Reflections*Newsletter*

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The Power, Beauty, and Dignity of Hospice, In Their Own Words

New Ad Campaign Raises Awareness about What Hospice Is, Where It is Delivered, How It Supports Diverse Needs and Interests

To raise awareness about what hospice care is, where it is delivered, and how its various services support families, Gilchrist recently launched a novel advertising campaign led by those who know us best: patients' loved ones.

The initiative includes a series of television and radio ads, with each spot featuring a testimonial from a family member of a former patient. The commercials were not scripted. The individuals who appear are speaking in their own words about what they and their loved one experienced in the care of Gilchrist.



For example, former Baltimore City Councilwoman Rikki Spector addresses how important it was for her darling Oscar to receive hospice in his home where he could spend time with family in his preferred setting. Oscar also benefited, she says, from Gilchrist's programs devoted to Jewish Care and Support and to military veterans.

For Ron Berk's mother, who was a Rockette dancer in her teenage years, one of the highlights of hospice was our music therapy program, he says. A music therapist played songs that inspired her "to stand up, with the assistance of her walker, and dance." She just loved it and for her it was so uplifting. It added a whole new dimension to her life.

Gilchrist's involvement in my mother's life changed everything, he says. "It was all doing more and more and living her life the way she wanted to live it."

In her ad, Kathy Catzen highlighted how Gilchrist made it possible for her 100-year-old mother to visit her home in the Poconos while on hospice.

"If it hadn't been for Gilchrist, she wouldn't have had that time to be able to celebrate," Catzen says, adding: "Hospice isn't death; hospice is life."

"Hospice isn't death; hospice is life."

According to research and surveys, there is an information deficit in our nation about what hospice actually is and offers. For instance, there is a widespread misperception that hospice is a physical place. In fact, hospice is a type of care that can be provided in a variety of locations — in a patient's home, in a residential care community, or in an in-patient care center.

"We find that the more people learn about hospice, the more likely they are to seek it out for their loved ones," says Cathy Hamel, Gilchrist's president. "We're so thankful for those who shared their time and memories as part of this campaign to help inform the public about the vital role hospice can play in helping patients and their loved ones live every moment."

The campaign is not only raising awareness. It is also inspiring others to reach out to Gilchrist to share their stories with us and the community at large. While we did not anticipate this response, we certainly encourage it.

If you wish to share your story so others may learn about hospice care, we would love to hear from you. Although there will be no more television or radio ads, we publish our patients stories throughout the year in various newsletters and on the web. To take part, contact us at Gilchrist_Marketing@gilchristcares.org.



Family Drives Support for Gilchrist Kids, Literally



Although it was a long, long time ago, Jeff Givens still vividly remembers his first childhood encounter with a car that would inspire an adulthood hobby – and contribute to extraordinary acts of generosity on behalf of the children's program at Gilchrist.

His older sister's boyfriend paid a visit to the Givens' family home driving a shiny new Corvette. The owner was on a budget, so his vehicle lacked top-of-the-line features such as a radio. Even so, Jeff, an enthusiast of Hot Wheels and Matchbox toy cars at the time, was smitten. He never saw the boyfriend again, but his Corvette made a lasting impression.



Fast forward 50-plus years to 2023. There was Jeff driving his polished-to-perfection Corvette to bring joy to a little boy in need of some. And he wasn't alone. He called on 14 other members of the Free State Corvette Club – each driving a Corvette, of course – to join him in paying a special birthday visit to a car-loving kid struggling with the terminal illness of a sibling in Gilchrist's care. Brothers and sisters in such situations must contend not only with despair but

also with reduced attention from loved ones who are, understandably, focused on the sick child.

Jeff and his crew blocked off the family's street with their caravan of Corvettes, called on the birthday boy to select his favorite car, and presented him with gifts.

"We all got a charge out of it," Jeff said.

Likewise, Gilchrist Kids has gotten a big boost from the inspirational philanthropic efforts of Jeff and his wife, Vicky, since their son, Kyle, passed away in 2015.

Gilchrist was so good to his family, Jeff said, that he and his wife felt compelled to give back. In addition to visiting children, Jeff and Vicky have helped to raise thousands of dollars for Gilchrist through their participation in the Free State Corvette Club. Thanks to their initiative and leadership, a portion of the proceeds from the organization's annual convention in Ocean City has gone to Gilchrist for a number of years.

"The nurses and doctors and support staff at Gilchrist did us a world of good."

"The nurses and doctors and support staff at Gilchrist did us a world of good," Jeff said.

And now Jeff and Vicky are doing a world of good for the young people and their loved ones at Gilchrist.

Not-for-profit hospices outperform forprofits in care experiences, study finds

Caregivers of patients receiving hospice care reported substantially better care experiences in not-for-profit hospices than in for-profit hospices, according to a new study based on more than 650,000 survey responses and published by the Journal of the American Medical Association (JAMA).

