



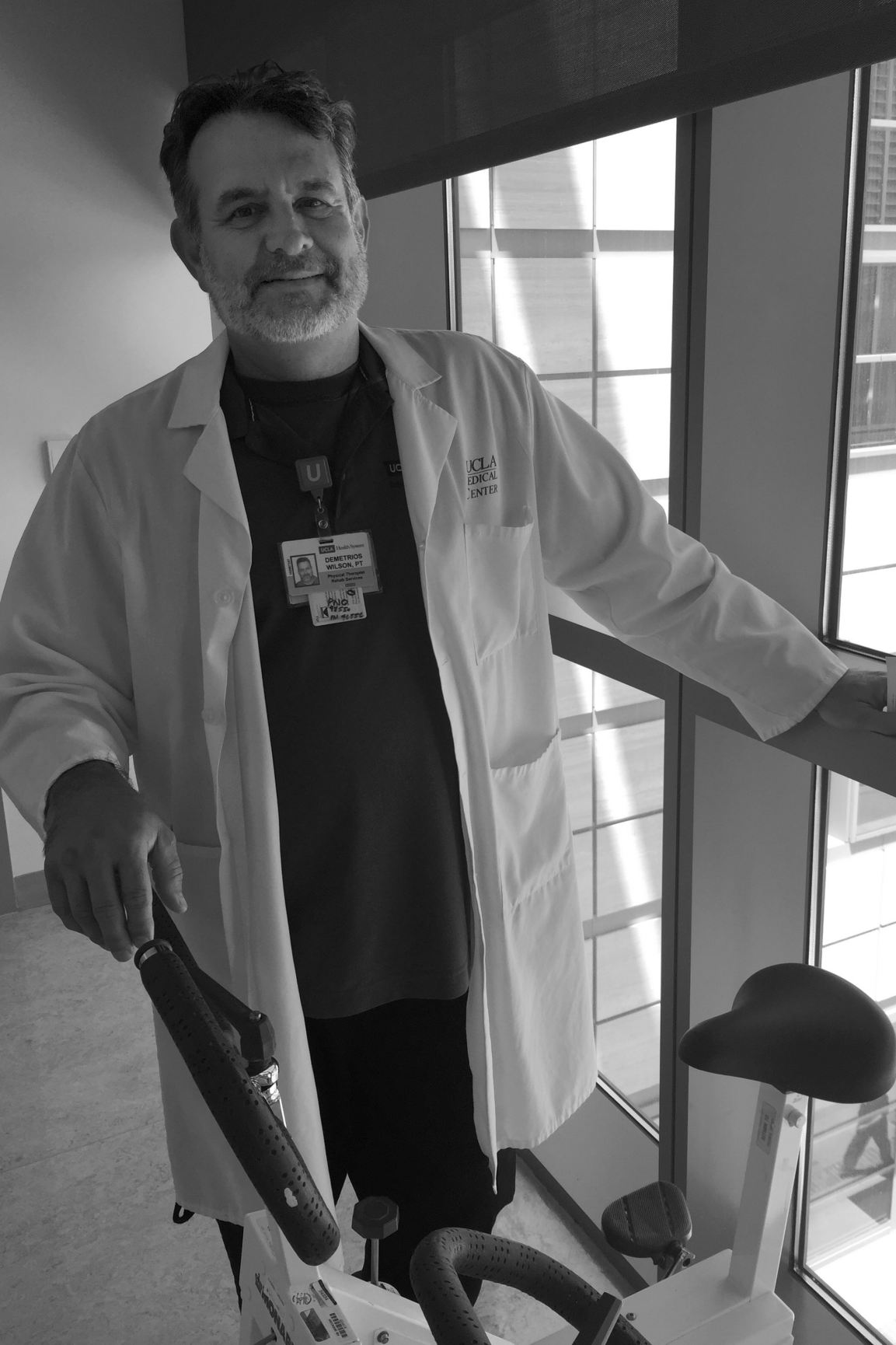
A JOURNAL OF ORTHODOX FAITH AND CULTURE

ROAD TO EMMAUS

Help support
Road to Emmaus
Journal.

