

Reflections Newsletter

Summer 2018 | 888.823.8880 | gilchristcares.org



Care When It's Needed Most

In this Issue...

The new inpatient pediatric hospice unit at Gilchrist Center Baltimore fills a critical need for seriously ill children and their families. Read about one family's journey with Gilchrist Kids. **Also in this issue:** the role of a Gilchrist chaplain, things that may surprise you about hospice care, and how Elder Medical Care can help seniors remain in their home. Don't miss our volunteer opportunities, upcoming events and support groups.

Above: Gilchrist Kids physician Bridget Pekrul, MD, checks on patient Lilley Garlow at the Gilchrist Center Baltimore inpatient pediatric hospice unit.



The Unknown Road Ahead

The first time Joan Garlow walked through the doors of Gilchrist Center, she broke into sobs and had to run back outside. She knew she needed help, both for her daughter, Lilley, whose health was progressively declining from a degenerative brain disorder, and for her and her husband, who were struggling to care for their medically fragile child themselves. It was too much to go through alone.

When Joan worked up the courage to walk back inside, a kind woman connected her with Gilchrist Kids. Since that day over a year ago, Gilchrist Kids has wrapped the family in its care.

When Inpatient Care is Needed

While Lilley receives medical care at home, she has also received care at the newly opened inpatient pediatric hospice unit at Gilchrist Center Baltimore, the only one of its kind in Maryland. Under the care of Dr. Bridget Pekrul and the pediatric nurses and aides, Lilley received treatment there for a week in June, when she was having complications from a gastrointestinal problem.

"The Gilchrist Kids Inpatient Unit is a truly unique concept, and is a huge benefit for children and families throughout the community who need hospital level care, but don't want to go back to a hospital environment," says Mary Tiso, Gilchrist Kids clinical manager. "We provide supportive, compassionate care in a small, home-like unit, using pediatric-trained staff who recognize and support each child's unique needs."

"I feel held in supportive loving care—everything is aligned with what's good for Lilley and what's good for us. It's priceless."

—Joan Garlow, mother of Lilley

Support and Guidance

Lilley's disorder is degenerative, and there is no treatment or cure. There are hard decisions that come with the illness. Invasive surgeries and intravenous feedings may prolong life by small increments, but at the cost of quality of life. Dr. Pekrul and Lilley's nurse, Jody Staley, help Joan and her husband, Will, weigh these decisions, and they offer non-invasive therapies and medications to help improve Lilley's quality of life.



Lilley shares a smile with the Gilchrist Kids nursing team (L to R: Madeline MacKean, Jody Staley and Chris Snyder) during her stay at the inpatient pediatric hospice unit at Gilchrist Center Baltimore.

The family's Gilchrist social worker, Susan Scarvalone, has also been a helpful sounding board for Joan. "When you have a child who's really sick, you never feel like you're doing enough because you can't fix it," explains Joan. "She helps me understand that I am doing as much as I can."

Caring for the Whole Family

Families like Lilley's can also use Gilchrist Center Baltimore for respite care, which offers around the clock care for children so that parents can have a break from the demands of caregiving. The first time Joan used respite care, she hadn't had a vacation for 17 years. Because of Lilley's medical needs and her inability to eat, speak, walk or use the bathroom, leaving her with a family member or friend wasn't an option. But with Lilley in the care of a team familiar with her needs and daily routine, Joan and Will felt comfortable going on an out-of-town trip. When they returned to pick Lilley up, she met them with a smile.

"Using respite has been so restorative," says Joan. "When I come back I have the mental, emotional and physical capacity to be really present with Lilly. I can find the energy to interact and play with her."

Though the family travels a difficult and unknown road, Gilchrist has been there by their side every step of the way, with loving support and guidance. The care Gilchrist Kids has offered has been life-changing for Joan and her family. "Gilchrist saved our lives," says Joan.

To learn more about Gilchrist Kids, visit gilchristcares.org/gilchrist-kids or call 1.888.823.8880.

7 Things I Never Knew About Hospice

A firsthand account from a family caregiver



The author, Deanna (right), with her mother and Gilchrist nurse Renee Wolfe.

