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Key Points

Critical End of Life Need #2: Ensure Informed Choice

Few today would disagree that those who desire it should have the opportunity to know their diagnosis and what lies ahead, to decide what treatments they want, to complete unfinished business, to express where they want to die, and to appoint someone to make their health decisions when they cannot.

When state legislators enacted the Michigan Dignified Death Act in 1996, they recognized that persons with terminal illness fear unwanted interventions. They knew that people often are unaware of their legal right to make decisions about treatments. Their intention was to increase awareness of the right to informed choice. Their hope was that better doctor/patient communication would ensure final days lived with dignity and meaning.

The Michigan Dignified Death Act (MCL 333.5651 et seq.) establishes individuals' rights to be informed about:

- The medical treatment the doctor recommends;
- Alternative medical treatments; and
- The benefits, drawbacks, and risks for each option.

The physician is required to inform the person or advocate orally and in writing about the right to choose palliative care, including hospice, and to appoint a health advocate to make treatment decisions when the person no longer can.

Legislators amended the Act in 2001 to extend these rights to a broader group of people—those who are diagnosed as having reduced life expectancy due to advanced illness. According to input from stakeholder and hospice contacts, current practice does not yet reflect the law.

This section reviews the extent of the problem, obstacles to improvement, encouraging factors, and implications for policy and programs.

The Extent of the Problem

Informed decision-making at the end of life includes treatment decisions for late stage illness and advance care planning to guide future choices if the person becomes incapacitated and unable to decide for himself.

- In discussing these issues, hospice contacts talked about treatment choices for late stage illness, most often related to aggressive versus palliative treatment for cancer.
- Stakeholders were more likely to talk about decisions regarding withholding or withdrawing life-sustaining treatment in a critical care unit.
- Both groups spoke with passion about the problems and consequences of people being ill-informed about treatment options.

How Many Are Ill-Informed?

Of the 57 hospice contacts interviewed, 85 percent reported enrolling patients who lack understanding of their prognosis and treatment. When hospice nurses enroll new patients, they often hear that they are the “first to explain what’s going on with me.” People say this when the nurse explores their understanding of their diagnosis, disease process, and prognosis. Although this is a common remark, its incidence is not formally tracked.

However 42 hospice contacts were able to estimate how many of their patients say something like this (see Table 6.1). Note that 40 percent of them estimated that half or more of their new patients are ill-informed about prognosis. Another 11 hospice contacts, rather than giving an estimated percentage, reported that this happens often (5) or sometimes but not sure how often (6).

Table 6.1. Distribution of 42 Hospices by Proportion of Enrollees Ill-Informed about Prognosis, Michigan, 2004

% of Ill-Informed New Patients	Number of Hospices	Percentage of Hospices
0% - 24%	16	38%
25% - 49%	9	21%
50% - 74%	11	26%
75% - 100%	6	14%



Of 57 hospice contacts, 85% reported enrolling patients who lack understanding of their diagnosis, disease process, and what lies ahead.

Families say that the hospice nurse is the first person to be honest with them, to take time to listen, to explain in terms they can understand, and to put all the facts together for them.

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“They have no clue what’s going on.”

One contact estimated that in her area 70 percent of cancer patients lack awareness of their prognosis, as do 50 to 60 percent of people with noncancer conditions. Others said that patients and families are poorly informed about diagnosis, disease process, and what lies ahead : *“They have no clue about what’s going on”*. Families say that the hospice nurse is the first person to:

- Be honest with them;
- Take time to listen;
- Explain in terms they can understand; and
- Put all the facts together for them.

Several hospices encounter ill-informed patients often enough to have set up a screening procedure to identify them. For each new referral they ask the source whether the doctor has discussed the prognosis with the patient and if not request that the physician have that conversation. One hospice director from a major metropolitan area noted:

Few people who are admitted to this hospice have had advance care planning discussions with their physicians. Some don’t even realize that they are dying until they see ‘Hospice’ on the nurse’s name badge.

The Consequences of Being Ill-Informed

When people are ill-informed about their condition, often what is missing is knowledge of the prognosis and the future course of the illness, awareness of treatment options, and the benefits and burdens of those options. At the end of life, this situation contributes to:

- Lack of choice;
- Overly aggressive treatment;
- Devastated families; and
- Delayed access to hospice.

Lack of Choice

People who do not have the full picture about their illness and treatment options may not realize that they have choices. When treatment is the recommended option, patients and families who are not fully informed may assume that the goal is cure when it is not. And when they do not understand the potential benefits and burdens of the treatment and whatever other options they may have, the consent they give is not informed consent. Sample comments:



Often there is no full disclosure of benefits and risks of proposed treatments. And there is rarely a discussion of patient goals or preferences.

When people don’t have the complete picture, they consent to procedures without truly being informed.

When they don’t know their options, people are more likely to accept what the doctor recommends without question. They are not aware that they could instead choose to be comfortable at home.

“People don’t realize that they have options. No one in the hospital explains the patient’s status to the family, so they can’t make informed decisions. I go in and ask, ‘Would you like to know what’s going on with your mother?’ They say yes, and I explain each specialist’s treatment, the problems each one is treating, and how it all fits together.”

We received a call from the family of a man in his 50's who had lung cancer which had spread to his brain and kidneys. He was getting radiation and chemotherapy. The treatment was not working but the doctor said it must continue. The family inquired about hospice support, thinking that the man has years to live. More likely he has weeks or months left. This is not unusual.

The physician may present aggressive treatment as the patient's only option. In one case the physician pressed so hard for a feeding tube that the family agreed, against the patient's wishes, only to have the patient die two days later. We discovered their guilt over this decision during a bereavement contact.

Often patients and families have no idea where the patient is in the course of decline. This is also true of people with dementia and their families. No one explains the decline and what to expect or how close the patient is to the end.

Overly Aggressive Treatment

A concern raised frequently by hospice contacts was that some oncologists treat people aggressively for so long that they die before the treatment ends. Often this was understood to be the decision of the physicians rather than the patients, who did not realize that they had a choice:

Families commonly complain about relatives being over treated and that the burden outweighed the benefit, but they weren't aware that they had a choice. It's hard to convince people that they HAVE choices; they don't believe it. And it's hard to make choices without an advocate.