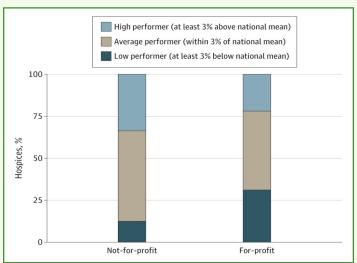
In what is believed to be the first-ever study examining the differences in reported quality of care between for-profit and not-for-profit hospices, researchers found that for-profit hospices trailed their not-forprofit counterparts in every measured quality category, including:

- · Timely care;
- Symptom management;
- Hospice team communication;
- Emotional and religious support;
- · Rating of hospice; and
- Willingness to recommend.

Since its founding more than a quarter century ago, Gilchrist has remained a not-for-profit provider of hospice care in keeping with the wishes of the organization's founder, Jeanne "Jinny" Gilchrist Vance.

The analysis is based on 653,208 responses from caregivers of hospice patients who died between the

Distribution of For-Profit and Not-for-Profit Hospices' Performance on the CAHPS Hospice Survey Summary Measure



Percentages are calculated as the proportion of not-for-profit and for-profit hospices, respectively, that are low performers (scores at least 3% below the national mean), average performers (scores within 3% of the national mean), and high performers (scores at least 3% above the national mean) on the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey summary measure.

Source: Consumer Assessment of Health Providers and Systems Hospice Survey summary measure

second quarter of 2017 and the first quarter of 2019 – prior to COVID-19 pandemic. The data cover a total of 3,107 hospices – 1,761 of them for-profits, 906 not-for-profits, and 440 either government-run or identified as "other."

For-profit hospice growth

For-profit hospice providers have exploded in number this century. In 2000, they accounted for 30 percent of all hospices. By 2020, they represented 73 percent of the total.

Ever since the federal government approved the Medicare hospice benefit in 1983, some have expressed concern that profit incentives could threaten quality of care, according to the JAMA Internal Medicine article "Association of Hospice Profit Status with Family Caregivers' Reported Care Experiences." And prior research has reported that for-profit hospices have higher rates of hospitalizations and emergency-room visits, as well as a narrower range of services.

In the new study, researchers wrote: "caregivers whose family member received care in a not-for-profit hospice reported the best care experiences, generally followed by those who received care in a for-profit independent hospice." Meanwhile, those who received care in for-profit regional chains and for-profit national chains reported the worst care experiences.

Review Options Carefully

Although not-for-profit hospices outperformed forprofits on average, researchers urged potential hospice users to consider and carefully evaluate all options when selecting a provider. Indeed, some for-profits received high marks from caregivers, while some notfor-profits received low marks. "Publicly reported survey measure scores provide important information to guide selection of a hospice," they concluded.

Consumers can compare and contrast hospice providers, using the same data that researchers used for this study, by going to https://www.medicare.gov/carecompare.

Cultural humility is key to caring for communities of color

When her mother said she no longer wanted to be poked, prodded, and tested by doctors striving to treat her cancer, Jin Yang initiated a critically important – yet relatively uncommon – conversation with physicians.

Let's consider the possibility of hospice care, with its focus on comfort rather than a cure, Yang suggested.

A health care professional herself, Yang had a deep familiarity with hospice. She'd seen some of her terminal patients benefit and thought her mother might, too.

Indeed, many millions of people have benefitted from hospice care in the United States. For example, during the five-year period from 2016 through 2020, there were 7.8 million Medicare-insured hospice users in our country, according to the National Hospice and Palliative Care

Organization (NHPCO). This number does not include those covered by private insurance or philanthropy.

So what made Yang's decision to investigate the possibility of hospice for her mother uncommon? Hospice utilization among communities of color – particularly the Korean community of which Yang is a part – has been traditionally lower than among their white counterparts.

This underutilization is something that Yang and Gilchrist want to change to ensure that all communities can receive the care they deserve and desire.

Deep disparities

Medicare guarantees insurance coverage for up to 180 days of hospice care for all residents nationwide. But some are more likely to avail themselves of the offering than others.

In Maryland, 53.07 percent of White Medicare beneficiaries who died in 2019 passed away in hospice. The rates were significantly lower for Hispanic (38.95 percent), Black (37.17 percent) and Asian (36.47 percent) beneficiaries. These data are presented in a diversity project report by the Hospice & Palliative Care Network of Maryland (HPCN).

Now 65 years old, Jin Yang — a retired pediatric physical therapist with a special interest in issues associated with death and dying — speculates that lack of awareness

about hospice, language barriers and cultural differences play a part in the low utilization rate among Koreans.

With the help of Gilchrist, the Yang family – Jin, her siblings, and her mother, Hong Bo Yang – were able to overcome the typical obstacles. Yang was well aware of hospice, having encountered it multiple times during her career. And various staff, including Gilchrist Chaplain John Yoo, helped with both language and culture.

