

PRIME TIME LIVING

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55+
LIFESTYLE

Movement Disorders
Parkinson's and Essential Tremor

Stress and Isolation
Mental Health Issues in Older Adults

Treating vascular disease
Improve blood flow and prevent strokes

Prescription Use Research
Deprescribing and cognition

Telemedicine
What's next?

Maryland Access Point
One-stop shop for seniors

Quality of life
Hospice and palliative care

Scams are rampant
Staying financially safe



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CONTINUING CARE

Your quality of life

Hospice and palliative care

By Margit B. Weisgal, Contributing Writer



In her 80s, Fredricka Whistler developed myelodysplastic syndrome (MDS), a blood disorder with multiple variations that is considered to be a form of cancer. In her case, she was constantly anemic, always tired and weak, which required regular iron infusions. The hospital where she was treated brought in the palliative care team for support. Each time she went for a treatment, she was warmly welcomed. All the staff members knew her and cheered her on. She valued those relationships.

The quality of life is
more important
than life itself.

— Alexis Carrel,
Nobel Prize in Medicine

When she celebrated her 90th birthday, and with her family's agreement, she decided she had had enough and stopped the treatments. Her doctor wrote a prescription for hospice care, knowing that without treatment she was coming to the end of her life. The hospice team – at first a nurse practitioner, a social worker and a counselor – met with her and set some goals, the most important of which was she wanted to die at home. No hospitals. No extraordinary measures. She got her wish. She died peacefully after several months.

There may come a time when you require specialized care. It may be when you have a serious illness such as cancer or heart failure, debilitating chronic conditions like dementia, Parkinson's disease

or chronic obstructive pulmonary disease. It is a time when you make choices based on your quality of life: palliative care or hospice. Whatever the prognosis, there are more options available than you might expect.

Both types of care are built around the patient and his or her needs and wants and those same benefits extend to the family.

- With palliative care, a person may choose to continue curative treatments, benefiting from extended support from the palliative care team.
- With hospice, a person decides to discontinue any curative treatments or recognizes the disease is no longer responding, benefiting from extended support from the hospice care team.

In both cases, health care providers add additional support. Hospice is always palliative, but palliative care does not always denote a hospice arrangement.

"Palliative care is meant to enhance a person's current care by focusing on quality of life for them and their family," says the National Institute on Aging, part of the National Institutes of Health. "Hospice care focuses on the care, comfort and quality of life of a person with a serious illness who is approaching the end of life." It always

comes down to the quality of life.

Palliative Care

"Palliative care focuses on those who are living with a debilitating, life-limiting, serious illness to increase the quality of life and relieve symptoms while assisting them holistically," says Tracie Schwoyer-Morgan, D.N.P., ANP-BC, lead nurse practitioner and manager of integrative and palliative medicine for Gilchrist and GBMC. "We take care of the whole person, providing support wherever the patient lives: nursing home, hospital, outpatient office or in their own residence. We look at the individual's goals, educate them on their illness so they can make informed decisions, and figure out what we can do to help.

"What's changed and improved over the last few years," she explains, "is the addition of non-pharmaceutical therapies to patients' treatments. We added a mind-body specialist approximately two years ago, to complement the services being provided to both inpatients and outpatients. The therapies are not invasive or harmful, and some work better than oth-

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ers. When the patient is open and willing to try something, we see the positive results. And each palliative care plan is customized for the individual.”

“The Integrative and Palliative Medicine program is available to all patients receiving outpatient cancer treatment at GBMC,” according to the GBMC website (www.gbmc.org/integrative-medicine). “Our integrative and palliative medicine team is focused on caring for a patient’s mind, body and spirit. Services are offered free of charge to help prevent and manage symptoms for cancer patients who are experiencing pain, fatigue, depression, or anxiety.”

Some of the services Gilchrist and GBMC has added in its integrative and palliative medicine program include:

- Nutrition consultations
- Evidence-supported approaches to supplement use
- Meditation
- Guided imagery
- Reiki
- Massage
- Craniosacral therapy
- Yoga-based wellness classes

One change Schwoyer-Morgan has observed is that doctors are now recognizing that there are different ways to handle illness. “When someone is receiving palliative care, hope is a big component so, at first, the clinicians were worried we weren’t being supportive when we recommended these alternatives. Once they learned about the offerings and saw how their patients responded, they were more accepting of what we contributed and are happy to make referrals. Now we’re meeting patients earlier ... when they are diagnosed. Patients trust the specialist, the oncologist and their team, and understand we’re there to help them cope with their illness, to figure out what’s next.”

What differentiates palliative care from regular care? It’s about the interdisciplinary team that works with a patient and his or her family. This team takes into consideration support for the social, emotional and practical aspects of the illness along with the medical care. If you opt for palliative care, you’ll have a specialized team, depending on your specific requirements, in addition to your clinician: doctors, nurses, social workers, counselors, nutritionists and chaplains. So, it’s both

personal and holistic. If palliative care is not offered, you can request it.

Another differentiator is that someone can recover from the illness or disease, or the symptoms decrease so palliative care is no longer necessary. If, on the other hand, the patient declines, and the goals change, care may shift to hospice.

