

Written Testimony to Senate Special Committee on Aging

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**“Empowering Patients and Honoring Individuals’ Choices:
Lessons in Improving Care for Individuals with Advanced Illness”**

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At Midland Care Connection our mission is “meeting individual needs through innovative health care solutions”. Over the past 35 years we’ve developed a continuum of services that can serve people once or several times over the course of years. Services can be accessed at the time patients need them and increased as care needs dictate. Currently, we offer hospice (in home and inpatient care), palliative care, home health, home support, adult day care, Program of All-Inclusive Care of the Elderly (PACE), residential care and grief counseling services.

I have personally been involved with this work for more than 25 years, originally as a caregiver to my father, then as a member of the board of directors and for the past 22 years as an employee of Midland Care. My father was diagnosed 25 years ago with renal cell cancer and had extensive bone metastases throughout his body. His prognosis was six months to live which came with a referral to hospice. He lived for 18 months and died at the age of 56. My mother was served on hospice 12 years ago. Her diagnosis was advanced colon cancer for which she sought aggressive experimental treatment. She died six months after diagnosis and was only on hospice a few days. She was 62. Then 2 years ago my grandson was diagnosed with Ewing’s Sarcoma. It’s a very rare soft tissue cancer that generally strikes children (primarily boys) between the ages of 10 and 18. He was nine. After a full year of very aggressive chemo therapy the decision was made to amputate his leg followed by yet another round of chemo, treatment did not work. He died on October 21st 2011 at the age of 11 after being on hospice a few weeks. All three of them died with grace and dignity at home with family by their side. I myself am a two time cancer survivor. Doing this work for more than 25 years, I know how difficult it can be for patients and families to have the tough conversations about their disease, about their treatments and about their dying. I know first-hand what it means to have those conversations and what it means to understand the options and make those life and death decisions. It is never easy, but the more one understands about the options, the better equipped they are to be a part of their own treatment team and the easier it is for their professional care team to collaborate with them in achieving their goals.

Evolution Based on Community Need

Our organization began as a small volunteer program. Like many smaller community organizations across the country, it started with a conversation between a few people who had an idea to improve the quality of life at the end of life. In our case, it was four women who had a vision to create an option for persons in the last few months of life. An option called hospice that would mean people could live and die in their own homes, in familiar surroundings, with family and friends at their side. As our hospice and others around the country were formed and grew, the thing that differentiated hospice from the rest of the health care system was that it truly focused on the whole person (not just their disease) and what they, the patient, wanted. We are guided by a simple question: “What were their goals and dreams for the time remaining?”

In hospice we work at controlling pain and symptoms so that each day can be the best possible for patients and help them reach their goals. The types of goals we hear from our patients can include living long enough to walk their daughter down the aisle on her wedding day, or share their 50th wedding anniversary with their spouse, or see a son graduate from college, or hold that first grandchild. There has occasionally been the dream to get to a Kansas City Chief’s game or take a plane ride, and with donations we’re often able to make those things happen.

But it’s the simple things people usually want. Not the things that money can buy; usually what they want is a little more time and they want it on their terms. It is very common to see patients die soon after reaching their goals. One of the challenges we have in hospice today is the lateness of referrals. Patients and families miss out on the opportunities that could be afforded them with an earlier referral to hospice in terms of understanding their disease and being active participants in decisions related to their terminal condition. In hospice we have learned care is best provided through a team of professionals; individuals with specific expertise who can come together and develop plans of care that will serve the whole patient and compliment what the patient wants. The use of an interdisciplinary team is also the backbone of PACE and an effective way to provide care in all programs, understanding people are more than their disease. Working with the patient’s physician and focusing on the patient at the center of care, we have served all ages and all diagnoses. We’ve grown from serving one county in Kansas to providing hospice care in 15 counties.