A couple of doctors keep wanting to treat. In a recent case the wife halted her husband's radiation before the series finished. He was feeling so poorly that she couldn't get him to the office. The doctor pressed to continue, but the wife called hospice. The patient died the next day.

Lack of informed choice is not a problem just among the imminently dying. Hospital stakeholders talked about what they consider to be overly aggressive treatment for older adults with reduced life expectancy due to advanced illness:

We need better criteria for who is appropriate for aggressive interventions. For example, medically frail patients with



Gravely ill people become very dependent on their physicians and look to them for guidance about treatments.

Truly informed consent easily fades into the shadows.

Hurried physicians offer treatments that offer hope and prolonged life. They often fall short in realistically explaining the goals, risks, and outcomes of the treatments for serious illnesses. (Della Penna, 2000)

"Oncologists treat to death. They continue chemo and radiation to an extreme degree. People have a false sense of expected benefits of treatment for far too long, and they are not aware that they have other options. If they ARE aware of options, it is because a social worker told them."

bacteremia, exacerbation of an end-stage problem or degenerative conditions often do not recover to baseline status after a critical illness despite the best treatment. And persons with advanced age and multiple illnesses often do poorly after any major surgery. The physiological odds are stacked against them. Compromised organ function, reduced nutritional status, and diminished immune response—all due to advanced age—make it difficult to survive a major injury, illness, or surgical intervention intact. As a result, many do not recover to their previous functional level. Yet the physician may present the intervention as their only option for survival. It would be more useful to frame treatment decisions in terms of potential harm vs. potential gain.

Devastated Families

According to hospice contacts, when patients who have been receiving aggressive treatment discover that they are at the end of life, many feel that they have been robbed of precious time that they might have spent differently had they known earlier. They also feel robbed of choice and robbed of the time to settle loose ends before dying. Many commented that patients and families are unprepared. They have no idea that the patient is close to death. Some still expect a cure based upon the doctor's assurances. They are devastated when they discover that there will be no cure:

Two groups in our area treat patients to death. Some spend their life savings. It is not unusual to see patients receiving chemotherapy and radiation who are actively dying and don't know it.

Doctors don't talk about hospice until they've tried the last aggressive treatment option and nothing has worked. Then they mention hospice, and the patient and family are grief-stricken. Patients give up and die within a few days. Families have horrific grief—last week the cure was working, and this week their loved one is dying. There is no advance warning.

Delayed Access to Hospice

A number of hospice contacts reported that patients and families often say that they wish they had known about hospice earlier.

- Of the 38 who could estimate how often they hear this remark, half said that 50 percent or more of their patients say it.

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- Thirteen hospices (34 percent) reported hearing the comment from 70 percent or more of their patients. Interestingly, 9 of the 13 are located in the southeastern Michigan counties where end of life hospital admissions and intensive care days are highest.

Several contacts talked about late referrals:

The patient gets hospice when the physician is ready to stop treating. We get late referrals for people who were getting aggressive treatment and then switched to hospice at the last minute. Some are actively dying and die within 45 minutes after we open the case.

Aggressive oncologists don't stop radiation or chemotherapy until the patient can no longer make it to the office. Then they refer to hospice.

Oncologists are the biggest offenders for late referrals. Patients are discharged with death impending to die at home.

Physicians don't deal with end of life prognosis and conversations until late in the disease. We get late hospice referrals and see patients for short stays in the hospital before they die.

Hospice care has become mainly crisis intervention with later referrals and shorter stays. With more high tech options, patients may receive curative treatment until the end, when they are actively dying. Of all patients admitted to our hospice, 10 to 15 percent die within 48 hours. Some die in the elevator on the way from the hospital to the hospice residence.

Late referrals to hospice have a negative impact on the hospice team. It is discouraging for them to admit people whose death is imminent and realize that they could have been helping these individuals and their families weeks earlier. Some team members feel guilty because they cannot deliver the full physical, emotional, and spiritual support of hospice in just a few days. Hospices receive grateful thanks even from families who had hospice support for 24 or fewer hours. While the thanks are gratifying, they also inspire a sense that people do not realize what they have missed.

Delayed access to hospice has a public consequence as well. The pattern of late referrals contributes to consumer perception that



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hospice is a brink of death service intended only for those for whom death is imminent. Short lengths of service also fuel the misconception that hospice hastens death. Hospice staff encounter comments like: “Everyone I know who gets hospice dies in a few days.” One contact dubbed it the “enroll today, die tomorrow” stereotype. Hospice has become a bad word, and that is a barrier to access to a needed service.

Obstacles to Improvement

While Michigan has established informed choice as a legal right for persons with limited life expectancy due to advanced illness, it is apparent that policy and practice are not in sync and that lack of informed choice contributes to unnecessary suffering at the end of life. Ensuring informed decisions about medical treatment is challenging, and stakeholders and hospice contacts described a number of obstacles to improvement. They include policy, system, physician, and consumer issues.

Policy Obstacles

Experts and consumers alike believe that providing informed choice and honoring a person’s treatment preferences are critical aspects of high quality end of life care. Michigan laws solidly protect an individual’s rights and preferences at the end of life, but reality does not fully reflect the law. Informed choice for medical treatment decisions is not ensured in practice as it is laid out in the Michigan Dignified Death Act, and there is confusion about guardianship and non-hospital do-not-resuscitate (DNR) orders.

Confusion about Guardianship

A number of stakeholders in legal and health care fields expressed concern about unsettled issues related to the role of public guardians in end of life decision-making. Guardians are appointed by the court when an individual (the “ward”) is determined to be legally incompetent to make his or her own decisions and when there is no family or other natural surrogate available. When a treatment decision is required, the guardian follows the ward’s wishes if they are known and considers the ward’s best interests if they are not.

Confusion about a June 2000 opinion of the Michigan Attorney General has caused some professional guardians to question their authority to withhold or withdraw treatment and to refuse to



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“An attorney who serves as guardian for an incapacitated nursing home patient refused to request a do-not-resuscitate order, explaining that Michigan law prohibits legal guardians from making treatment decisions if they are not designated health advocates. The patient is unresponsive and curled into a fetal position and has advanced dementia, heart failure, and bedsores. Based upon the guardian’s response, she will have to be resuscitated when she dies.”

consider end of life issues in general (Felt, n.d.). Stakeholders described the impact of this confusion:

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People with legal guardians always have to have everything done regardless of their condition. The guardians never see them, and often these people have no family to advocate for them. For example, one dear sweet old lady lived here for years and used to walk around. Then she was in and out of the hospital, crippled with arthritis, and not eating. She ended up intubated and moved to another facility on a ventilator. We should be able to let these people go.