The *Road to Emmaus* staff hopes that you find our journal inspiring and useful. While we offer our past articles on-line free of charge, we would warmly appreciate your help in covering the costs of producing this non-profit journal, so that we may continue to bring you quality articles on Orthodox Christianity, past and present, around the world. Thank you for your support.

Please consider a donation to Road to Emmaus by visiting the Donate page on our website.



UCLA
MEDICAL
CENTER

UCLA Health System
DEMETRIOS
WILSON, PT
Physical Therapist
UCLA Health System
UCLA Health System
UCLA Health System

PELOTON
11000

A PEACEFUL PASSING

Negotiating the Hospital and Hospice

In an interview enlivened by years of experience and his own deep Orthodox faith, Demetrios Wilson, Senior Physical Therapist and member of the Ethics Committee at UCLA Medical Center in Los Angeles, speaks with *Road to Emmaus* about final stage medical decisions and how to prepare for a peaceful Christian end.

RTE: Demetrios, please tell us about yourself.

DEMETRIOS: I was baptized and grew up Orthodox in a small California church. At that time there was so little to anchor the youth that when evangelical Christian friends invited me to a Bible study, I was encouraged to go by the Greek priest. I found real sustenance in this while remaining Orthodox and even brought my Protestant friends to church for Pascha and other feastsdays.

Eventually I joined a nondenominational Christian youth mission group and worked as a missionary in the South Pacific for eight years, where I met my wife Linda, an Italian-American teaching in a Catholic school. We both knew that there was something missing in Protestant worship and after we returned to the U.S. around 1994, I read St. Athanasius' *On the Incarnation* and *The Mountain of Silence*, a book-length interview with a Cypriot abbot. Through this reading I discovered a deeper Orthodoxy than I'd known earlier, and loved the idea that you don't learn Christianity from a textbook, even the Bible, that you learn it from a person.

Opposite: Demetrios Wilson

In 2009 my wife and I went to Holy Cross Greek Orthodox School of Theology in Brookline, Massachusetts. She finished a Master of Theological Studies while I worked on the Master of Divinity seminarian's degree. At Holy Cross you are overwhelmed by the vastness and beauty of Orthodoxy and you leave wanting other people to have that same experience. The classes answered my questions, yet made me hunger to know more. I just couldn't get enough, fast enough. I'm now going back to finish my last semester of seminary.

At Holy Cross my understanding of the person was radically transformed and I now look at people completely differently. Sometimes it shakes me to the core. Many of my patients at UCLA Medical Center are Eastern European or Middle Eastern, and I can tell them that their illness is not just a physical journey, it's a multi-level pursuit of healing that is also psychological, social, and spiritual, and they understand this. We are just scratching the surface of this understanding in western medicine, but it's very easy to connect in this way with people from the East. As Frederica deGraff said in her interview, it's as simple as asking them if they know their saint.¹

An example of this was a Coptic man, whose family couldn't decide whether to treat his cancer or take him home to die. I didn't have a Coptic icon, but I did have a Byzantine icon of St. James of Jerusalem, which I brought in. He grabbed it and kissed it, saying over and over again, "Thank you, thank you." I told him to pray, that it would strengthen him and that his prayer would help me with his physical therapy. This also happens with Roman Catholics from Mexico, South America, or even Europe. As I said, people from other cultures often experience their religion existentially in a way that doesn't happen as often in the West, where you come to your belief as a well-thought-out reasoned choice that is somehow considered more responsible than to receive it from your parents or godparents. It becomes almost impersonal, more an ideology than a religion.

I came back from Holy Cross with an understanding from the Church Fathers of what makes up a person, and found that I was now able to connect much more deeply with people—not only other Christians, but with Jews, Muslims and Bahai—in a way I never could before. This helps me in treating them.

