prevent the artery from blocking up again. There are two different types of drug eluting

balloons being used in the trial, one for the upper leg and one for the lower leg.” Northside Hospital is the only one in Georgia involved in this trial.

Another research effort is the MOSTEGRA (MODified STEnt GRAft) clinical trial, which is Ricotta’s FDA-approved creation and modification of fenestrated-branched endografts for the treatment of thoracoabdominal aneurysms (described above).

Additional trials are underway for peripheral artery disease, aneurysms (aortic, iliac), carotid blockages and venous disease.

An Integrated Approach

The integration of cardiology and vascular services has allowed Northside’s cardiology and

vascular specialists to work closely with other physicians in monitoring patients who are at risk of developing heart problems as a result of other health conditions.

“For example, women who are pregnant can develop preeclampsia high blood pressure, or cancer patients may experience toxic side effects to the heart from radiation, chemotherapy or bone marrow transplants,” explains Patricia Tyson, Administrative Director of Northside Heart & Vascular Institute. “So, obstetrics and oncology specialists can work together with the physicians at our Heart & Vascular Institute to monitor patients’ heart function and prevent major damage to their hearts.”

As part of this integrated approach to cardiac health, the Heart & Vascular Institute offers several preventative care programs to assist patients, says Tyson.

“We offer smoking cessation and cardiac rehabilitation classes, as well as free cardiovascular screenings,” she states. “Additionally, we have physicians who specialize in women’s preventative care, preeclampsia follow-up, and a clinic established for the specialized post-hospitalization treatment of heart failure patients.”

Balk adds that the Heart & Vascular Institute offers a level of specialization that can be crucial to these at-risk patients.

“We have unique, combined experience in dealing with complex problems. Our ‘cutting edge technology’ actually lies in our people — our physicians and support teams,” he says. “We’re always trying to think ahead to how we can do things more efficiently, more cost-effectively and with better outcomes for the patient.” ■

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Cancer

By Helen K. Kelley

According to the American Cancer Society, more than one million people in the United States are diagnosed with cancer each year. Here, we highlight some of the latest research, statistics and treatments for different types of cancer, including advances made by Atlanta-area physicians.

MarginProbe Allows Real-Time Detection in Breast Cancer Patients

Physicians at Cancer Treatment Centers of America (CTCA) at Southeastern Regional Medical Center are among the first in the Southeast to use the new MarginProbe™ System for breast cancer patients. The MarginProbe System delivers real-time cancer detection in the operating room for a simple and immediate assessment of cancer on the margin of the

excised tissue, thus reducing the doubt and likelihood of a second surgery.

Dr. Anita Johnson, medical director of breast surgical oncology at Southeastern Regional Medical Center, says the new technology is beneficial to both the surgeon and the patient because with an indication of cancerous cells at the margins, the surgeon can remove additional tissue – which saves time and, potentially, a second procedure.

“At times, removing the tumor with clear margins can be challenging. Assessment in the operative suite has been shown to be beneficial in assessing these margins using several techniques,” says Dr. Johnson. “The MarginProbe is used to detect close or involved margins after the lumpectomy has been performed. Previous data has shown that there is a more than 55 percent reduction in re-excision rates.”

Johnson adds that the largest value from a patient perspective is how it reduces the chance of having to go

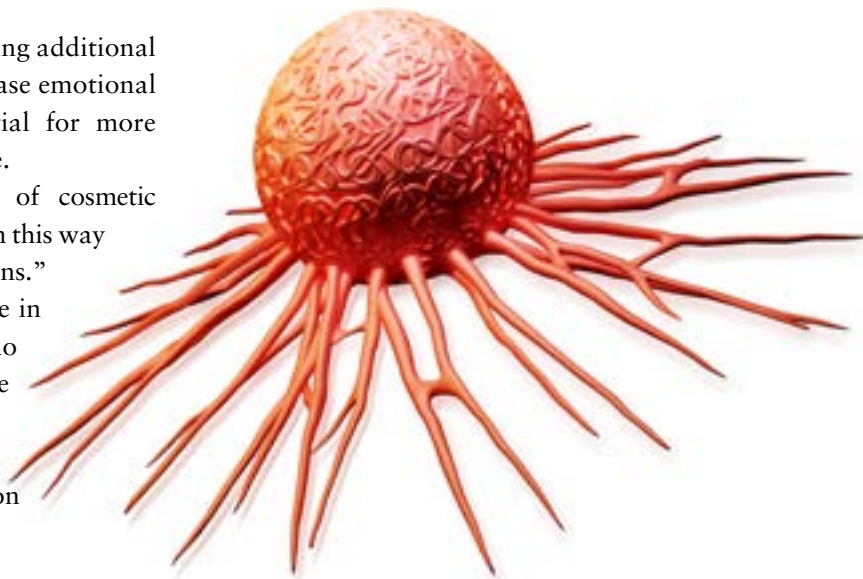


Dr. Anita Johnson, medical director of breast surgical oncology at Southeastern Regional Medical Center

back for surgery a second time. Those resulting additional procedures not only add cost, but also increase emotional distress for patients and have the potential for more scarring and deformation at the surgical site.