A large percentage of folks who were never competent are now old and ill, and nothing is set up for their end of life decision-making. They mostly live in group homes through Community Mental Health. We need processes for emergency medical guardianship and end of life decision-making. We need to know when to call probate and the courts need to be aware too.

One health care provider voiced caution about proposed surrogate laws that would codify rules for choosing a family advocate. Her experience is that each family has its own culture for sharing information and decision-making, so the clinician needs the flexibility to work with the family to choose a health advocate that fits their style and the situation. Sometimes the best choice is a natural surrogate who may be a friend rather than a relative.

Confusion about DNR Orders

Michigan's Do Not Resuscitate Procedure (MCL 333.1051 et seq.) protects a person's preference not to be revived even if the person dies in a place other than a health care facility. The person must wear a DNR identification bracelet or have a copy of the doctor's order to ensure this protection.

A hospice contact in southeastern Michigan expressed concern about paramedics who ventilate or resuscitate actively dying patients in ambulances despite valid DNR orders. In the described

instances, the individuals were being transported home or to another setting. This scenario happens with emergency medical service providers as a group, not just with a single company.

System Obstacles

Stakeholders with experience in quality improvement pointed out that as a rule, 85 percent of quality concerns are due to system problems and 15 percent to professional performance. If the system does not support the desired behavior, even the best intentions fail. By far the two most commonly mentioned system problems for people at the end of life are the lack of person-centered care management and the lack of advance care planning. Other obstacles are the dominance of technology and the lack of time and reimbursement for end of life conversations.

Lack of Person-Centered Care Management

In most health care systems as currently designed, it is no one's role to stick with a person through all treatment settings to coordinate care and facilitate communication among patient, family, and providers. Several stakeholders, many of them palliative care clinicians, cited this as an important flaw that hinders informed decision-making at the end of life:

Physicians see multiple admissions but don't connect the dots and miss the big picture. And patients and families don't realize the significance of multiple inpatient admissions—no one explains. Hospital case managers are not able to coordinate care over time because their roles are limited to discharge planning. No one talks to the patient about prognosis, goals, and preferences.

Hospice and palliative care folks need to get organized. The same people should do both and introduce hospice early on as an eventual part of the treatment plan. Otherwise the chronically ill fall through the cracks. No one initiates the conversation about prognosis and expected disease course, and people suffer through uncoordinated treatment by multiple doctors—always wanting and expecting to get better.

It is not uncommon for families to say that even though their loved one has been in and out of the hospital many times in recent months, the hospice nurse is the first person to explain what's happening and what it means. 'No one has said anything until now.' Too often at this point the patient is actively dying.



Care is not person-centered or coordinated.

"With many specialists involved in the case in the critical care unit—oncologist, internist, intensivist—no one looks at the whole person or accepts full accountability for the big picture. Each doctor is only comfortable talking about his or her own piece of the treatment."

"One function of the palliative care nurses is to help families understand what each consulting specialist is doing so they can connect the dots and see the big picture. Until this conversation, no one integrates the care and explains what's going on to the patient and family."

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Lack of Advance Care Planning

Michigan statutory law does not recognize advance directives or living wills but does allow a person to designate a patient advocate.

- The advocate is authorized to make medical treatment decisions when the person can no longer speak for himself, including at the end of life.
- The designation form generally includes instructions about preferences for life-sustaining treatment in the event the individual is in an irreversible coma or persistent vegetative state.
- Some people also include instructions for terminal illness and other circumstances when the burden of treatment may outweigh the expected benefits.

The document is most useful when the person also talks with the advocate to clarify his or her values, goals, and preferences about longevity and quality of life.

Despite more than a decade of effort nationwide to urge people to choose an advocate and complete an advance directive, only about one in five adults has done so (Schwartz et al., 2002; Yates & Glick, 1997). In Michigan communities where end of life needs have been assessed, citizens want their end of life wishes to be honored but most have taken no steps to ensure that this will happen.

Hospital stakeholders pointed out that the majority of treatment decisions do not relate to irreversible coma, vegetative states, or even terminal illness with death imminent. Most are too complex to be resolved by a simple checklist of unwanted interventions. Instead most people dwindle with progressive disability. They and their families have hard decisions to make about withholding or withdrawing treatment during an exacerbation when the person may or may not survive and may or may not be incapacitated.

These scenarios often play out in critical care units. The bewildered family struggles to sort out treatment options. When they have to make difficult choices with no idea what the person would want, they often feel lasting guilt about their decisions. A number of stakeholders talked about how the situations unfold:

Much of the effort to facilitate decision-making is directed toward the family. It is a time-consuming process which



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involves establishing a trusting relationship, helping them tell their story and come to understand their loved one's condition, and answering many questions about treatment—how it works, what it's like for the person, benefits, drawbacks, and so on. When family members approach a decision from conflicting perspectives—Dad is a fighter and would want everything vs. Dad values his dignity and wouldn't want any of this—the process is more difficult. Ultimately family members can make a difficult choice with their minds, but then they need more time to feel comfortable with it in their hearts.

It takes time for families to come to grips with the reality that a loved one is dying. Clinicians who realize that a patient is near death may be ready for a do-not-resuscitate order, but families may not be able to act until the news sinks in.

In cases where a patient dies suddenly and then is revived but is in fact terminally ill, hospital staff must break bad news to an unprepared family and then help them with decision-making. But the hospital doctors and nurses often have no previous relationship with the patient or family. Building rapid bonds of trust during this highly emotional circumstance is a challenge.

Technology Rules

Without a strong advocate or clear instructions, incapacitated individuals are likely to receive aggressive life-sustaining treatment. Physicians have an ever-growing arsenal of medications and technological tools that allow them to treat much further into the course of a disease. So when there is no advance care planning, the default approach is to continue to treat. This is true in institutional and community settings.

