Letter from the Chief Medical Officer

This issue of Clinical Connections takes a closer look at the benefits of palliative and hospice care for patients with advanced neurodegenerative diseases. While diseases such as amyotrophic lateral sclerosis, multiple sclerosis, and Huntington’s disease have diverse pathologies and trajectories, all are associated with a complex range of symptoms that lead to progressive physical decline and the potential for high levels of prolonged suffering.

Patients have several common care needs, and their caregivers experience an extraordinary degree of stress. Earlier in the course of disease, palliative care used in conjunction with disease modifying treatments is effective in treating the full range of symptoms, and in establishing a transdisciplinary model of care that will remain in place through the entire course of the illness.

In the final stages of the diseases, when the prognosis is measured in months rather than years, transitioning into hospice provides the same intricate web of physical, psychosocial and spiritual support needed to relieve symptoms, maximize patient dignity and choice, and improve quality of life for both the patient and the family.

As the number of Americans living with serious illnesses continues to climb, hospice care makes it possible for individuals to have a choice in how they spend the final stage of their life. They are able to remain in their own homes, if they prefer, surrounded by their family and friends.

Whether measured in terms of the patient’s quality of life and family satisfaction or savings in health care costs, palliative and hospice care play integral roles in delivering care through the full spectrum of life.

Your partner in care,

Dr. Charles Wellman MD
Chief Medical Officer, Hospice of the Western Reserve

Hospice Allows ALS Patient to Live Safely at Home

Michele Tripi Living Life to the Fullest

Michele Tripi, who is living with advanced amyotrophic lateral sclerosis, focuses on making the most of each new day. With the support of her family and her hospice home care team, she is able to live safely and comfortably in her own home in Seven Hills.

Tripi and her husband, Joe, were educated about the benefits of hospice earlier in the course of the disease when they attended a support group offered by the Northern Ohio Chapter of the ALS Association. The group also provided insights on adaptive medical equipment she could use to safely maintain a degree of personal independence and autonomy.

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Research Enhances Hospice, Palliative Care
Two Clinical Trials Underway

By Christine Morehead

Editor's Note: Christine Morehead, B.A., CCRP, has been a full-time Certified Clinical Research Professional at Hospice of the Western Reserve for the past four years. For more information on the agency's research initiatives, contact Morehead via email or phone: cmorehead@hospicewr.org; 216.472.2279.

The agency's research team was created in 2010 as a way to enhance hospice and palliative care through evidence-based research. Currently, Hospice of the Western Reserve is one of only five hospice organizations within the U.S. that conducts research.

Survey studies show that hospice patients often choose to participate in research as an altruistic act, and as a declaration of autonomy, life and independence. In fact, for some hospice patients, it is the very act of giving back that is the missing puzzle piece that helps them find peace at the end of life.

We actively engage in interdisciplinary research, and our ultimate goal is to improve the care of patients with advanced illness and their families. This is done through our collaborative efforts with local universities - Case Western Reserve University and Kent State University - with pharmaceutical companies, and with national collaboratives, such as the Palliative Care Research Cooperative and the Population-based Palliative Care Research Network.

Two clinical trials are currently underway:

• A cancer-related pain study researching the efficacy of cannabinoids on relieving cancer-related pain
• A study on the efficacy of the drug Nuedexta on emotional lability (pathological laughing and crying) in patients with a diagnosis of stroke or traumatic brain injury

The agency also actively engages in nationally funded research. Case Western Reserve University recently collaborated with Hospice of the Western Reserve to conduct a study examining the effects of palliative care interventions in patients with HIV disease.

The reasons people choose to volunteer for clinical research differ. Every story is unique, but when hospice patients choose to become involved, they become partners in a special relationship with members of the research team who are searching for better ways to understand and treat pain and control other chronic symptoms. Their participation can lead to genuine progress in palliative care and to a better quality of life for patients at the end of life. I encourage physicians who are interested in learning more about sharing the gift of participation with their patients to contact me.

Michele Tripi at Home – Continued from Page 1

Together, the family developed a plan that included modifying their home to make it easier for her to navigate. She completed all of her advance care directives so her family would not be left guessing about what she would want.

Tripi’s daughter, Jackie, negotiated with her employer to work part time from her mother’s home, and her husband, Joe, made similar arrangements. The couple’s son, Joe Jr., is equally committed to the care plan and is available to help 24/7 when called.

Although the decision was not an easy one, as the disease progressed, Tripi was prepared with the knowledge, resources and family support she needed to transition into hospice care.

Expressive therapies and legacy work add richness and depth to her experiences while providing a conduit for focusing on her family and her faith, which have always been at the center of her life.

Under the tutelage of art therapist Holly Queen, Tripi and her husband worked together to create a collage of the Leaning Tower of Pisa, commemorating a 25th anniversary trip they took to Italy. She has also created a legacy book, which hospice arranged to have published and bound for members of her family. Music therapist Brooke Baker worked with Tripi to set her original lyrics to music and to have the songs professionally recorded so they can be played and sung anytime Michele needs to find comfort and inspiration from them.

Hospice allows Tripi to appreciate the little things. After-school visits from the grandkids. Coffee with a neighbor. Dinner with her family. It’s hard to place a value on that.
The Benefits of Palliative Care for Individuals with Progressive and Advanced Neurodegenerative Diseases

By Dr. Michael Harrington, Director of the Palliative Care Consult Service at MetroHealth Medical Center in Cleveland - Dr. Harrington is board certified in Internal Medicine, Geriatric Medicine and Palliative Medicine, and is also an assistant professor at Case Western Reserve University, College of Medicine.