Schwoyer-Morgan sums it up succinctly. “We make a difference with everyone we touch. Some more, some less, but we make a difference.” Patients value that.

Hospice Care

“Hospice is always palliative,” Denise Conway, hospice administrator for Stella Maris, says. “It becomes an option when a person receives a prognosis of six months or less. We provide patient-centered comfort care, whatever patients need, along with spiritual care. Spiritual care is not necessarily religious. It can be but doesn’t have to be. It’s whatever your spiritual journey is. We provided the state’s first integrated home hospice and inpatient hospice program in 1983.”

Hospice is a specialized program for terminally ill persons and their families. Rather than focusing on curative measures, the goal of hospice is directed toward palliative care for the patient’s comfort, pain alleviation, symptom management and support for the family. “Hospice isn’t just for the patients,” says Conway. “We’re there for the families and the caregivers, too.”

A majority of hospice care takes place in the patient’s home or wherever a person calls home, where they are most comfortable: a continuing care retirement community or assisted living facility, small group homes or nursing homes. If the symptoms or pain require additional care, the person may be moved to an inpatient facility; once everything is under control, they can return to their residence.

Mark McKenzie, administrator, and Steph Walker, divisional director of business development, oversee ProMedica Senior Care’s hospice and palliative care in the Maryland region. ProMedica is a not-for-profit organization, operates multiple skilled nursing facilities in Baltimore City and Baltimore, Anne Arundel, Harford, Howard, Prince Georges, and Montgomery counties and partners with

Stella Maris in Baltimore County to provide some of its hospice services.

“Both hospice and palliative care are unique to the individual,” Walker explains. “There is no cookie cutter plan. Based on the symptoms, with an interdisciplinary team, you get to create a plan to bring you the best life possible for the time remaining. We view hospice as something intimate, a beautiful experience that ensures you are safe and loved.”

“When it comes to hospice patients, we focus on the three Rs,” McKenzie adds, “restoration of dignity, reconciliation of relationships, and renewal of hope for the patients and those who love them. Too often, people are treated as the disease, not as an individual. We love advocating and supporting patients.”

“There’s a terrific family and caregiver benefit you can receive from Medicare that few know about or take advantage of,” says Walker, “and that’s respite care. Sometimes the caregivers, whether or not they are family, are overwhelmed and exhausted with caring for the hospice patient at home and just need a break. For them, respite care is available. With the recommendation of a social worker, the patient is moved to a skilled nursing facility for up to five days. It alleviates the pressure on the caregivers. This can be repeated and some use it every month.”

“Stella Maris, operated by the Sisters of Mercy, is known for its kindness,” Conway says, “Our hospice patients receive visits from different disciplines, not just the nurses; maybe it’s the counselor, chaplain or social worker. You never know what someone is dealing with. And we offer grief and loss counseling for up to 13 months after a loved one has passed.”

Gilchrist’s Counseling and Support Program “offers a wide range of services to meet your needs. Gilchrist can help whether your loved one has just received a serious or life-limiting diagnosis or is already receiving our care. Our counselors are available to provide emotional support before and after a loss through one-on-one grief counseling, support groups, workshops, and remembrance events,” according to its website.

Both ProMedica and Gilchrist offer navigators, trained personnel to help families with any questions and to connect

them to resources that can help them.

Stella Maris and Mercy Medical Center, Gilchrist and GBMC, and ProMedica are excellent organizations that revere, respect and care deeply for palliative care and hospice care patients and their families. If or when the time comes that you or someone you care about needs one or the other, know that they all will go above and beyond to provide comfort and support throughout.

Your Action Item

With age, we all lose people precious to us and wish for them the compassionate care as described above if needed. In any case, especially for those for whom you’re responsible, it’s essential to know what they want for the end of life. For that to happen, everyone should have an advance directive. Only this document allows you to plan for future health care decisions and what type of care you receive if you are not able to speak for yourself.

What happens when you don’t have the conversation with those important to you? Your next of kin has to make a choice in a vacuum. As one woman put it when she had to choose for her parents, “Not knowing what they would want is an unbelievable burden to put on people.”

A form is downloadable from the office of the Maryland Attorney General. On the same page is a video along with additional instructions. You’ll want to share this with your family, friends and your doctor. As it says in the introduction, “The conversation is just as important as the document.” www.marylandattorneygeneral.gov/Pages/HealthPolicy/advancedirectives.aspx

Other forms you may want to include are MOLST (Medical Orders for Life-Sustaining Treatment) at <http://maryland-molst.org/>, and one for organ donation.

It goes on to say: “Life-threatening illness is a difficult subject to deal with. If you plan now, however, your choices can be respected, and you can relieve at least some of the burden from your loved ones in the future.”

Be kind to your family and do this today.

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Hospice care, palliative care and Medicare

Steff Walker, divisional director of business development, home health and hospice – Central Division with ProMedica, talks about access to hospice for older adults. “Hospice is a Medicare Part A benefit. You have to be diagnosed with an illness that has a prognosis of six months or less, when you’ve exhausted curative treatments available, or are in constant decline. It was created to be provided in a patient’s home. If it’s too burdensome, you may be transferred to an inpatient setting. Patients are provided end of life care with the goal of increasing the quality and catering to whatever that person wants for their remaining time.”