Nurses, too, have a greater focus on technology because they are responsible for operating much more equipment at the bedside than ever before. One nursing educator noted that to keep pace with therapeutic advances, there is growing attention to technology in medical and nursing education and dwindling attention to caring skills. Salient comments from other contacts:

There is such an emphasis on technology that when it doesn't work some doctors and nurses feel they have nothing more to offer the patient.

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Many young nursing students watch ER and approach their training with a desire to do the exciting high tech interventions they see portrayed on television. In the nursing curriculum there is a brief hospice rotation. Some of the students complain that there was nothing to do there—‘All I did was sit with a patient.’ Some are reluctant to touch a dying person.

There is a widespread sense among hospice providers that people prefer high touch to high tech at the end of life. Their observations are supported by public opinion polls that consistently turn up preferences for a comfortable death at home surrounded by family. If high touch is indeed a patient and family preference, the growing high tech emphasis in health care may well interfere.

Inadequate Time and Reimbursement

Facilitating discussions about treatment decisions with people and their families requires compassion, patience, skill—and time. According to physician and nurse stakeholders many doctors have no time to facilitate advance care planning dialogues with their patients in the hospital or in the office setting. There is no reimbursement for the service. One doctor explained it:

The time for advance care planning discussions is not adequately reimbursed. The payment does not come close to matching what the physician could have earned in the same period of time seeing many more patients with ‘usual’ needs. Some physicians struggle with the ethics of doing a certain number of procedures—‘trawling for warts’—to earn revenue to cover the time required for poorly reimbursed elements of good medical care like these talks.

Among the stakeholders interviewed, it is common for the nurses to facilitate decision-making discussions with patients and families. They work in palliative care and ethics roles and have hospice, palliative care, critical care, and ethics backgrounds. The nurses commented:

Family meetings about end of life decisions are complex, intense, and time-consuming (30 to 60 minutes), and the unexpected often surfaces. Talking about end of life is never easy, and it also is difficult for a busy physician to set aside the time to facilitate such a meeting.



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Patients often don't understand what's going on and therefore can't make informed choices about treatment options. We are very committed to informed consent. Before we admit a patient to our hospice, a nurse meets with the person and at least one family member (but as many as desired) to lay out the future honestly and to talk about advance care planning. At best the conversation requires an hour, and it is not unusual to have 2 or 3 meetings before everyone understands everything and has had time to think about what it all means. It takes time to work through family dynamics, and understanding and acceptance take time to evolve. Some patients choose not to elect hospice, but our nurses are committed to investing the up-front time for explaining and counseling so people can make an informed choice. This counseling role is not reimbursed, but we believe that it's a necessary and valuable service.

Physician Obstacles

Barriers attributed to physicians were the most frequently mentioned obstacles to informed choice at the end of life. They relate to physician culture and communication issues.

Culture of Cure

Physicians have been characterized as warriors who battle disease. They do not acknowledge pain, they fight to the death, and they consider death to be a horrible outcome (Twaddle, 2002). Stakeholder clinicians offered similar comments:

Doctors are programmed to fix things; it's hard to turn from that mode to palliative care. Specialists in particular may find it difficult. Some feel morally obligated to treat a condition as aggressively as possible regardless of the patient's functional status, goals, or likely response. For instance, the cardiologist wants to aggressively treat congestive heart failure in a patient with advanced dementia and renal failure.

The director of the critical care unit announced at an administrative meeting that 'as a physician group we do not know how to do palliative care; all we know how to do is a full court press.

When a doctor is allowed to treat, he continues to treat even if it is not effective. When challenged, the doctors here can't always say what symptoms they're trying to relieve with a particular chemotherapy drug.

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The physician culture here is resistant to hospice and palliative care. The pulmonologist will put a patient on a respirator if he thinks he can get her off in a week, even with end stage lung cancer, but his expectations are unrealistic. Doctors are not comfortable with palliative care.

In their zeal to defeat disease, some warriors forget that the battleground is a person. One contact observed that when doctors focus on the disease and the symptoms and not on the person, they miss the big picture and treat too long. A physician commented:

The 'atta boys' for managing end of life care are different than those for managing and curing acute problems. They don't appeal to everyone.

Researchers recently conducted the first study to investigate the criticism that oncologists “treat people to death.” They examined 1996 Medicare claims for chemotherapy during the last six months of life for more than 7900 cancer decedents aged 66 and older (Emanuel et al., 2003).

- They found that 33 percent received chemotherapy in their final six months and 23 percent received it in their final three months.
- There was no difference in prevalence of use between persons with cancer responsive to chemotherapy and persons with cancer unresponsive to chemotherapy.

The researchers were unable to distinguish curative versus palliative intent for therapy. And they could not tell if the therapy was the doctor's recommendation or the patient's request. They did note that in the final months, oncologists can typically predict which patients will die shortly regardless of treatment. They concluded that chemotherapy in the final months of life deserves further study.

Reluctance to Initiate the Conversation

In Western cultures, most patients with terminal illness want their doctors to be honest with them. They use the information to make treatment choices and to decide when to put their affairs in order (Lamont & Christakis, 2003). But predicting patients' deaths and talking to them and their families about it are among a physician's most difficult tasks. For the most part doctors are not well prepared for either one (Christakis, 1999). For some the conversation represents an admission of failure; for others a gamble that may



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destroy hope and hasten decline. Physician stakeholders commented about the difficulties:

Our number one critical need is managing the transition to the end of life. This involves an in-depth discussion to help people understand what's going on and how to navigate the transition. It's hard to know when it's time for the discussion. A physician asks himself: Have I done everything possible? Have I met the standard of care? It's hard to start the conversation and hard to have it. It's important to frame the discussion positively, but even carefully chosen words may trigger a hopeless reaction in the patient and family. It's easier when THEY raise the issue. It takes skill and stamina to have these tough discussions day to day and at the end of a long day. It feels like a failure to hear a family say 'I had no idea he was that sick.'

Younger physicians may not be ready for transition discussions. They are still into fixing things, as they were trained to do. It takes a certain amount of experience to feel comfortable with the role; less experienced physicians are not yet confident enough to say that we've done all we can do. Role models and mentors can help, but what they need is exposure to lots of cases.

Physicians are scared to have end of life discussions. There is no model for these, and we need to normalize the conversation. It's like taking a patient's sexual history used to be. It was difficult when it was first required; we felt reluctant and awkward. But we were forced to do it and now it's better, more normal. Sometimes physicians insist that families are not ready for an honest discussion, but more often it is the doctor who is not ready.

