

Still Me: A Comforting Presence, a Dignified Approach and a Partner in the Process



Dementia is a debilitating disease that not only takes away one's independence but also buries their memories, alters parts of their personality and diminishes their ability to communicate. To address the many unique obstacles dementia patients and their caregivers face, Hospice of Holland introduced a new end-of-life advanced dementia care program, "Still Me", in August. Our goal is to provide dementia patients and

their caregivers a comforting presence, a dignified approach and a partner in the process.

The "Still Me" program centers around learning about a patient's history and current preferences in order to help connect with them, create meaningful interactions with their caregivers, and ease frustrations and difficult behaviors. Hospice of Holland staff help families assemble Stimulation of Senses (S.O.S.) kits, containing items that stimulate all five of a patient's senses in order to bring joy, comfort and necessary distraction. These kits are utilized by staff, volunteers, and the caregivers themselves to help comfort the patient.

A customized approach to personal care and pain assessment is another important feature of the "Still Me" program. Bathing and personal care tasks can be quite challenging for dementia patients particularly at end-of-life. Hospice of Holland staff approach these necessities from the patient's point of view, incorporating their preferences as much as possible. Staff are trained to assess non-verbal cues that a patient might be in pain or otherwise physically uncomfortable, since most dementia patients are not able to put this into words.

Educating and instructing other professional caregivers on these skills and approaches will be another important way this program can benefit the community.

The caregivers of advanced dementia patients often have a long term and difficult role. The "Still Me" program focuses not only on providing care and support to the dementia patient, but to the caregiver as well. Hospice of Holland social workers offer education and assistance with advanced planning for common health care decisions that end-of-life dementia patients and their decision makers often face. Caregivers are offered opportunities for respite to receive necessary breaks, and caregiver support groups to share, learn, and feel understood by others dealing with similar circumstances.

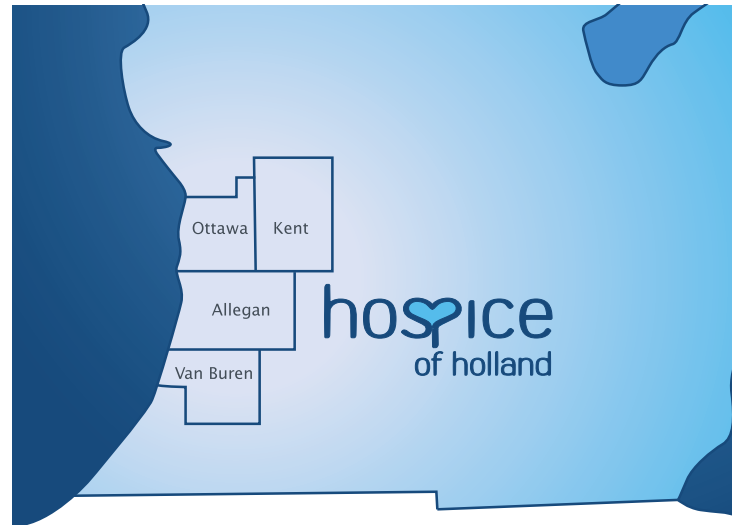
With a growing number of hospice dementia patients, Hospice of Holland has recognized the need for a specialized approach to attend to the many distinct

Still Me (continued)

challenges faced by dementia patients and their caregivers. It is our hope that the “Still Me” program will provide increased comfort, support, and quality of life to the patients and their families, as well educate the professional care giving community to utilize similar approaches and techniques. Even with the devastating losses dementia creates, Hospice of Holland is dedicated to honoring the uniqueness of each individual and preserving the dignity that every person deserves.



24% of Hospice of Holland patients have some form of dementia



Hospice of Holland serves people in Ottawa, Allegan, Kent and Van Buren Counties.

The Right Place...at the Right Time



Torrey Husmann, MHA
Executive Director

This past summer Pat Summitt, the popular head women’s basketball coach for the University of Tennessee, announced that she has early onset of dementia at the age of 59. Many of us think of dementia as a disease for the elderly and do not think it can affect someone in the prime of their life. However, research is showing that dementia currently affects more people and at younger ages

than ever before. On average, 24% of the patients’ now receiving care from Hospice of Holland have some form of dementia - from minor onset to advanced symptoms.

If you have had a personal experience with someone with dementia, you know how difficult communication can be. Imagine what it is like to have a terminal illness and not be able to express how you feel or tell someone what you need. We see this struggle every day.