RTE: This isn't the first time *Road to Emmaus* readers have heard from you. Your compelling remarks in a Holy Cross classroom discussion on bioethics

¹ Frederica deGraff, "The Doorway to Eternity: Sustaining Compassion and Love in the Final Hours," *Road to Emmaus*, Issue #62, Summer, 2015.

led by Dr. Timothy Patitsas were incorporated into an issue on contraception, abortion and *in vitro* fertilization that we printed in 2012. As a physical therapist and a member of the UCLA Medical Center Ethics Committee, you are now at the other end of the spectrum. When did these end-of-life issues first become important to you?

DEMETRIOS: When I was trained as a physical therapist we had to do three semesters in a cadaver lab. I didn't know how to be around a dead body, but it soon became very clear to us that the bodies we were working on and dissecting were people, and even the most secular students had to put a towel over the face. You had to keep an intellectual distance to perform the procedure properly, but then you'd look down and think, "Oh my goodness, this lady still has her nail polish on!" It was that kind of realization that was earthshaking. You were suddenly aware that this person was part of a family, she was loved, and yet had chosen to give her body to science. You think, "This is what she died of, but she was probably a mother, certainly a daughter..." This was no longer just a dead body.

RTE: What end-of-life issues do you deal with on the ethics committee?

DEMETRIOS: There are many ethical problems that arise because it has taken a long time for medical science to come up with a definition of death. Is it when the heart stops? When the brain stops? When you stop breathing? Is it all of these, or just one or two? In earlier times, death was recognized when a person's breathing stopped. Now, because medicine is able to artificially keep the lungs functioning with a respirator, does this mean that the person is alive? If they can artificially keep your heart beating, have you died or not? More commonly now, the scientific determination of death is made after assessing brain function. This can be quite difficult because there is often a huge tension between what medicine can do and what the family hopes for. People often have a strong hope and faith that their loved one is going to pull through even though medicine has nothing left to offer and brain function has ceased.

People often don't realize that these decisions are also traumatic for the staff and even for the hospital ethics committee. It takes a long time for the staff to draw a line and take a stand. They want to stop care once they see it is futile and leave the person to die in peace, but not to do so in a way that is

traumatizing to the family. The families are often desperate and fearful if they don't have hope in Christ that their loved one is passing on to a new reality.

Nevertheless, there is a point in modern medicine where further care is considered futile. You never want to give up hope, but sometimes we come to realize that our hope is misplaced and that this is the person's time to die. On the other hand, in Orthodoxy we don't consider any care futile, we emphasize the hospitality aspect of care, which encourages active help if there is hope of recovery, gives physical and spiritual comfort when there is not, and doesn't end until the person passes. The spiritual care never ends, as we continue to pray for them. In this sense, while a person lives there is no care that is futile, and when they die there is no care that is futile.

RTE: As an ethicist, how do you help the families negotiate this?

DEMETRIOS: The most important thing is to give the family clear explanations and education. Once doctors determine that death is imminent and that their ability to save the person is at an end, they want to remove the artificial aids and allow the person to die naturally. However, if a family member isn't ready to let go, they can exert a lot of emotional and psychological energy on the staff to keep their relative alive. It's important to help the family let go and allow their loved one to be, to let nature take its course.

Part of the problem is that up until this point the medical people have been so hands on in keeping the person alive that when they pull out it seems like abandonment or giving up. At this point both the doctors and hospital nursing staff hand the person over to a hospice nurse. All of this is part of the unnaturalness and fragmentation of modern medicine. The hospital staff are part of the team if the person is going to get better, but not really part of the team if the person is going to pass.

RTE: Yet many hospital staff feel these losses, don't they?

DEMETRIOS: Yes, very much so. And if your parents or grandparents pass in a hospital you will often find that the staff you thought were strangers, are often actually very connected to your folks. Sometimes they even come to the funeral. Also, the hospital chaplain not only assists the patient and his family, but also helps the staff to grieve. I've seen chaplains reach out in wonderful ways to the staff.