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When starting the conversation hinges upon certifying a terminal diagnosis and the six-month prognosis required by the Medicare hospice benefit, physicians are even more reluctant to act. They understood from the beginning that access to hospice care hinged upon their ability to accurately predict when a patient is likely to die (Brody & Lynn, 1984). They warned that they were not good at this, and 30 years of studies show that their prowess has not improved much (Iwashyna & Christakis, 2001).

Prognosis is especially difficult and imprecise for patients with chronic disease marked by a declining up and down course with no clear turning point to the terminal phase. Stakeholders and hospice contacts offered these observations:

Looking for a prognostic trigger to shift from cure to care fits the medical model of treatment, but it is the wrong paradigm for end of life care. It risks the scenario in which the patient wants to talk about what's happening but the physician and family avoid it, perhaps in an effort to preserve hope. Decline with chronic disease is incremental. There is not one point at which the terminal decline begins.

The worst problem for doctors is patients with congestive heart failure and chronic lung disease. They have a longstanding relationship with these people and find it hard to be frank about end of life. Both types of patients survive repeated crises with ER visits and hospital stays when they thought they'd die but did not. If they survived then, why not this time?

As a group, physicians are not comfortable facilitating conversations about prognosis and end of life treatment options. Many do not have the words to initiate the conversation and so wait for the patient to bring it up.



Well-intended clinicians who are not skilled at talking about end of life face many pitfalls. Medical or vague words, a brief talk, and a bleak tone all make it hard for the patient to get the message.

Physicians who don't know what to say may wait for the patient to bring up the topic.

Communication Challenges

Once the conversation is initiated, many pitfalls can make it less than effective. Remember that 85 percent of hospice contacts encounter new patients who lack understanding of their illness and what lies ahead. When they contact physicians about the problem, they most often hear that the doctor explained everything to the patient, sometimes more than once. Why then the lack of comprehension? A handful of contacts pointed out that there could be a problem with the patient being in denial or not grasping what the doctor said. But the majority of concerns centered around the physician's delivery of the message.

- Choice of words can be a problem. Sometimes physicians use jargon that the family doesn't understand. Or they speak in such vague terms that patients don't get the message.
 - One palliative care nurse was with an oncologist colleague as he explained to the patient in the simplest of medical terms that there were only a few nodes and that there had been a response to chemotherapy. It appeared to the nurse that the patient did not comprehend that "nodes" meant cancer and that "response" did not mean cure. She asked questions that allowed the physician to clarify.

He was surprised and chagrined that the patient had not understood.

- Brevity also can be a problem where end of life conversations are concerned. Hospice contacts noted that the conversation is a process, not a one-time event:

Most doctors do not have the time required to truly inform a patient and family and respond to their reactions. Such a conversation requires at least an hour and often several sessions. When physicians try to do a quick condensed talk, the message often is not clear to the patient and family.

- Another key factor is how the message is framed—choice and order of words and overall tone. Bleak talk of a grim future makes it difficult for people to hear and absorb the rest of the discussion:

Doctors are not comfortable talking about end of life and want to get it over with. But they personally wouldn't want to hear the message for themselves the way they present it to others. You need to say what the patient needs to hear in a way that allows them to listen and absorb the message. You need to crawl into their skin to figure this out—who they are and how they need to hear it. You have to be a good listener. People will open up if you give them enough time.

- Studies of decision-making for health care problems consistently find that people's choices are influenced by how the information is presented. When physicians discuss end of life decisions with patients, their own views color the way they describe each option (Orentlicher, 1992).
 - When doctors present aggressive treatment as the only option for survival and frame comfort care as awaiting the inevitable, few patients choose the latter.
 - When doctors describe hospice as aggressive treatment of symptoms to ensure comfort, it becomes an option worth considering.

"As a group, physicians are not comfortable facilitating conversations about prognosis and end of life treatment options. Many do not have the words to initiate the conversation..."

"When physicians try to do a quick condensed talk, the message often is not clear to the patient and family."

"Doctors are not comfortable talking about end of life and want to get it over with. But they personally wouldn't want to hear the message for themselves the way they present it to others."

Consumer Obstacles

Consumer obstacles related to end of life decision making were raised much less often than were physician obstacles. Stakeholders and hospice contacts mentioned a number of issues, all of which relate to one overriding theme—not ready yet.

Not Ready Yet

Dying is not acceptable in America, said contacts. People resist talking about it and planning for it. When they do consider dying, impressions from television programs foster unrealistic expectations for the success of treatment and resuscitation to forestall death. Often patients or families push for more treatment and do not want to stop:

Younger people especially are likely to try anything to stay alive. But it's these patients who ultimately say 'why didn't I do hospice sooner?'

Families are reluctant to give up. The elderly are on board with choosing comfort, but their sons and daughters are less so. They want to fight, and choosing comfort feels like giving up. The patient is tired and wants to stay home and be comfortable but is reluctant to say this because the kids don't want to hear it. Later, these family members wish they'd accepted hospice earlier.

Americans value independence and do not want to think about help or talk about hospice until they absolutely cannot manage on their own. One stakeholder from a physician practice commented that patients and caregivers are reluctant to consider hospice care for several reasons:

They do not understand that chronic illness is life-limiting and cannot be cured. They feel entitled to all possible treatments. They cannot accept the implication that the person is dying. The person feels afraid and not ready to die. Difficult family dynamics complicate and block decision-making.

People's misconceptions about hospice also stop them from making the choice earlier:

They think there will be no more aggressive treatment. We still do it, but for comfort. They are surprised that they still have the option of calling 911. They think they must stop all meds and give up all treatments, even those that are reasonable to maintain comfort. To them hospice represents giving up hope.



Consumers resist talking about end of life. Sometimes patients and families are reluctant to give up and push for more treatment. Later they wish they had accepted hospice sooner.

Encouraging Factors

While there are troubling obstacles to informed decision-making at the end of life, there also are reasons to be encouraged. Michigan has model policy, innovative programs, expert clinicians, receptive consumers, and useful resources.

Model Policy

When the Robert Wood Johnson Foundation completed a national study of end of life care and released state report cards in 2002, Michigan's only A grade was awarded for its advance directive laws (*Means to a Better End*, 2002). The top score reflects Michigan's clear, comprehensive statutes for advance care planning and for out-of-hospital DNR orders.