With our senior population living longer and growing in numbers, it is not farfetched to say that someday 50% of our patients will have some sort of dementia. Hospice of Holland is preparing to meet the needs of the community in caring for patients who have advanced dementia and are facing end-of-life.

On August 1, 2011, Hospice of Holland launched a new program called “Still Me”. Our clinical staff and volunteers are specially trained to care for patients who have a terminal illness and struggle with advanced dementia. The goals of this new program are to provide quality care to the patient, be a resource to the caregivers, and support the caregivers through this journey. Individuals who care for those with dementia have a tremendous burden on their shoulders. Our goal is to help reduce that burden as much as we can through support, education, training, and caring for the caregiver, as well as their loved one.

Your gifts make programs like “Still Me” possible. It’s just the beginning of how Hospice of Holland is preparing for the healthcare needs in the community, and for the increased demand for hospice care.

Select members of the medical community and the leadership team at Hospice of Holland are working together on additional programs where the need is great and the skills and talent of dedicated staff can add more life to every day for our patients who are nearing the end of life.

Hospice of Holland is truly the right place at the right time.

Honoring a Mother “who was always there”



Florence Baker (left) pictured with daughter Suzi Kraus (right)

Not since the first years of her life has Florence Baker had the attention she is receiving now. The oldest of 7, Florence has always been the care-giver, starting when her first brother was born.

Florence and her husband, George, had six children of their own. Daughter Suzi says, “We were poor but our mother was always there - often with homemade cinnamon rolls or freshly fried doughnuts.” Son Al

remembers his mom sewed his school shirts and a coat.

Florence was a beautiful woman who enjoyed dressing nicely, fixing her hair, and wearing a bit of make-up. Her faith was very important. She loved to sing hymns and write poetry, and helped often at church. For years Florence was guardian for her disabled niece, visiting her weekly in Kalamazoo. Then, just one year after George retired, he had a massive stroke. Florence cared for George for the next 20 years.

At 94, Florence’s personality hasn’t changed much. She still loves visitors and singing hymns, but now has cancer, heart problems, and advanced dementia. She mistakes her children for her parents or a best school friend. She cannot bathe or dress herself, remember to eat, or follow a conversation. She must be watched closely or she will leave their home on a busy road.

Al moved from California to be his mother’s full time caregiver. “I’m honored to do it. She has taken care of so many other people.”

Last December, the family called Hospice of Holland in to help. Now nurse Shelley visits weekly to monitor Florence’s symptoms and medications. Support counselor Heidi C. visits monthly and maintains phone contact with Al and Suzi. Home health aid Heidi D. visits 3 times per week to bathe Florence and take care of her personal needs. Volunteers Christine and Kendra each visit weekly, giving Al much needed time off, while they chat with Florence, read to her, take her for walks, and help her do crafts.

Al is challenged to keep Florence occupied. He often gets his mom involved in the tasks he is doing, including scraping the garage and weeding the garden. Heidi C. suggested a big basket of clean laundry to sort & fold.

Al notes, “It is important to have good people around.” He showed us an article (The Quiet Crisis, from the Sept 2011 Reader’s Digest, about the difficulties and isolation of care-giving) given to him by volunteer Christine, saying, “An example of a volunteer going above and beyond.”



Pictured here: Florence Baker with son Al Baker

From her home in southern Illinois, daughter Suzi says, “*Hospice has made such a difference. I live 500 miles away. If I need to know details, I can call and ask her social worker Heidi or nurse Shelley. They are health care professionals who can tell me what is going on, explain medications, and tell me who I can talk to.*”

We couldn’t keep her at home without all the help from Hospice. The respite time for Al each week is very important. Mom is happy. She loves having company. She was isolated before [Hospice].

I thought [Hospice] just sat with a dying person and comforted them and the family. I now know they do sooooo much more. Yes, they are with dying people but they give them a life while they are still living. I don’t know of a happier life my mom could have even though she is ill and nearing 95. She loves the care of her new Hospice friends, which makes the rest of us happy for her.”

Dementia may take away
my independence, but I’m still me.

Dementia may erase
my memories, but I’m still me.

Dementia may steal **my plans**,
my thoughts and **my words**,
but I’m still me.