“Patients tell us about the importance of cosmetic outcomes,” she says. “MarginProbe helps us in this way by eliminating the need for additional resections.”

CTCA surgeons also use the MarginProbe in conjunction with some of their patients who meet the criteria to have IORT (intraoperative radiation therapy) performed. Johnson notes that in the past few months, the device has significantly decreased re-excision rates for these patients.



ACS Releases New Report on Childhood Cancer Statistics

The American Cancer Society’s Surveillance and Health Services Research Program has produced a detailed report summarizing the progress made and challenges ahead in fighting childhood and adolescent cancers. Key findings include:

- In 2014, an estimated 15,780 new cases of cancer will be diagnosed and 1960 deaths will occur among children and adolescents aged birth to 19 years.
- Approximately one in 285 children will be diagnosed with cancer before age 20.
- Today, about one in 530 young adults between the ages of 20 and 39 is a childhood cancer survivor.

The report points out that although advances in the treatment of childhood cancer have saved many lives over recent decades, there has been less progress made in understanding the causes and prevention of childhood and adolescent cancers. And while there have been substantial improvements in survival for many cancers of childhood, others have seen little progress.

In addition, the report confirms that while advances in survival for many types of malignancies have resulted from improvements in surgical techniques, delivery of radiation therapy and use of chemotherapy, children treated for many cancers have a high risk of immediate and long-term health issues that interfere significantly with quality of life for these children and their families.

New Drug Shows Promise for Pancreatic Cancer Patients

According to the National Cancer Institute, although pancreatic cancer is rare – with approximately 45,000

cases diagnosed each year in the United States – it is the fourth leading cause of cancer-related death in this country. At diagnosis, most patients with pancreatic cancer have advanced disease that has spread, or metastasized, to other parts of the body. Only two percent of patients with metastatic pancreatic cancer are still alive five years after diagnosis.

A recent article in *The New England Journal of Medicine*, co-authored by Dr. Mansoor Saleh, director of research with Georgia Cancer Specialists affiliated with Northside Hospital Cancer Institute, reported that in an international randomized phase III trial, patients with metastatic pancreatic cancer who were treated with a combination of albumin-bound paclitaxel (nab-paclitaxel [Abraxane®]) and gemcitabine (Gemzar®) lived longer than patients who were treated with gemcitabine alone. Patients who received both drugs also lived longer without their disease getting worse (progression-free survival).

Patients who received the drug combination had a median overall survival of 8.5 months, compared with 6.7 months for patients treated with gemcitabine alone. This difference in overall survival was statistically significant.

“Metastatic pancreatic cancer remains a very difficult malignancy to treat, and until now progress had been slow,” says Dr. Saleh. “But that has changed dramatically since the recent paper in the NEJM, which demonstrated improvement in overall survival as well as survival at one and two years when patients were treated with the combination of Abraxane and gemcitabine. The combination was superior to the use of gemcitabine alone, which used to be the standard of care until now. Thanks to this study, patients have a new treatment option, and future studies will use this combination as the gold standard.”

Piedmont Doctors Study Benefits of Manuka Honey in Managing Cancer Patients' Pain

The healing properties of honey have been recognized for thousands of years, dating back to its use by Egyptians in 1500 B.C. Today, doctors at Piedmont Atlanta Hospital are conducting a Radiation Therapy Oncology Group (RTOG) sponsored clinical trial to see if daily manuka honey consumption can delay or prevent radiation esophagitis-related pain during chemotherapy and radiation therapy for lung cancer.

“There is evidence to suggest honey in any form can reduce mucositis, a debilitating complication that occurs as a result of combining chemo and radiation therapy,” states Adam Nowlan, M.D. “Patients who develop mucositis often experience a lot of pain, making it difficult for them to speak, eat and continue uninterrupted treatment to fight the cancer.”

Patients participating in this trial are selected randomly to receive one of three treatments: liquid manuka honey, given four times a day; honey lozenges taken four times a day; or medications already on the market to help with pain associated with mucositis. To date, no trials of honey in the treatment or prevention of radiation-induced esophagitis have been reported, but three randomized trials of honey for the prevention of radiation mucositis have been published and serve as the basis of this study.

“Until we prove this, it is only a hypothesis,” says Dr. Nowlan. “But we have a fair amount of evidence that shows manuka honey will be effective. In one of the randomized trials, 15 percent of the patients who received honey developed complications of mucositis as opposed to 65 percent those who did not. And we have no reason to believe the honey will affect a patient’s ongoing treatment.”

Manuka honey is produced by bees that mainly feed on the manuka tree flower, native to New Zealand. It is distinctively darker than most other kinds of honey and is hailed for its antibacterial and healing properties over the world. Considered the standard medical honey, manuka honey has been proven to reduce inflammation and serve as an effective wound dressing. This study is only being conducted in the U.S. due to a limited supply of manuka honey.