Editor's Note: This column features perspectives from guest physicians. Submissions are welcomed! Send column ideas to: lhenrichsen@hospicewr.org.

Patients with progressive neurodegenerative diseases such as amyotrophic lateral sclerosis or Huntington's disease benefit from palliative care services, which aim to relieve pain and other distressing symptoms and to affirm life while empowering and preparing patients and family for disease progression and death.

Early in the disease course, palliative care develops the patient’s “goals of care” that provide the foundation for future medical decision making and care. These goals of care are made jointly by educating patients and families on the prognosis and future disease course, and at same time, exploring and understanding what is most important to patients as they become more debilitated so the palliative team can help interpret and guide future medical decision making.

Historically, the focus for patients has been disease modifying medical therapies that become less effective and often, quite burdensome. Palliative care can be administered in conjunction with disease modifying therapies, and can empower patients and families by discussing prognosis, expected distressing symptoms, functional decline to expect in the future, advance care planning, discussion of artificial hydration and nutrition, respiratory support, engaging supportive home care services and death planning.

The last few months in these diseases are often marked by an expected decline in strength and respiratory effort, decreasing alertness, and worsening dysphagia. Already having had thoughtful, advance discussions framed in the patient’s goals of care helps make each patient’s care proactive rather than reactive when discussing artificial life-sustaining therapies, especially at this end stage of illness. Palliative care anticipates and re-enforces that this is the expected natural history for the disease, which will help improve end-of-life care for patients, family and health providers.

Hospice of the Western Reserve Earns High Satisfaction Scores

Hospice of the Western Reserve has been awarded “Hospice Honors” and “Hospice Honors Elite” awards by Deyta LLC, a data-gathering company that partners with approximately 1,600 hospices across the country. Hospice of the Western Reserve is the only hospice organization in Northeast Ohio to receive the awards.

The “Honors” award received by Hospice of the Western Reserve’s Ashtabula regional teams denotes excellence in care provided to patients and their families, and was awarded to only 10 percent of the 1,600 hospices nationwide that use Deyta to benchmark patient and family satisfaction scores. The “Honors Elite” designation was awarded to the Mentor regional teams and denotes superior care was provided; only two percent of hospices achieved Elite recognition.

The performance criteria are based on results compiled from Family Evaluation of Hospice Care (FEHC) surveys Deyta provides to each family following a patient’s death to evaluate patient and family satisfaction across many categories. The survey asks families to rate Hospice of the Western Reserve in a wide range of categories such as control of the patient’s pain and anxiety, personal care, keeping the family well-informed, providing families with the tools needed to care for their loved ones, respecting religious, spiritual or cultural beliefs and providing emotional support both before and after a death.

Clarification of Medicare Part D Medication Coverage

Recent direct mailings from the Centers for Medicare and Medicaid Services (CMS) and Part D Providers (PDP) sent to patients and clinicians have caused confusion. This article is an effort to clarify Hospice of the Western Reserve’s implementation of the changes in medication coverage.

- CMS affirms that the hospice physician/team continues to determine what medication, supplies and procedures are reasonable and necessary for the palliation and management of the patient’s terminal illness and related conditions.
- Some medications that have been previously prescribed for some conditions may no longer be necessary or appropriate, and therefore will not be covered.
- The CMS changes may trigger the need for discussions with patients/family members regarding futility of treatment, discontinuation or changing of medications.
- Additionally, some medications will need prior authorization from the hospice provider in order to be paid through Part D.

Hospice of the Western Reserve will review any medication changes with patients and their provider. We share your concern for the patient’s well-being. As our plan is to partner with you, we carefully analyze each case to make the best treatment decisions.

Thank you for your continued care, commitment and collaboration. If you have any questions, contact Wayne Grant, Pharm D, or Janice Scheufler, Pharm D, at 216.454.0399 or one of the Hospice of the Western Reserve administrators at 216.255.9071.
2014 Hospice of the Western Reserve End-of-Life Series
Celebrating Nearly 20 Years of Excellence in End-of-Life Education

Hospice of the Western Reserve is pleased to introduce the new 2014 End-of-Life Series, a continuing education opportunity for health care professionals. In response to requests from past attendees, this year’s educational opportunities will all be morning half-day events.

TENTATIVE EVENT SCHEDULE:

Friday, August 22
Telling the Stories: The Deeper Voice of Hospice, Compassion Fatigue
Location: Corporate College East

Friday, October 10
Transitioning from Curative to Comfort
In collaboration with The Gathering Place
This educational opportunity is inspired by the life and work of medical doctor and hospice patient, Dr. Elizabeth McKinley. Dr. McKinley’s choice of hospice care after a career in curative medicine was featured in the New York Times. Her family is working with Hospice of the Western Reserve to create a clinical lecture in her memory.
Location: Benjamin Rose Institute

Friday, November 14
In collaboration with MetroHealth Medical Center and The Gathering Place, the November session will be presented with a focus on the Hispanic community. (Details to follow.)
Location: MetroHealth Medical Center Main Campus

For more information, contact institute@hospicewr.org, or call 216.383.3751.