Unlike most of the other 50 states, Michigan's statutory approach to advance care planning recognizes only a designated patient advocate. Written treatment preferences are expected to guide that person's decisions but are not binding if they are not in the patient's best interests in the particular situation. A recent analysis of the hurdles involved in getting people to complete advance directives and in assuring that health systems follow them concludes that appointing a patient advocate is the preferred approach (Fagerlin & Schneider, 2004).

Innovative Programs

There are promising programs in Michigan that focus on improving end of life decision-making in a variety of settings. These are a few examples.

Advance Care Planning

A number of community end of life coalitions are interested in advance care planning. Those in Traverse City, Muskegon, and Lansing have sponsored trainings in the Respecting Choices process and tools so their members can help people develop advance directives. The Jackson coalition has led the way in developing a form and procedures to honor people's end of life treatment preferences in health care and community settings.

The Advance Care Planning Department at Munson Medical Center in Traverse City is a model of community engagement. Along with a well-established Respecting Choices program, there are efforts underway to improve end of life decision making in nursing homes, in critical care units, with legal guardians, with heart failure patients, and with community mental health clients.



Michigan has model policy, skilled clinicians, and innovative programs for end of life decision making support.

Proven models from other states would work in Michigan. They can be used in home settings and in clinics.

Evidence shows that when clinicians facilitate caring, patient-centered conversations about end of life options, people choose hospice more often and earlier.

End of Life Decision-Making

The Family Matters Support Service at Oakwood Healthcare System in Dearborn is a team of nurses who use a patient-centered process to help patients and their families with end of life goals and treatment decisions in the inpatient setting. Evaluations show high patient, family, and physician satisfaction. The team has developed an advance directive tool, resources, and planning process that can be licensed for use by other organizations. They also have cultivated expertise in cultural diversity issues and end of life decision making.

Hospices in Lansing, Jackson, and Holland dedicate staff to in-home information visits to help prospective patients and their families consider goals and treatment options and make informed choices about end of life.

The inpatient palliative care service at Sparrow Hospital is staffed by two nurse clinicians that focus primarily on facilitating decision-making for patients nearing the end of life. They report that when information is presented in a compassionate, person-centered manner, people and their families understand their prognosis and choices. They participate capably and willingly in end of life decisions. Guiding decision-making is a key function for palliative care teams at other large hospitals in the state as well.

Pre-Hospice Programs

Many hospices that are affiliated with home health agencies have created special programs to provide varying degrees of hospice-like support. They target patients who most often have late stage chronic illness but are not ready (emotionally or physically or both) for hospice. The nurses are cross-trained or blended to ensure continuity of care if the person does elect to enroll in hospice. In the meantime the team provides palliative symptom management and decision-making support.

Physicians (especially those who are not comfortable with end of life conversations) like the programs because they can refer patients to a “special home care program” where a nurse or social worker can gently facilitate the decision-making process.

National Innovations

In addition to in-state practices for supporting end-of-life decision-making, there are national models that could work in Michigan. Two of the most relevant ones are kitchen table discussions and the surprise question.



When information is presented in a compassionate, person-centered manner, people and their families understand their prognosis and choices. They participate capably and willingly in end of life decisions.

Many nurses and social workers are more comfortable facilitating such discussions than are most doctors. Physicians appreciate being able to refer their patients to special programs where a nurse or social worker gently facilitates end of life decision-making.

Kitchen Table Discussions—In a Minnesota project, home health nurses identified seriously ill patients who in their judgment could die within two years. All but one of the 84 patients (median age 75) agreed to participate in the project, and their physicians approved as well.

- The intervention was a series of visits from a social worker—one to three visits, each lasting 1 to 2 hours.
- The process was a person-centered advance care planning discussion conducted with the patient and family around the kitchen table.

Rather than transfer of information, this kitchen table discussion emphasized mutual understanding, respectful relationships, cultural sensitivity, and open, honest dialogue. The basis for the conversation was the patient's desire to be in a preferred setting—85 percent chose home—at the end of life.

- Of the 84 patients, 47 percent died within 90 days after advance care planning was initiated. Another 21 percent died within 18 months.
- Of those who died, 61 percent enrolled in hospice and 70 percent died at home.

The intervention targeted appropriate people and enabled them to achieve their preferred ending (Ratner, Norlander, & McSteen, 2001).

The Surprise Question—When clinicians in a primary care clinic in At Franciscan Health System in Washington set up a program to link seriously ill patients and their families with community support services, their greatest challenge was helping physicians identify people who were approaching the end of life. They discovered that physicians' clinical sense was as accurate as formal guidelines and much more comfortable and convenient for doctors to use.

The team gave each physician a list of patients they had seen within the prior two months. Each person had a diagnosis of heart disease, cancer, advanced lung disease, or Alzheimer's disease. They asked the doctors: "Would you be surprised if any of these patients died within the next 12 months?" The question seemed to allow physicians to think in a new way about those patients and their needs; it was as if a switch had been flipped. Physicians were



Physicians' and nurses' clinical sense seems to be as accurate as formal guidelines for identifying patients nearing the end of life. And it is much more familiar and comfortable to use.

Doctors are comfortable referring these patients to talk about end of life decisions, especially if they have been given words to start the conversation.

willing and able to answer the question. They began to target patients who could benefit from a discussion of treatment choices.

The team provided physicians with words they could use if they chose to refer any of the patients for supportive services: “My expectation is that this condition is going to continue to worsen over the next few months, and we need to plan for that. I have a special support program that I’d like to refer you to”. With that start, the physician then seamlessly introduced the patient to a nurse specialist with the skills and the time to continue the conversation (Pattison, 2000).

The team found that the program turned patients into informed consumers who felt empowered to make choices. As a result:

- Hospice referrals increased six-fold; and
- Hospice length of service rose by 50 percent.

A physician leader attributed the success of the program to several factors. The program:

- Focused on high risk patient populations;
- Educated physicians to improve their understanding of the value of the program;
- Made the change uncomplicated—provided words to start the conversation and a nurse specialist to continue it; and
- Had a rapid and obvious payoff in patient satisfaction and improved care.

Overall, the key to success was introducing changes in the process of care—the system—that made it easy for physicians to do the right thing (Della Penna, 2000).