Discerning Hope

We really need discernment in these end-of-life issues, and that's a problem because neither the medical staff, the patient, the family, nor the priest is clairvoyant. Sometimes we hold onto the hope that God is going to come through and work an amazing miracle, and this does happen occasionally. I've seen two instances of this in the last few months: one was just last week when the team of doctors said, "There's nothing else we can do, he needs to go into hospice." The very next day the patient regained consciousness, stood up, and walked.

Having said that, these miracles are rare and I'm very much against sustaining false hope, that is, prolonging the life of a person whose time has come to pass on. I've seen families refuse to allow their fathers and husbands to die peacefully, and they live another nine months in pain and suffering, sustained by machines, only to die in the end anyway.

There are two things to be concerned about here: the medical community sometimes trying to give you their false hopes because they are so intent on cure, and the patient and family coming in with their own. This is why the family needs to be able to talk this over with a priest or with someone else who is objective. They need to discern whether they are holding onto a false hope or a true one, and what motivates it.

Sometimes these hopes are selfless love, and sometimes they are motivated by things like financial issues or emotional blocks where family members feel they need to forgive or to be forgiven, and can't let the person go until that happens. When we find ourselves in the midst of this turmoil, we have to remember that our only true hope is in the Resurrection. All of these problems and death itself have been conquered by Christ, and through death we come to a more perfect resolution with each other in Him. Christ is the hope that we can hold on to. Let God's will be done.

One of the roles of the priest is to step in here and say, "You can let go." That's a beautiful thing. My mother died last year, and although we were a medical family, we were also her children and now had to cope with her lingering illness in a personal way. When the priest, who knew her well, came in and saw the state she was in, he said to us, "You know, you need to start reading the psalms." We did and she passed two days later. Once he said this, we were finally able to let go and it was wonderful to have that to hold onto. In the Divine Liturgy we pray, "for a peaceful end to our lives, without shame

and suffering....” This doesn’t mean that it’s going to be easy, but in Christ your human dignity is protected and restored, and your death can be peaceful.

Thoughts on Organ Donation

RTE: As an aside, earlier you spoke of your medical school training in a cadaver lab. How was that for you, and as a medical professional, what light can you shed for us on organ transplants?

DEMETRIOS: The entire time I worked in the lab I was uneasy; the only word that really fits is sorrow, and I felt that I really wanted to talk to a priest.

RTE: Your response reminds me of a passage in *This Holy Man*, the biography of Metropolitan Anthony (Bloom) of Sourozh. Before his priesthood Metropolitan Anthony was a doctor, and in medical school he was unexpectedly faced with dissecting the cadaver of an elderly friend who had left his body to science. In his last years, Metropolitan Anthony spoke of it as, “one of the most tragic experiences of my life.”²

DEMETRIOS: Being on the ethics committee and having seen as much as I do, I would now say strongly, don’t just hand your body over to science. They talk about dignity, but in my experience, there is no way that they are going to handle your body with any sort of dignity. Your body is just a commodity and this is a business. In fact, the word they use in describing the process is “harvesting.” Several priests that I’ve talked to recently have the position, “anything we can do to promote life,” but this is very unclear and confusing, because where do we draw the line? In addition, you face the problem that some procedures use aborted fetal tissue, either in development or in the procedure itself.

In regards to specific organ donations, I’ve worked as a physical therapist in transplant medicine departments long enough to have seen dramatic transformations of lives with kidney and liver transplants, and there is a lot of pressure to accept this as normal. This is a cloudy issue, though, and there are things to consider. For instance, people often don’t know that even a kidney, the most successful type of transplant, only lasts for ten to fifteen years. I do know of one man who has lived for thirty years, but he is on his

² Gillian Crow, *This Holy Man: Impressions of Metropolitan Anthony*, SVS Press, Crestwood, NY, 2005, pp. 58-59.

third kidney. Also, after the transplant most people have some degree of disability. In some cases your life can become very restricted, and people are frequently bound to medicines with side effects. Liver, heart, and other types transplants are even more difficult to live with.