My 91-year-old mother, Evelyn, moved in with my husband and me after Dad died in 2010. Five years ago, she was diagnosed with dementia. After a recent fall that resulted in a broken leg, her health further declined and the doctor suggested hospice. I can honestly say that Gilchrist has given me back my life. I feel strongly that **more people need to hear exactly what hospice care can do**, as I thought it was only for those close to dying. How wrong I was! Here are seven things I never knew about hospice before coming to Gilchrist.

1 Medications and supplies are fully covered

Before enrolling in hospice, we were paying out of pocket for medication, copays and supplies. Now, everything related to her diagnosis is covered under the Medicare hospice benefit. That means we pay nothing for medication, supplies and visits from the hospice team. Our Gilchrist nurse takes care of ordering whatever is needed, and everything is delivered to our door—trips to the pharmacy are no longer required.

2 We have an entire team focused on our care

Each week, Mom's hospice doctor, nurse, social worker, aide and chaplain meet as a team to talk about her care. That means everyone on the team is sharing information with each other and discussing any care changes that may be needed.

To learn more about Gilchrist Hospice Care, visit gilchristcares.org/hospice or call 1.888.823.8880.

3 No more traveling to doctors' appointments

Before, I had to worry about finding and paying for wheelchair transportation to take Mom to the doctor. Now, her medical team comes to my home instead. That alone is a huge burden off my shoulders.

4 Hospice care lowers stress for caregivers

Gilchrist cares for the whole family. Seeing a loved one age and deal with health issues is very hard. Unfortunately, I was not always good at putting my needs first. Now I have a wonderful team to support me. My stress has lowered so much. Friends are even commenting about my more relaxed demeanor.

5 Our nurse helps me understand what to expect

It is so reassuring to know that our nurse is just a call away. She has been my saving grace. She comes at least once a week. As she checks Mom, she tells me what to expect with my mom's dementia—what is normal and what to observe for potential concerns. She helps me understand the progression of the disease and answers all my questions.

6 Nursing support is available 24 hours a day, 7 days a week

If Mom were to show any signs of needing urgent medical attention of any type, my first call would be to Gilchrist, not 911. Gilchrist has triage nurses manning the phone 24/7. The nurse will ask questions and then indicate if 911 is the appropriate action. If non-emergency medical attention is needed, Gilchrist will send a nurse within one to two hours. When I called the nurse line with a question, I felt I had caring arms holding me up.

7 Hospice care can continue beyond six months

While entry into hospice requires a life expectancy of six months or less, I know that if I am lucky to have Mom longer, hospice will continue to be covered, if appropriate. My mom is living without discomfort at home with us instead of in a hospital or nursing home, and I have all the support I need to take care of her.

Chaplain Helps Medal of Honor Recipient Reflect on Life



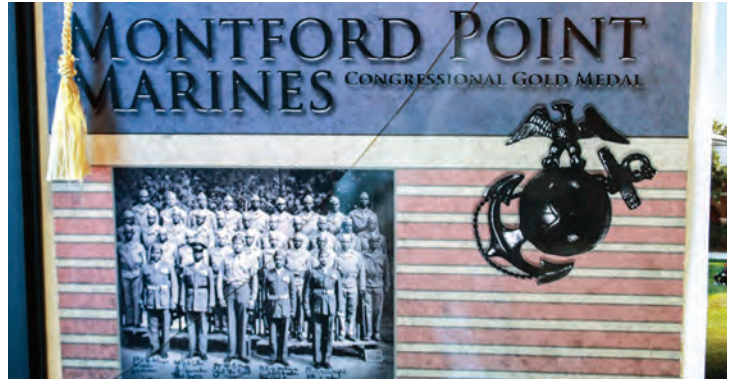
Chaplain John Yoo offers James Dixon spiritual support and helps him reflect on what is most meaningful at the end of life. Chaplain John is part of an interdisciplinary hospice care team that regularly visits James.

As a chaplain at Gilchrist, John Yoo's role goes beyond prayer and spiritual counseling. Much of his work involves listening to patients talk about the relationships and defining experiences that have made their lives meaningful.

For 93-year-old James Dixon, who receives hospice care for bladder cancer and dementia, being awarded the Congressional Gold Medal was one of those defining experiences.