In the early days, patients were referred earlier in the trajectory of their disease and were on service longer, many of them for several months. Several years ago, we identified the suffering that occurs from social isolation often accompanying a longer terminal or chronic illness. We began an adult day program at Midland Care Connection to serve that need; a safe place where patients could come and be cared for and socialize with others giving caregivers a respite break and patients an opportunity for interaction with others. Originating especially for hospice patients, it wasn’t long before we had others calling for our help. “My Mom’s got Alzheimer’s” or “Dad’s had a stroke.” They weren’t terminally ill but they needed some help. In fact, typically they are individuals with four or five chronic conditions and often times Alzheimer’s or some type of dementia. Eventually, we saw a decrease in the average

length of stay of our hospice patients, who were too ill to attend adult day care, and an increase in calls needing the help adult day care could offer. And, so our evolution began.

Within 4 years all of our adult day clients were coming from the community at large. They were not our hospice patients. They were adults (18 and older) who had a medical or cognitive frailty that made it unwise or unsafe for them to be at home alone all day. One of the most common diagnoses for those seeking adult day care is Alzheimer's or dementia. The adult day center could meet some basic health care needs, provide new friends in a secure setting for clients, and an opportunity for caregivers to continue working or have much needed respite. The socialization that adult day care provides is one of the most valuable characteristics of the program. Often, those who enroll have been very isolated and the opportunity to interact with others helps them socially, cognitively and ultimately physically as their overall outlook improves. Adult day care really is and has been a bridge for many. It allows individuals to remain in their own homes and avoid premature nursing home placement. The support that adult day provides for caregivers is immeasurable. Not only does it provide education and support with the responsibilities of care giving but it also provides much needed respite for the caregiver allowing time for them. Many of our adult day enrollees have been served in adult day care for as long as 7 years before they were transferred to another service, died, or were institutionalized usually because of increasing dementia care needs.

For Midland, adult day care grew to be more of a community program than an enhancement to hospice services. With that change, we recognized the exhaustion that many caregivers experienced over the course of the many months and years they provided care. That realization led us to begin providing overnight respite care in a small 12 bed residential center. It created a place where a patient could stay when family was called away for business or family emergencies, or just needed to take a break for a few days. It is amazing what a week without caregiving responsibilities can do for a caregiver to rejuvenate and empower them. It is a gift we give when we provide care to someone we love and it is a gift they give to us to allow us to do so, but it can be physically and emotionally exhausting.

At the same time, as our hospice program continued to grow and the needs of our patients became more complex, we added a hospice inpatient facility where we could assist patients struggling with pain or special care needs beyond the family capabilities, or in some cases, where there was no family or friends to give assistance. We also began to encounter more patients who did not fit the 6 months or less requirement of the Medicare Hospice Benefit, but who were experiencing pain and symptoms not manageable by their primary care physician or medical specialist. In response, we developed a palliative care program, providing hospital and clinic consults with some limited home visits. Our physicians, credentialed in hospice and palliative medicine, can intervene with pain and symptom management, but also in assisting patients with the emotional trauma or other aspects of the suffering that often accompanies serious illness. Working with the physicians are nurses, social workers and chaplains with expertise in helping patients at a tremendously difficult time, explaining and educating them about their care, their disease and their choices, and being there to support them in the decisions they make.

Midland Care enrolled our first PACE participants in February 2007. It's a program primarily serving dual eligible individuals, over the age of 55 whom, because of their functional frailty, are eligible for nursing home placement but choose to remain in their own homes. With the help and support of PACE that can be a reality. PACE wraps services around the individual. Through PACE, our team serves both the care provider and the payer for all services. We are at full financial risk for all primary care, acute care, long-term care, supportive care, rehabilitative and maintenance therapies, transportation, adult day care and all personal medical equipment and medications. In short, all the services and care needed. As the 37th PACE program to begin in this country and one of only two in Kansas, we have had the unique opportunity to offer to our community residents a different option from institutionalization. Clients are involved in their care planning based on their goals and working in partnership with the PACE team to achieve those goals. In PACE we have the opportunity for care coordination that is not always available when individuals are piecing their care services together.