Also, people may not realize that about fourteen percent of donated and extracted organs are never used, either because underlying disease is discovered or the procedures don't happen fast enough. There are living donors for kidney transplants, but most organs are taken after a fatal trauma, such as a car accident. If things don't move quickly enough, usually within 48 hours, the organ is unusable.

There are statistics for all of this, but for me the main problem is the ethical issue. The longer I work in the medical world and the closer I come to my own death, the more uncomfortable I feel about transplant. We need to remember to pray in these situations, because we really do want God's Providence. Do you know what the different Orthodox Patriarchates say about transplants?

RTE: There isn't a unified voice in Orthodoxy, although most seem to be in favor of voluntary organ donation, and speak of it as a gift of generosity and love. The Russian Orthodox Church is cautious in its approval and insists that the selected organ donation be done voluntarily, that both parties know exactly what the consequence of the act is, and that it not be for commercial gain or use fetal material or animal parts. The Romanian Patriarchate specifically forbids even voluntary living organ donations that will result in the premature death of the donor. The Greek State Church has a policy similar to the Russian, but perhaps without as many safeguards. Human dignity is a term used in all of these statements, and there seems to be an unquestioned assumption that medical institutions can and will honor the dignity of the person both before and after death.

Historically, because of the Christian view of the sacredness of the body, even dissection for research or education and autopsies was considered sacrilegious throughout eastern and western Christendom. Dissection was allowed in England, for instance, only in the eighteenth century, and then only on the bodies of executed murderers. We are now far beyond these restrictions and the problem facing European Orthodox churches that require voluntary consent is that in Austria, Belgium, France, Italy, Norway, Sweden and Switzerland, there is a "presumed consent" law, in which a

patient and family must opt out in writing if they choose not to be automatic organ donors.

Although in the U.S. we have a voluntary donor practice, in quite a few states if a coroner or medical examiner has a body under his jurisdiction, such as someone found dead on the street with no written indication that they were against donation, the coroner may take certain organs if they haven't found the next of kin within a few hours. Unfortunately, our ability to transplant organs means that trafficking is now a problem worldwide.

DEMETRIOS: Yes, the cat is out of the bag now. We should have dealt with this thirty years ago.

Bedside Advocacy

RTE: It's often said that every critically ill or dying person needs a close relative or friend as an advocate to keep an eye on what is going on in the hospital or hospice, to ask questions, and even to explain necessary details to the staff if the patient can't speak for himself. But many times we are afraid or embarrassed to ask questions: we don't want to waste the staff's time, and we just hope that "the doctor knows best," leaving us feeling conflicted.

DEMETRIOS: We all need advocates when we are ill. You are much more than your physical body, but with the medical staff concentrating so hard on your physical wellbeing, you are in danger of slipping into a state of simply being a collection of organs. Your family and friends are there to safeguard you as a person, to preserve your humanity, and family members shouldn't be afraid to ask questions, even if they seem simplistic. It's important to keep asking until you are satisfied.

To return to the problem of educating about end-of-life concerns, families need to know simple things about feeding tubes, nutrition and oxygen. If you take your friend or family member home, then you've got the problem of incontinence, which you may never have dealt with before. From these simple practical matters to very complex medical procedures, there have to be explanations. End-of-life decisions come down to what you want for your loved one and what they want in order to have a peaceful transition to the next life. One thing my own mother did was to make clear requests ahead of

time about what she wanted in the hospital and at the funeral home. It took a lot of pressure off of her children because we didn't have to try to decide what was best, or guess at what she would want. I think she even chose when to die, as she went on Thanksgiving morning when we all had a four-day weekend. The more you can discuss these topics beforehand, the better. This takes time and energy and we need to pay attention because in this society we have so little time and energy to spare.