He recalled to Chaplain John how he joined the Marines shortly after President Franklin D. Roosevelt signed an executive order allowing African Americans to enter the armed forces for the first time.

Despite the mandate, discrimination lingered. James trained at Montford Point, a segregated training camp in North Carolina, and fought in Okinawa in World War II. After the war, James went to college on the GI Bill and served 33 years in the Baltimore City Police Department.



Seventy years after his military service, James and other surviving Montford Point Marines received the Congressional Gold Medal, the highest civilian award bestowed by Congress, in recognition of the contributions they made to the U.S. Marine Corps and the country.

At Chaplain John's first visit with James, he formed an immediate connection—in part because his own son is a Marine. "I have great respect for James and for his service," he said. "He was one of the pioneers advancing civil rights not just for African Americans but for other minorities, including my son."

To honor James for his service, Chaplain John helped arrange a veteran pinning ceremony at the assisted living facility where James lives. His son, William, attended along with a veteran volunteer and members of his Gilchrist team.

"Gilchrist has been here for us... They have done so many things to make my father feel good and to honor him."

—William Dixon, James' son

In James' conversations with Chaplain John, one thing became clear: his accomplishments far outweigh his regrets. "The medal of honor is the highest honor you can get in this country," said James. "And that, I consider an achievement."

To learn more about Gilchrist Hospice Care, visit gilchristcares.org/hospice or call 1.888.823.8880.

Elder Medical Care Helps Seniors Remain in Their Homes

When you hear the name Gilchrist, you might immediately think of hospice. But one of the most helpful services Gilchrist offers is medical care for seniors with serious illness. Gilchrist Elder Medical Care is a much-needed service for those who are elderly, frail and have difficulty traveling to doctors' appointments.

Medical Care at Home

With Elder Medical Care, a team of medical professionals provides comprehensive, coordinated medical care for the patient in their home or residential care community. This care is overseen by a physician, with regular visits by a nurse practitioner.

We often find that, prior to coming to Gilchrist, these individuals have no choice but to go to the emergency department for health crises. This is not only expensive, but it leaves seniors without anyone managing their symptoms between visits or overseeing their overall care. Being shuffled from home to the hospital and back again can be frightening and disconcerting for both patients and their family members.

Our nurse practitioners provide consistent, personalized medical care that prevents unnecessary hospital visits and ensures that patients receive the care and attention they need when and where they need it. This care allows patients to stay in their homes, if that is their preference. Nurse practitioners also educate patients about their illness, so they know what to expect as the illness progresses.



24/7 Nurse Helpline

One of the things our patients appreciate most is being able to call a nurse any time, day or night, either to ask questions or to talk about a medical concern. Our trained triage nurses will answer questions, send out the nurse practitioner to the patient's home or arrange emergency medical care, depending on the situation. Knowing they have someone to call at all times is so reassuring to patients and families.

Emotional Support and Guidance

In addition to medical care, we also offer visits from a social worker to provide emotional support, guidance on advance care planning, and help connecting the patient with community resources. The social worker can also help patients navigate the complex and often-daunting health care system.

Patients may also benefit from visits by Gilchrist volunteers, who provide companionship, respite for caregivers and assistance with errands.

No Gaps in Care

There is no limit to how long Elder Medical Care can be provided. If and when the patient needs hospice care, they can be quickly and seamlessly transitioned, with their medical history and care preferences communicated to the hospice care team.

Sometimes people come to Elder Medical Care after "graduating" from hospice, meaning that their symptoms have improved to the point that hospice care is no longer needed. In either case, Gilchrist provides a safety net so that the medical care and support these individuals have come to rely on can continue. Our goal is to make sure no one falls through the cracks of the health care system.

To find out if Elder Medical Care is right for you or a loved one, call our care navigators at [1.888.823.8880](tel:1.888.823.8880).

Gilchrist Center Baltimore Team Wins Art of Nursing Award



Congratulations to our Gilchrist Center Baltimore care team, who won the 2018 Art of Nursing award in the Diversity in Nursing category.

The award recognizes nursing staff throughout Gilchrist who exemplify and embody the fundamental elements of the art of nursing in seven categories. In addition to the staff at Gilchrist Center Baltimore, 12 other employees were nominated for the award.