Expert Clinicians

There are physicians in Michigan—all over the state—who have the words and communication skills to conduct excellent end of life conversations. They invite patients to tell their stories and listen with compassion. They offer hope with bad news, use analogies to help patients understand, and sequence questions to help patients clarify their preferences. They are hospice medical directors, hospital-based palliative care physicians, oncologists, geriatricians, neonatologists, and other physicians who face end of life issues most often. There also are primary care physicians who are comfortable facilitating advance care planning with people that have advanced illness. Several contacts named doctors whose communication prowess they admired.



One program helped doctors identify patients who were at risk of dying in the coming year. The doctors were given words to start a conversation about the expected decline. Then a nurse talked with the patient and family about treatment choices.

Hospice referrals and length of service grew significantly. A physician leader cited these reasons for success:

- Focus on high risk patients
- Informed physicians
- Uncomplicated process
- Rapid and obvious payoff in patient satisfaction and better care.

There are many nurses who regularly facilitate end of life conversations and are very skilled at approaching sensitive and emotional topics with people and their families.

- They know how to help families tell their stories, which allows them to reach their own understanding of the situation and make tough choices with less guilt.
- They know how to reframe difficult decisions in a way that absolves the family from responsibility for them:
 - If your dad were looking over you now, what would HE say to do?
 - Would it be a blessing if your mother died in her sleep?
- Questions like those are easier to consider than “Do you want everything done for your mother?”

Families’ answers to compassionate questions can help them determine whether to choose life-sustaining interventions or to allow a natural ending.

Clinicians can identify patients with late stage illness and initiate conversations. A palliative care nurse described it this way:

Although it is difficult to tell exactly when a person with an advanced illness like congestive heart failure reaches the end of life as defined by the hospice benefit (six-month prognosis), the doctor CAN tell that the person is declining based upon signs, symptoms, and test results. At some point, well before death is imminent, the doctor can alert the patient and family to the decline and begin anticipatory guidance and advance care planning.

Michigan is progress with informed choice. A number of hospice contacts reported that the physicians in their areas are better now at end of life conversations and that those who are not are distressed by their lack of skill. Most often progress has followed repeated presentations from guest experts or one on one visits from active hospice medical directors.

Receptive Consumers

Of all the hospice contacts who spoke of uninformed patients that said the hospice nurse was the first to explain, none said that the patients wished the nurse had not explained. In fact, some noted that when people get clear answers early with an open and caring

conversation, they feel empowered to make choices. Their quality of life is better. Other comments:

An unresponsive, very elderly man in a critical care unit had been intubated for some time. The doctor announced that it was time for a tracheostomy. The nurse sat down with the family to facilitate informed consent. Up until this time the man's elderly wife had been deferring to the adult children to make decisions. When the nurse explained that the patient would likely be on a ventilator long term in a nursing home, the elderly wife spoke up and emphatically insisted that her husband wouldn't want that.

This is a common scenario. Following an honest conversation with a clinician, the patient and his family understand the situation and take charge. The choice naturally shifts to how the patient wants to spend his remaining time. Some choose continued aggressive treatment and some choose other options. But in each case the choice is an informed one. Having the nurse's support for these conversations is a relief for physicians, because many don't know what to say.

There is evidence that people are receptive when physicians introduce hospice early on as a potential part of the treatment plan. A small study of 11 physician champions who referred most often to a southeastern Michigan hospice found two different approaches to the conversation and two different outcomes (Presby, 2003):

- One group of physicians talked about end of life options very late in the illness, sometimes after the patient was unresponsive. They linked hospice with bad news—*“There's nothing more we can do.”*
 - Of the patients they referred, 13 percent refused hospice and 20 percent died before they could be admitted.
 - The average length of service for their patients was 15 days, with a median of 6 days.
- The other group of physicians presented hospice early as an eventual phase of treatment if needed; they spoke of hospice in a hopeful way—*“I can't change the course of the disease, but I CAN help in other ways.”*
 - Of the patients they referred, 5 percent refused hospice and 3 percent died before they could be admitted.



When people get clear answers early with an open and caring conversation, they feel empowered to make choices. Their quality of life is better.

“This is a common scenario. Following an honest conversation with a clinician, the patient and his family understand the situation and take charge. The choice naturally shifts to how the patient wants to spend his remaining time. Some choose continued aggressive treatment and some choose other options. But in each case the choice is an informed one. Having the nurse's support for these conversations is a relief for physicians, because many don't know what to say.”

- The average length of service for their patients was 48 days, with a median of 23 days

Studies of people with congestive heart failure and chronic lung disease show that people in both groups tend to be ill informed about their condition and prognosis and rarely discuss end of life issues with their doctors. However both groups would welcome timely and frank conversations about prognosis (Curtis, Wenrich, Carline, Shannon, Ambrozy, & Ramsey, 2002; Gibbs, McCoy, Gibbs, Rogers, & Addington-Hall, 2002; Murray et al., 2002; Stewart & McMurry, 2002).

- One hospice director reported that she gave a presentation about hospice to a support group for end-stage congestive heart failure patients. They were receptive to the information and reassured to know that there is a team of professionals that specialize in relieving their symptoms at the end of life.

Useful Resources

Among the many resources available for consumer education about end of life decision making are these:

Caring Choices: A Guide to End-of-Life Decisions and Care

This toolkit, developed in 2004, includes activities and materials that advocates can use to educate their communities about end of life decisions. The contents reflect input from focus groups in four underserved populations (Latinos, Native Americans, African Americans, and rural communities) about how they prefer to learn about end of life issues. The project was a joint effort of the Michigan Partnership for the Advancement of End of Life Care and the Michigan Hospice and Palliative Care Organization. Development of the toolkit was supported by funding from the Michigan Department of Community Health.

Caring Conversations Booklet and Radio Public Service Announcement

The booklet offers guidance for talking about end of life issues and decisions. The Michigan Department of Community Health funded adaptation of the booklet for Michigan in 2003, the printing of 10,000 copies, and the development and airing of a radio public service announcement to promote its availability. The booklet also was translated into Spanish and Arabic.

Michigan Dignified Death Act Flyer

This resource provides a clear explanation of the rights to informed decision-making as enacted by the legislature. It was developed by the Michigan Department of Community Health. Doctors can use it to fulfill the statutory requirement that they inform patients of their rights in writing.