RTE: Another problem family members face is having to educate themselves about a new illness or condition, when often they don't even know the right questions to ask. One of the most difficult decisions is when a family is told that it is time to discontinue artificial aids such as heart or lung machines. To a layperson this sounds like passive euthanasia, that we are hastening a person's death. It is easy to think, "Perhaps if only we give it more time, they will recover." How do you respond in cases like this?

DEMETRIOS: I sometimes respond by saying that to prolong a natural death unnaturally is below a person's dignity, it is dehumanizing. When you remove the machine which is no longer enabling healing, but only forcing the body to function, you are giving the person back their dignity. Their life is no longer being artificially enabled or prolonged.

RTE: Although many families have been helped by hospice organizations, some tell me that they've felt pushed out of the hospital and into hospice care by for-profit hospice providers who are eager for their business. I've heard concerns about hospice representatives attempting to persuade the family to agree to the removal of nutritional IV's and other liquids, or lowering the oxygen level to meet the criterion for hospice care. What do you think of this?

DEMETRIOS: Issues like lowering oxygen and removing nutrition are different for each person. For a healthy young person who has been in a motorcycle accident and is close to death, but may just pull through, intensive IV nutrition is vital in their recovery. For an elderly person whose lungs or other organs have stopped functioning and there is no medical hope of recovery, IV nutrition can cause more distress and even pain, because the organs can't handle the incoming nutrients. When the body begins to shut down, rich IV nutrition can cause congestion in the kidneys, liver and lungs. Even water, given as a simple IV saline solution for hydration, can pool in the lungs,

making the person feel they are drowning, or it collects in the hands and feet, causing painful swelling because the body can't assimilate the fluid.

In earlier times, when our elderly people became frail, ill, and stopped eating and drinking, we would sit around their beds, moisten their mouths with ice or wet cloths, hold their hands, and pray and talk to them until they passed. Today we can force fluids into the body, and if the organs are functioning and there is a chance of recovery, that is the right thing to do. When the organs are shutting down, it will do them no good and probably only increase their distress.

In regard to oxygen and hospice transport, sometimes oxygen levels can be lowered and the person moved to hospice with no bad effects, but the respiratory therapist tests this by lowering the oxygen in small increments. If the person begins to experience shortness of breath, the oxygen level is returned to the amount needed to breathe comfortably. It is true that needing higher levels of oxygen may mean that the patient can't go into hospice, but remains in the hospital. Before the twentieth century, we would have just passed away naturally as our lungs failed.

RTE: So, it's a balance between discerning the natural end of life and the proper use of artificial or supplementary medical aids. In a nutshell, what do you see as the limits of modern Western medicine?

DEMETRIOS: Once you aren't responding to treatment, Western medicine no longer has anything to say. They know your body is shutting down, but they don't know when life ends so, when you get to this stage, they just back off and there are no protocols as to what to do next. This is usually when they send you to hospice. A modern hospital is a sort of an industrial complex, a place for you to get treatment and get out. If you aren't getting better you have to leave. The hospital bed is valuable both economically and ethically—the economic value is obvious, but also ethically because they need that bed for the next patient who might respond to treatment. Part of the problem is that western medicine is very good at keeping you alive, but very poor at transitioning you from this life to the next.

RTE: Is there any way to remedy this?

DEMETRIOS: It's not really possible to do anything else unless you are a country doctor who can stay by the bedside until the end, because you also have other patients who need you now.

RTE: That reminds me again of Metropolitan Anthony, who as a young Parisian doctor would sit by dying patients' bedsides for days and nights on end. What can we do as friends and relatives to fill this gap?

DEMETRIOS: It is important for the family to just be there with the dying person. When my mother was dying, my priest told me that it was important that we pray for her because her frail body was the only home her soul has known. When you read prayers or scripture you are inviting that heavenly realm into the room. We are part of the physical realm, but when the physical and spiritual meet there is a peace that allows the passing.