Systemic Challenges and Limitations

Unfortunately, PACE is not an option for everyone. Those who have PACE in their area, meet age eligibility, have Medicaid or have income to privately pay can access PACE, but for those younger, most of the middle class and our veterans, this is not an option. As we recognized this fact, we began providing home supportive services like assistance with light housekeeping, errands and personal care and home health services to meet skilled nursing and physical therapy needs. Those services along with adult day care can be integrated and managed to meet most of the care needs. One of the biggest holes in care today is basic case management, which is especially invaluable to our frail elders, those with multiple chronic conditions and those suffering with Alzheimer's. Having multiple providers involved in one individual's care often is challenged with poor communication and incomplete information between providers. We also provide grief counseling for surviving family members. Originally an offering as part of our hospice service, it has now become available for anyone served in any Midland Care program. In reality, grief starts at the time of any major diagnosis. Those families who are involved, educated and supported through the process, though still grieving, will be emotionally healthier as they face their grief at time of loss. For those friends and family members watching the slow deterioration of loved one with Alzheimer's, grief is interwoven into life as recognition and memories fade away. The support and commitment we can give to families through the dying and grieving process becomes a quality of life issue for them as they face a life much changed from what they previously knew.

All of this does not happen easily. There are a plethora of regulations and licensing requirements in every program. There are statutes and standards and surveys. There are billing codes and documentation requirements. Midland Care is licensed by the state of Kansas, Medicare certified and accredited by the Community Health Accreditation Program (CHAP) for hospice and home health. We have an additional home health agency license for home support. We have two licensed adult day centers, a licensed residential care center, maintain a physician clinic for PACE participants and palliative care patients, and have a contract with CMS and the state of Kansas to provide PACE services.

All of this we do with a great deal of commitment to service and quality, with staff who are cross trained to work in multiple programs. We have built a consolidated infrastructure, including central referral and after-hours teams, designed for easy access for patients, efficiency, compliance and an excellent electronic medical record system that functions across all programs.

Our goal is simply that people get the care they need. They don't need to know that it's called home support or that they have to be home bound to access home health or that they have to meet a certain functional level to enroll in PACE or that it's time to call hospice. They just need to call. It's our job to differentiate and comply with the regulations. What people need is the right help at the right time in the right place. Having a variety of programming available to them helps make possible so they're not bounced around to multiple organizations, trying to piece together for themselves what services might help.

The challenges we see in the current care delivery system are the silos that exist throughout not only the health care system but the state and federal regulatory bodies. Currently, in our organization, we undergo about 7 surveys a year. Many times surveyors are looking at the same record on the same patient only in a different program. If we are to effectively serve our communities, not only must we break down silos within our own organizations, we must also display more flexibility at the regulatory level. Utilizing an electronic medical record gives all authorized persons in our organization access to pertinent and real time information on the population we serve. It also cuts down on the redundancy of information patients must give and the time it takes to complete various forms. Even so, we often are spending time completing additional forms and documentation with the same information in different formats to meet regulations. I support the need for regulations and accountability, but most of the regulations we exist under today were developed in another time and without coordinated care in mind. A time when paper was king, triplicate was better and redundancy was expected. Many requirements in programs today are quite antiquated and don't take into account the communication tools and connectivity options we have available to us now. No longer is it necessary for everyone to be physically in the same room to develop effective care plans for patients; it can be done through the internet with electronic medical records and other tools.

As a hospice provider for more than 30 years there are four things that we at Midland Care Connection have learned that are now ingrained into our organizational culture and all the services we provide.

*We've learned that suffering is more than physical pain. As we journey with patients in the last days and months of life often those things with which they may be suffering the most are emotional, spiritual and sometimes even social in nature. Our job is to help identify the source of the suffering and help them where they are. The suffering of a chronic disease over several years, or the knowledge of one's own mind disappearing piece by piece to Alzheimer's disease, or the stark reality of an aggressive cancer all produce suffering that far exceeds the physicality of their disease.

*We've learned today is a gift. Our patients have taught us that each day is to be treasured with the focus on the people we love and not to be wasted on worries and circumstances out of our control. Our role is to add to the quality of life in those days no matter the number, so that patients and families have the opportunity to build memories that will go on.

*We've learned one person has the disease, but the whole family is going through the process. Whether it is someone with a terminal diagnosis with days to live or a new or long-term chronic diagnosis; the patient has the disease but sharing in it with them are those they love and who love them.