No matter how I change or what I lose,
don’t forget that **I’m still me.**

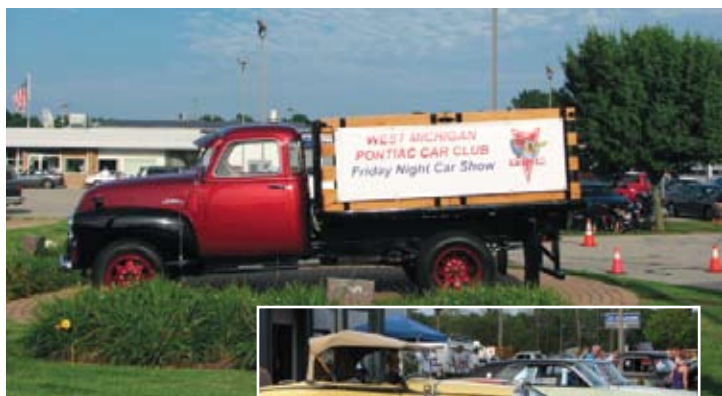
Written by: Stacey Wakely, LMSW,
Hospice of Holland Director of Counseling Services

Thank you! Thank You! Thank You!

We are very thankful for the many Friends of Hospice who raise & donate the funds that pay for the highest quality and most compassionate care, including new programs like “Still Me,” and fund the Tulip Tree Fund. Thank you:



Latin American Bikers Association raised \$500 with their First Annual Redneck Memorial Run in memory of Rick Norwood.



West Michigan Pontiac Oakland Club donated \$800 raised at their annual car show - always the first Friday in August at the Elhart Automotive Campus. Since 1999, the club has raised more than \$7,500 for Hospice of Holland patients.

West Ottawa High School students Stephanie Baird, Mercedes Manders, and Stephani Robinson, turned a school assignment into a fundraising and awareness-raising project for Hospice of Holland in memory of Stephanie Baird's mom, Debbie Baird. The girls raised \$56.42 at school and through an event at Buffalo Wild Wings.



Don's Flowers For more than 7 years, Don's Flowers of Zeeland has generously delivered a single rose to the funerals of Hospice of Holland patients. Doug Vos and the Don's Flowers team also faithfully provide gorgeous weekly flower arrangements to grace the Hospice House. Thank you for your beautiful support!

Enjoy a “sweet treat for Hospice” at Pereddies in November. Pereddies will donate 50 cents to Hospice of Holland for every dessert that is purchased in the dining restaurant for the month of November.

Can You Help Us – Please!

The items below are necessary for our mission of providing the most compassionate and highest quality end-of-life care. For more detailed information about the needs below, please see www.hollandhospice.org or call Ann Schutt at 616/396-2972.

Sleeper Sofas:
\$1,500 per sofa.

Chair replacements for the Hospice House:
Up to \$2,500

Outdoor furniture for the Hospice House:
Up to \$3,000

Bariatric Lift:
\$3,575

Bariatric Bed:
\$15,000

Shared Area Network (SAN) Hard Drive:
\$25,000

Nurse Call System for the Hospice House:
\$50,000

A 30th Birthday Celebration

The annual Celebration fundraising gala sported a birthday theme while raising \$142,000 for our patients who must rely on the Tulip Tree Fund.

In 2010, \$143,000 of Tulip Tree funds were used. **Thank you to all who participated. You make an incredible difference for patients and their loved ones:**



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2011 VanderLeek Cup Regatta

Weather was a big factor in the 5th Annual VanderLeek Cup Hospice Regatta, with thunderstorms delaying the sailing and the dinghy poker run.

Despite the challenges, the event was a wonderful success for our patients who must rely on the Tulip Tree Fund. With nine sailboats, 53 dinghies, and 400 people attending the dinner, auctions and dance at Yacht Basin Marina, more than \$42,000 was raised. For sailing & poker run results, see www.hollandhospice.org.

Thank you – for the generosity, enthusiasm, and hard work of all who participated!



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To receive future newsletters by email, or to request no further mailings, call 616.396.2972, or email info@hollandhospice.org

Truth, Time and Tenderness

Our new video, "Truth, Time and Tenderness", was developed by Murdoch Marketing and is available for viewing at www.hollandhospice.org. This compelling, 7 minute video tells the story of Hospice of Holland's compassionate care. Special thanks to Tom Murdoch and his team for all their work on this project!

Would your group like a showing, followed by Q & A period, at your next meeting? Please call Denise Stancill at 616/396-2972.