“All Medicare-certified hospices are required to offer four levels of hospice care depending on patient and caregiver needs. Medicare-certified hospice care is usually given in your home or other facility where you live, like a nursing home. You can also get hospice care in an inpatient hospice facility. Original Medicare will still pay for covered benefits for any health problems that aren’t part of your terminal illness and related conditions, but this is unusual. Once you choose hospice care, your hospice benefit will usually cover everything you need,” as stated at www.medicare.gov/care-compare/resources/hospice/levels-of-care.

Routine home care

- Most common level of care in hospice. Patient is generally stable and the patient’s symptoms, like pain or nausea and vomiting, are adequately controlled.
- Usually provided in the home.

General inpatient care

- Crisis-like level of care for short-term management of out-of-control patient pain and/or symptoms
- Usually provided outside the home, in an inpatient setting at a medical facility like a hospital or skilled nursing facility.

Continuous home care

- Crisis-like level of care for short-term management of out-of-control patient pain and/or symptoms
- Usually provided in the home.

Respite care

- A level of temporary care provided in nursing home, hospice inpatient facility, or hospital so that a family member or friend who’s the patient’s caregiver can take some time off.
- This level of care is tied to caregiver needs, not patient symptoms.

Depending on your terminal illness and related conditions, your hospice team will create a plan of care that can include any or all of these services:

- Doctors’ services.
- Nursing and medical services.
- Durable medical equipment for pain relief and symptom management.
- Medical supplies, like bandages or catheters.
- Drugs for pain management.
- Aide and homemaker services.
- Physical therapy services.
- Occupational therapy services.
- Speech-language pathology services.
- Social services.
- Dietary counseling.
- Spiritual and grief counseling for you and your family.
- Short-term inpatient care for pain and symptom management. This care must be in a Medicare approved facility, like a hospice facility, hospital, or skilled nursing facility that contracts with the hospice.
- Inpatient respite care, which is care you get in a Medicare-approved facility (like an inpatient facility, hospital, or nursing home), so that your usual caregiver (like a family member or friend) can rest. Your hospice provider will arrange this for you. You can stay up to 5 days each time you get respite care. You can get respite care more than once, but only on an occasional basis.
- Any other services Medicare covers to manage your pain and other symptoms related to your terminal illness and related conditions, as your hospice team recommends.

Medicare doesn’t cover room and board when you get hospice care in your home or another facility where you live (like a nursing home).

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in the wrist with gentle electric shocks. The therapy is being evaluated through clinical trials, and thus the Food & Drug Administration (FDA) is still determining its value.

Focused ultrasound

The University of Maryland Medical Center (UMMC) is the only health care provider in the state of Maryland to offer focused ultrasound (FUS) for treatment of essential tremor. With focused ultrasound, pinpointed acoustical energy is specifically directed to the targeted areas of the brain that are responsible for movement difficulties. Magnetic resonance imaging (MRI) is used to locate targets and create a heat map for the procedure, and the MRI technology guides the physician to visualize the targeted areas in real time. These pinpointed spots are treated with low energy to the lesions and evaluated before increasing the intensity to remove the affected brain cells.

With its gradual process, FUS enables physicians to interrogate the target and evaluate for changes in sensation and muscles strength, before initiating permanent changes to tissue.

“You can perturb that part of the brain enough so you can see the tremor go away,” Dr. Eisenberg explains. “The tremor is significantly reduced, and there are no off-target effects. Then, the energy is stepped up for ablation to make the change permanent.”

During the procedure, patients remain awake and undergo function testing throughout the several-hour treatment. They return home the same day – some even drive themselves home – and

resume regular activity within a few days. Patients notice improvement almost immediately following the procedure, and typically experience up to a 70% reduction in symptoms.

“With focused ultrasound, we can get enough energy to go through the skull and be specifically applied to the target area,” says Dr. Eisenberg. “There are multiple adjustments that can be made to account for variations in the skull and to specifically pinpoint the areas that are causing the movement abnormalities. This procedure has proven to provide significant reduction in tremors and other movement concerns.”

Over the last five years, Dr. Eisenberg and his colleagues at UMMC directed groundbreaking research that led to authorization for unilateral (to one side of the brain) use of the procedure for essential tremor by the FDA and Centers for Medicare and Medicaid Services (CMS). The use of FUS unilaterally for tremor predominant Parkinson’s disease also has been approved by the FDA and in some states by CMS. FUS unilateral treatment for Parkinson’s disease has received FDA approval but not yet CMS approval. Research study of the use of FUS bilaterally (both sides of the brain at once) for essential tremor has been completed; data analysis is underway.

“Deep brain stimulation is still the gold standard, but for patients who don’t feel they can tolerate deep brain stimulation, or they don’t want to have electrodes implanted in their brain, they choose focused ultrasound,” Dr. Eisenberg says. “This a great option for these patients.”