*And lastly, we have learned patients and families can get through anything with support. People given clear and honest information and allowed to be active participants in the decisions about their health care are stronger through the process.

Through the years, many patients have accessed multiple services in our continuum but one individual stands out in that he was able to access care in almost every program we offer.

What it Looks like through a Patient Experience

Denzel Ekey was a 78 year old man with Alzheimer's disease and Myasthenia gravis, a disease characterized with generalized weakness in the arms and legs and difficulty speaking and swallowing due to weak neck muscles. He was cared for in his home by his wife Mary. As she explained to me, they had many years earlier completed their advance directives for the sake of their children and for each other. So if the time came that they could not speak for themselves, their wishes could be honored. They first accessed our home support services. Denzel was a gentle giant. A large man both in size and personality, it became too difficult for his wife to provide bathing and personal care, so we arranged for a home health aide to assist with Denzel's showers a few times a week. That continued a few months, along with his attendance at the adult day care center which allowed his wife a break from the constant care-giving responsibilities. At first Mary provided the transportation to and from the day center but as Denzel's condition deteriorated that became more and more difficult. With enrollment into the PACE program we were able to increase services as care needs evolved. With PACE, not only would all of Denzel's primary care needs be taken care of, but we also provided his home support needs and all medical transportation, including daily trips to and from the day center. His decline continued and services were increased accordingly. His wife Mary had some health issues of her own which made it even more difficult to care for Denzel. Mary was hospitalized and required surgery which meant providing care for Denzel would be impossible Denzel was on service for over two years. During that time he utilized just about every service we had available. For the last several months of his life, he lived at our residential center where his wife visited and sat with him daily. When it became evident that his prognosis was not good and with a life expectancy of only a few months, the PACE team initiated end-of-life care, including calling on the hospice team. During the last weeks of his life Denzel

was in the hospice program, arranged for by PACE and living in the residential center. He died on Christmas Day at Midland Care, after having spent the day with his wife at his bedside.

Denzel is not only a wonderful example of the way a continuum of care services can serve someone with advanced illness, but he is also representative of the 13 percent of Americans over the age of 65 with Alzheimer's disease (AD) and 45 percent over the age of 85 who have AD and, the over 200,000 under age 65 with early onset AD. As the fifth leading cause of death for those 65 and older, AD numbers continue to rise. Between 2000 and 2008, deaths attributed to AD increased by 66%, while deaths attributed to the other major diseases of stroke, prostate cancer, breast cancer, heart disease and HIV have decreased. AD is the only cause of death among the top 10 diseases in America without a way to prevent, cure or even slow its progression

It is not just the individual with disease who struggle it is also their caregivers. More than 60% of caregivers rate the emotional stress of caregiving as high or very high, and one third report symptoms of depression. Caregiver health care costs also increase due to the emotional and physical demands of caregiving for a person with this progressive and terminal disease.

All of our patients are very special. Denzel was even more so, because he served on our Midland Care Board of Directors 25 years ago. When we decided to seek Medicare certification for our small not-for-profit volunteer hospice program, he was on the board. When we decided to start adult day care to enhance the care provided in hospice, he was on the board. When we decided to purchase a campus of buildings where we could expand the continuum of services provided to our community, he was on the board. He was a visionary man that saw not just what we were, but what we could be. And we had the honor of serving him with all that we had become. Today his wife continues with our grief support program and has talked of volunteering for us. And that's where we began.

Looking Ahead: Obstacles and Opportunities in Meeting the Needs of an Aging Population

Today there are only 90 PACE programs across the United States. And yet, this is a program that honors what frail elders want, aligns incentives of all the stakeholders and is a predictable budget item to the states. The growth has mostly been stunted because of extensive regulatory and capital requirements. Also, at the state and federal level it is easier and faster to infuse more money into long-term institutional care. In PACE, the provider bears full financial risk for all the health care and long-term care costs of the individuals served and yet many states continue to limit the number of people who can enroll in the program including states like ours who have the 5th highest use of institutional care per capita in the country today. Hospice has grown much faster than PACE but mainly because it's much easier for providers to open a hospice. Even so, of all decedents in this country, roughly 40 percent received hospice and while not all of the others deaths might be appropriate for hospice care, a significant portion are or would be.