To see all the nominees for the 2018 Art of Nursing, visit gilchristcares.org/art-of-nursing.

Gilchrist Launches Capital Campaign for Gilchrist Center Baltimore



Gilchrist is undertaking a \$10M capital campaign to build a state-of-the-art inpatient hospice center at Stadium Place, the former site of Memorial Stadium, which will be the new home of Gilchrist Center Baltimore.

For 30 years, Gilchrist Center Baltimore has provided compassionate end-of-life care to thousands of terminally ill Baltimore City residents. The center provides care to those who are medically underserved, ensuring that all individuals have access to hospice care and a place to stay, regardless of background or ability to pay.

Building a new hospice center will ensure this care can continue for years to come. Gilchrist Center Baltimore will have 18 beds for adult care and 4 beds for pediatric care. It will remain the only inpatient hospice in Baltimore.

To learn more about our campaign, contact Ted Blankenship at tblankenship@gilchristcares.org.

Volunteers Needed

Gilchrist volunteers are invaluable to the care we provide families, and there are many ways volunteers can help. Gilchrist is currently looking for volunteers to fill the following roles:

- **Spiritual Support** – We are looking for volunteers to provide spiritual support for our palliative care patients living in residential communities. These volunteers will visit with individuals who are feeling disconnected from a spiritual community. They will provide comfort, offer prayer and read from spiritual or religious texts.
- **Healing Arts** – Gilchrist is growing our healing arts program, and we're looking for volunteers who are certified or trained in Healing Touch, massage, Reiki, meditation, aromatherapy and pet therapy.
- **Gilchrist Ambassadors Speakers' Bureau** – Do you have a background in public speaking or teaching? We are looking for engaging, experienced speakers to join our team of Ambassadors. These volunteers will go into the community to speak at senior centers, corporations, the Department of Aging, and other venues to talk about Gilchrist and end-of-life issues.
- **We Honor Veterans** – Gilchrist cares about our veterans and we are working hard to recognize each and every one of them. We are looking for men and women who are either veterans or are currently serving in the armed forces to conduct Final Salutes to Service when one of our veterans nears the end of life. We are also in need of knitters, quilters and crocheters to create patriotic red, white and blue lap blankets to present to our veterans.

Volunteers must attend training. To learn more, contact Mary Antonucci at mantonucci@gilchristcares.org.

Ushering the Dying

Listen to Gilchrist Bereavement Program Manager Deborah Jones talk about Gilchrist's end-of-life doula service.

wypr.org/post/ushering-dying



RUN GBMC

Join us on **Saturday, October 20, 2018**, at the Baltimore Running Festival. Team **RUN GBMC** is open to all runners and walkers with any level of experience. All proceeds benefit Gilchrist Center Baltimore.

To learn more, make a donation or register to join the RUN GBMC team, visit:

gilchristcares.org/events/teamrungbmc



**Taste of
Howard County**
*Merriment in
Masquerade*

Sunday, October 21, 2018
Turf Valley ♦ 5 p.m.

Join us for *Merriment in Masquerade* at the 2018 Taste of Howard County on Sunday, October 21, at Turf Valley. Featuring the sweet and savory creations of more than 20 Howard County restaurateurs, as well as live and silent auctions, the event will support Gilchrist Center Howard County, our 10-bed acute inpatient center in Columbia.

For tickets, sponsorships and other details, visit gilchristcares.org/Taste or contact Julie Kolankiewicz at 443.849.8245.



1.888.823.8880

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Gilchrist provides services without regard to race, color, creed, sex, sexual orientation, disability, religion, ability to pay or national origin.

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The Gilchrist Ball
Saturday, December 1, 2018
Baltimore Marriott Waterfront
7:00 p.m.

The biannual Gilchrist Ball, formerly The Holly Ball, will be held on Saturday, December 1, at the Baltimore Marriott Waterfront. Kick off the holiday season at the premier fundraising gala in Baltimore, benefitting Gilchrist Center Towson and featuring fine dining, dancing and mingling with friends. Honorary chairs of the 2018 Gilchrist Ball are Jana and Richard Burch and Lorraine and Mark Schapiro.

For tickets, sponsorships and other details, visit gilchristcares.org/GilchristBall or contact Julie Kolankiewicz at 443.849.8245.