Support Center Addresses Patients', Families' Needs

Gwinnett Medical Center recently opened its Cancer Support Center as part of a comprehensive care plan for cancer patients.

The Cancer Support Center offers a variety of support for patients and their families, including oncology nutrition counseling, social work services, support groups, genetic risk counseling, patient navigators, a wig bank and a resource library for independent research. The center also houses a classroom where patients and their families can learn more about topics like cancer survivorship and wellness.

“Cancer is nothing short of overwhelming to patients and families, and it is imperative to provide the tools that they need in a convenient location,” says Katherine Michaud, director of oncology services at Gwinnett Medical Center. “We are hopeful this center will open up some new opportunities for our patients that can help them to feel less anxious and more confident in their ability to cope with their diagnosis and treatment.”

Cancer Survivorship Information Center

Georgia CORE, the Center for Oncology Research and Education has received a gift of \$100,000 from Tom and Karen Chapman to fund a unique, high-quality and impactful interactive online cancer survivorship information center. Developed by Georgia CORE, the website will be designed to meet the needs of Georgia’s cancer survivors, caregivers and healthcare professionals and will be the first of its kind in the state.

“Karen and I are very happy to support the development of Georgia’s only statewide interactive website dedicated to survivorship,” said Tom Chapman. “There are more than 340,000 survivors in our state. Now they and those that care for them will have at their fingertips all the survivorship information, navigation, tools and support available here in Georgia.”

The interactive site will be mobile-enabled and housed within GeorgiaCancerInfo.org, the state’s comprehensive online information center on all things related to cancer care, according to Georgia CORE Vice President Angie Patterson, who also happens to be a survivor. “The purpose of the site is to be a bridge between active cancer treatment and long-term survivorship, with information and connectivity that will support survivors in their ongoing cancer journey,” she said. “It will have tools and interactive maps to locate navigators and survivorship programs and resources, as well as blogging, chatting and social media capabilities.”

Georgia CORE began developing the interactive survivorship information center in December 2013 with implementation targeted by mid-year 2014. ■



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In every issue, *ATLANTA Medicine* will feature a couple of the association's board members. If you would like to consider becoming a board member, please contact David Waldrep at dwaldrep@maa-assn.org.



Randy F. Rizor, M.D. is an anesthesiologist sub-specializing in treatment of musculoskeletal pain. His clinical practice is focused on painful spinal disorders, complex regional pain syndrome (CRPS/RSD), pain in the injured worker, and non-opioid treatment of chronic pain. He is a founding partner and President of The Physicians' Spine and Rehabilitation Specialists of Georgia and practices in Sandy Springs.

He graduated Phi Beta Kappa from Bates College and received his Doctor of Medicine Degree from the University of Toledo School of Medicine in 1976. He completed a residency in Anesthesiology at Dartmouth-Hitchcock Medical Center, serving as Chief Resident. Dr. Rizor was certified by the American Board of Anesthesiology in 1981. He received subspecialty certification in Pain Management from the American Board of Anesthesiology in 1993 and was re-certified in 2005.

Dr. Rizor has been named one of Atlanta's top doctors by *Atlanta Magazine* and one of the top doctors in the country by *US News and World Report*. He is a member of the Chairman's Advisory Council of the Georgia State Board of Workers' Compensation. He is also a member of the Executive Board of the Atlanta Area Council, Boy Scouts of America.

In response to the events of September 11, 2001, Dr. Rizor volunteered to join the US Army Reserve. He currently holds the rank of Colonel in the Medical Corps. He has served on active duty in Kosovo in 2004, and in Iraq in 2007-08 and 2011.



Earl Thurmond M.D., MBA, FACP is an internist with The Southeast Permanente Medical Group (TSPMG). He practices ambulatory medicine, caring for Kaiser Permanente members throughout the metro Atlanta area. Dr. Thurmond is physician director for care experience for TSPMG and is co-chair of the Kaiser Permanente Georgia Credentialing and Privileging Committee.



Dr. Thurmond earned his medical degree from Howard University. He completed his training in internal medicine at Howard University Affiliated Hospitals. He has an MBA from Kennesaw State University. Dr. Thurmond is a fellow in the American College of Physicians.

He sits on the board of directors of the East Lake YMCA and is an active member of the Cascade United Methodist Church. Dr. Thurmond and his wife Phyllis live in Lithonia.



Charles L. Wilmer, M.D. received his undergraduate degree from Amherst College in Amherst, Massachusetts. He then received his medical degree from the University of Virginia School of Medicine in Charlottesville, Virginia and completed an internal medicine internship and residency and a cardiology fellowship at Emory University Affiliated Hospitals in Atlanta, Georgia.

Dr. Wilmer is board certified in internal medicine and cardiovascular disease. He is a fellow of both the American College of Cardiology and the American College of Physicians. His specialties include cardiology and interventional cardiology.

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