Born in Korea, Yoo speaks Korean and is attuned to differences between Korean and American culture. Yang gives Yoo a lot of credit for making her mother's experience in hospice successful.



Hong Bo Yang and her daughter, Jin Yang

For his part, Yoo says the key to caring for a diverse population is cultural humility. "You have to really know what Korean culture is like – what any other culture is like – to deliver culturally competent care," he said.

Thanks to Yoo and others, Yang says "I quickly came to rely on their support, knowing I could pick up the phone, explain our needs, and somebody would respond within minutes if not faster."

At the age of 91, Yang's mother died at home, just as she wanted to, Yang said, adding that she hopes others will avail themselves of hospice so they can spend their final chapter of life on their own terms.

"Hopefully, little by little, Koreans will become more aware of the benefits of hospice and the choices that family members can make when they feel that their care of their loved one is all up to them," Yang said. "Gilchrist ... was so incredibly supportive of our entire family.

What I Learned from Leaning into Loss

Written By Graeme Thistlewaite

"Grief and gratitude are two sides of the same coin."

These are the words shared by a family member of a hospice patient whom I visited at the end of life. This insight came at the conclusion of a beautiful experience of family togetherness, where all present relations were given the opportunity to share their favorite memories and express their love and appreciation for this person.

In this moment of simultaneous sadness and joy, they reflected on the ways their loved one had guided their lives and forged a family bond through an emphasis on kindness, humor and acceptance. I have come back to these words as a touchtone that guides both my grief support work at Gilchrist and my own project of mourning.

As an intern with Gilchrist's bereavement team and as a student working toward my master's degree in social work at the University of Maryland, I am tasked with supporting bereaved hospice families and community members alike. This support takes the form of individual counseling, facilitating support groups, providing workshops and reaching out to family members after the death of hospice patients.

While some may expect this work to be grim, my experience testifies to the opposite. This work is filled with so much love. Though everyone's grief journey is their own, there is a common undercurrent of love. The grief, pain, anger and sadness all result from the wound of a parted love, the loss of a person who we shared our lives with and who knew us in ways unique to them.

"This love gives meaning and shape to our lives and that grief is the cost of this gift."

Through my experience with this work at Gilchrist, I have learned that this love gives meaning and shape to our lives and that grief is the cost of this gift.



Graeme Thistlewaite, Gilchrist Bereavement Intern

The work I have been honored to share in during the past six months with the bereavement support team is not grim but beautiful. When I speak with bereaved, I share not only their sadness but their joy. I invite them to tell me stories about their family members and reflect on how their own lives are forever connected to those they've lost. Each session can be a monument, a memorial, a love letter, a confession, or a conversation, and every one of them reveals the traces of those we've loved.

I am grateful for the opportunity to support clients in their experiences of grief and witness the legacy of those they've lost.

Graeme Thistlewaite is a graduate student at the University of Maryland School of Social Work and an intern with Gilchrist's bereavement team.

To learn more about Gilchrist's Grief Counseling program, visit gilchristcares.org/grief-counseling.

Volunteers with Gift for Sewing Create Memory Bears for Families to Cherish

Thanks to the artistry and industry of our dedicated volunteers, Gilchrist's Memory Bear program has now created and delivered 11 handmade bears to seven families – and more are in the works.

These bears are crafted for family members from their loved one's clothing – items such as sweaters, t-shirts and pants – to bring them comfort and even joy.

Bear recipients have all stated that it feels like a piece of their loved one has come back to them. It has become a transitional object for them, providing comfort and security.

For example, Judy says she is beyond excited to have been able to take her mom's favorite sweater and have it transformed into something she can hug and look at on a daily basis. Meanwhile, Mike loves the bear that volunteers made in memory of his wife, Peggy, so much that he requested additional bears for his granddaughter and grandson.

Mike

This program is clearly making a positive difference in the lives of the families we serve. As a result, we would love to extend our reach.

We are actively recruiting volunteer sewers to join our current corps of four. If you know sewers who might be interested in participating, please let them know about our program and direct them to Jane O'Hara, Gilchrist's volunteer services recruitment coordinator, at johara@gilchristcares.org.







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For referrals call: 443.849.8300

HOWARD COUNTY 6336 Cedar Lane Columbia, Maryland 21044 410.730.5072

TTY Maryland Relay Service: 1.800.735.2258

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Ashley Waters

Digital Marketing Manager



Sunday, June 4, 2023, 2:00 p.m.

> Cromwell Valley Park, Parkville, Maryland

Join us at the 8th Steps of Hope event to remember loved ones with an afternoon of healing in nature. Honor them as we walk together in reflection. This event will be held rain or shine.



REGISTRATION:

By May 25, 2023, visit: gilchristcares.org/StepsOfHope OR contact Christy Broderick at 443.849.8251.