I don't know much about practices in Orthodox Christian countries once the person has passed, but traditional Jews never allow the body to be alone until after the burial. Someone is always there. Wakes in almost every country used to be at home, not at the mortuary, and so it was a gathering of family in a place that is familiar, which seems more wholesome.

RTE: That was my experience in Russia and Greece. In villages the wakes are at home, and then the funeral in church and the burial in the graveyard. In Russia, even in the large cities, the bodies are often overnight in the church with people taking turns reading psalms through the night until the funeral.

DEMETRIOS: There is also a need to educate ourselves about the tradition of the Church in regards to funerals and burials, which now involve a whole range of choices. Another odd thing in America is that children and young people don't come to funerals. This is very strange because they've known these elderly people from church, perhaps for years.

We also have a responsibility not only to the Orthodox and to our children, but to tell non-believers and pagans what we believe about death and the afterlife. We have something to say about this area and it's not just about breathing tubes and IV nutrition.

RTE: Speaking of spiritual matters, how do we go about inviting a priest to visit?

DEMETRIOS: I would call your parish priest and explain the nature of the hospitalization and the level of urgency: is the person facing imminent death, or are they in the hospital for major surgery, or for a less serious procedure? Tell him the length of the hospitalization so that he doesn't have to rush if the person will be there for some days or weeks. Also, tell the priest

whether you are requesting a simple pastoral social visit or if they need the sacraments of Confession and Holy Communion. People's needs and desires can be very different.

Also, don't be surprised if the priest of a large metropolitan Orthodox parish isn't able to come. They are often not able to make hospital visits due to their intense workload, but perhaps the priest of a smaller parish would be free. Also, the hospital's Spiritual Care Center often has the phone numbers of Orthodox priests who are willing to be called. If you don't know your priest personally or only attend church occasionally, it might be best to go through the Spiritual Care Center. If you want a pastoral visit and the priest can't make it, there may be a deacon or subdeacon, or someone on the parish visiting committee who will be glad to come. These are often very pious people who have a lot of experience and wisdom. Also, a pastoral visit is not just for the person who is sick, it is also a way for the family to become more connected to the parish.

RTE: The medical world is complex and hospital staff are so often overworked. How is it for you?

DEMETRIOS: As a staff member you just have to train yourself to be totally in the present. This is a real challenge for anyone who works in health care because you have a busy schedule and many patient needs to meet, and it's difficult to be as present in the moment as you need to be with each person. Staff like Frederica deGraff and myself, who spend quite a bit of time with people, can see them getting weaker and measure their ability to move, walk, talk and eat. We see their outer shell is weakening, but their minds and spirit are often still vitally alive. Their humanity is intact although their body is giving up. We need to offer them the dignity of being what they truly are: the temple of the Holy Spirit, at every stage of this transition.

Even your mind and reason isn't all of you and there are many levels of the mind that we don't understand. One of the major problems with older people with Alzheimer's or some form of dementia is that they may not know anyone, so their whole life becomes a world of strangers. But even if they don't know who you are, if you try to be fully present they will somehow feel safe with you. How do you know that one person on the street or bus is safe, while another makes you feel stressed? It's intuitive, and so it is with them.

RTE: Can you give us a final word on facing the passing of a loved one in a hospital, hospice, or at home?

DEMETRIOS: When someone is passing you have to stop and give up your life. You have to just be present. One of my Orthodox friends told me that as her mother was passing, she read the whole Psalter, the Book of Psalms from the Old Testament, so I did the same with my mother. This is a long-standing Orthodox tradition and it was a spiritual act that put me in the moment with her. Neither I nor anyone else in the medical community had any way of knowing if my mother understood what I was reading, but it was my last opportunity to read for her and pray with her so that her final moments in this life would be peaceful and focused on her Savior. ✦