Clearly there is an evolution, if not a revolution, in health care today. Partly driven by budgetary and resource allocations, but much of it being driven by a generation that has been making its mark since the

end of World War II. Those baby boomers who advocated for change in the 60's are still advocating for change today. And change will surely have to come because of the sheer volume of individuals who will need care and the disproportionate number of caregivers available to provide the care both familial and professional. The number of Americans surviving into their 80's and 90's and beyond is expected to grow dramatically due to advances in medicine and medical technology, as well as social and environmental conditions. By 2025 the number of people with AD will be 6.7 million, a 30% increase from the 5.2 million currently affected.

We have in this country two programs that have developed around what people desired for their health care - hospice and PACE. Both programs born out of grassroots efforts have been placing the patient at the center of care for 40 years. Both developed to serve patients in their place of residence, honoring choices and the right to be involved in their own health care decisions. Both serve holistically utilizing a team, understanding patients are much more than their disease process. Both have been empowering patients and those who loved them to be educated on options and involved in the process of their health care delivery. Both have been shown to decrease emergency room visits and hospitalizations not only because of the comprehensive nature of the service they provide but because they're available twenty-four hours a day, seven days a week, making the home visits, providing the needed care at the bedside and calming fears. There is much discussion out today about new and innovative ways to deliver health care. In reality we have two of the best examples already in our midst and yet both continue to be underutilized.

I would like to provide a framework for developing a health care delivery system that works well for patients with advanced illness. Patients with advanced illness need access to care models with the following features:

- **Provider-based:** as illness advances, the direct link between those who provide care to an individual and those responsible for coordinating and planning care becomes especially important. In hospice, our programs are not only paying for care, or managing care, they are also providing care. Through hospice services, providers and patients work together to identify health care needs, develop care plans, and implement those care plans. This closely-knit community embodies a patient-centered approach and facilitates patient/provider relationships that ensure coordination, quality, and personal satisfaction.
- **Interdisciplinary Teams (IDT):** Hospice programs use an interdisciplinary team (IDT) that includes doctors, nurses, therapists, social workers, dieticians, personal care aides, and others who are directly responsible for the day-to-day care of our participants. This daily interaction between the team's members and the individual receiving care, and between the team's members themselves, allows for ongoing and timely patient and caregiver education, advanced care planning, and care coordination.

- Caregiver support: Caregivers are an integral part of quality care for individuals with complex and advanced illness. The hospice model strives to support caregivers by including them in the care planning process, discussing care planning such as advanced directives, and providing respite and family support.
- Financing and accountability: Hospice programs receive capitated payments that provide incentives to ensure high-quality care. The financing model bundles fixed payments from Medicare and Medicaid or private sources into one flat-rate payment to provide the entire range of services a person needs. As a result, hospice is accountable to its enrollees and their families while accepting full responsibility for the cost AND quality of care provided.

Each of these characteristics contributes to the high quality of care that hospice programs provide to individuals as they address advanced illness. I would add that my conviction that these are essential attributes of quality care for people with high care needs has been affirmed by my experience as a PACE provider. PACE programs serve a population similar to hospice, reaching the people they serve when they are at a nursing home level of care. These programs share hospice's provider-based model, its effective use of interdisciplinary teams, strong caregiver support and financial accountability. As our country seeks better care for people with advanced illness, hospice and PACE are leading the way as effective care and financing models.

I encourage the Committee and Congress to take what is working within the existing system, namely hospice and PACE, and use these programs as the model for how to improve on the larger health care continuum. More patients, if not all patients, with advanced illness should have access to this type of seamless, coordinated and patient-focused care. And, they should have access to it earlier.

I want to thank Chairman Kohl, Ranking Member Corker, Senator Whitehouse, my own Senator Moran, and the Committee for allowing me to testify. With me and with Midland Care, you have a willing partner in expanding high quality care across the health care system.