Designation of Patient Advocate Form

This booklet contains forms that consumers can use to appoint a patient advocate and indicate treatment preferences to guide that person's decisions when needed. It is sponsored by the State Bar of Michigan, the Michigan State Medical Society, the Michigan Osteopathic Association, and the Michigan Health and Hospital Association. The Michigan State Medical Society distributes 300,000 to 400,000 copies per year to consumers through physician practices, hospitals, and professional associations.

Implications for Policy and Programs

Assuring that persons with advanced illness have informed choice about treatment options remains a critical issue for Michigan. Legislators enacted the Michigan Dignified Death Act in 1996 in an effort to protect citizens from unwanted treatment and inform them of their right to choose. This was a valuable first step, and efforts to raise consumer awareness since then were natural next steps. But now, nine years later, stakeholders and hospice contacts alike report that informed choice is not yet the norm. And it is seriously ill people and their families who pay with unnecessary suffering and heart-wrenching experiences.

Refocus Efforts

Educational efforts to date have focused on encouraging people to choose a patient advocate and talk about treatment preferences in the event the person cannot decide. In fact, the end of life decision-making concerns described most often by interview contacts did not involve incapacitated persons. Instead they involved people who were still able to participate in their own care planning and treatment decisions for advanced illness but lacked the facts needed to make an informed choice.

- The focus of consumer education should include advance planning and informed choice about treatment for serious illness as well as designating ant advocate and having caring conversations.

- Consumer education should be implemented in hospital, nursing home, home, and physician practice settings.

Target Those at Highest Risk

Since resources are limited, they should be directed first toward these populations at highest risk:

- Persons with late stage, life-limiting chronic illnesses in all health care settings;
- Persons and advocates who face decisions about withholding or withdrawing treatment;
- Persons with advanced age and multiple diagnoses; and
- Persons who are family members, advocates, or guardians for the above.

Promote System Change

Physicians have made a strong case both in word and in action for their lack of skill and time for facilitating advance care planning discussions. There is evidence in Michigan that many seriously ill patients are not well informed about their treatment options despite doctors' best efforts.

On the other hand, nurse-facilitated decision-making interventions have shown success both in Michigan and elsewhere. They increase patient understanding, satisfaction, and use of hospice services. Physicians have responded favorably to collaborative models that allow them to introduce the need for planning in advanced illness and then refer to a nurse specialist to finish the task.

There are innovative programs for end of life decision support in Michigan, and there are national models that would work here too. Both feature the essential element for effective change—a process that makes it easier for doctors to do the right thing.

- The MDCH should educate stakeholders about current problems and potential solutions and build consensus for system change. Many health care organizations have used the rapid-cycle Plan-Do-Study-Act quality improvement model to create real improvements in less than a year (Lynn, Schuster, & Kabcenell, 2000).

Educate Consumers

A number of stakeholders were convinced that only consumer demand would drive change. And a number of physicians observed that end of life conversations are easier when the patient initiates



To ensure informed choice about end of life options, Michigan should:

- Focus on advance care planning for high risk persons
- Use rapid-change quality improvement methods to help providers adopt new processes for end of life decision-making
- Conduct a sustained and comprehensive consumer education
- Monitor outcomes of efforts and share best practices statewide.

them. Given the comments that consumers did not realize or believe that they have a choice about treatments, it makes sense to educate them about their right to informed choice as well as their right to designate a patient advocate and make their wishes known.

- To be effective, the approach to education should be comprehensive, sustained, and sponsored by a neutral organization like the Michigan Department of Community Health.
- The interventions should be consistent with appropriate behavior change theory, since people need to be aware of their rights, motivated to exercise them, and prepared with strategies to do so.

Educate Professionals

Some physicians are willing to talk about treatment choices with their seriously ill patients but do not know how to begin the conversation. Others have the conversations but need a more effective approach. They all can benefit from the expertise of their peers who are experienced and skilled at these discussions. While education is not sufficient to change behavior, it is a necessary first step. The Franciscan Health experience shows that giving physicians a process and sample words helps them to initiate talks about end of life issues.

The MDCH should partner with medical societies, health plans, physicians, and other providers to:

- Alert physicians about their responsibilities under the Michigan Dignified Death Act.
- Promote continuing education about communication techniques for initiating and facilitating conversations with seriously ill patients; and
- Target specialties that are most involved with advanced chronic illness and end of life issues, such as oncology, geriatrics, and internal medicine.
 - Specialties with the highest percentage of billings for last year of life costs include oncology, critical care, hematology, infectious disease, pulmonary disease, radiation oncology, and nephrology (Hogan et al., 2000).

Track Efforts and Outcomes

Currently in Michigan there is no central repository for information about end of life infrastructure, programs, and

projects. So there is no way to track and share best practices or to monitor outcomes of projects and their impact on critical needs.

- The MDCH should partner with stakeholders to develop a process for identifying and sharing best practices and for tracking indicators to measure the outcomes of our collective efforts to improve advance care planning and informed choice for targeted populations.

Key Points

Of 57 interviewed hospice contacts, 40 percent estimated that half or more of their new patients are ill-informed about their disease and prognosis.

As a result of being uninformed, patients receive aggressive treatment without full understanding of potential benefits and burdens. They may assume that the goal is cure, when it is not. Patients and families are devastated when they discover that the patient is close to death. They feel robbed of precious final moments that might have spent differently.

Key obstacles to informed choice in Michigan include:

- Lack of person-centered care and advance care planning for seriously ill persons;
- Some physicians' tendency to treat beyond benefit;
- Physicians' reluctance to initiate and lack of skill at facilitating advance care planning discussions; and
- Consumers' lack of awareness that they have a right to choice about treatment.

Michigan has model policy, skilled clinicians, innovative programs, and helpful resources for end of life decision-making support. Proven models from other states would work here as well.

Lack of informed choice leads to unnecessary suffering and limits access to hospice care. Evidence shows that when people get clear answers through an open and caring conversation, they feel empowered to make choices. Hospice referrals and lengths of stay increase.

To ensure informed choice about end of life options, Michigan should:

- Target advance care planning in all health care settings toward persons with late stage chronic illness and their caregivers;
- Adopt proven models and promote system change to support informed choice;
- Conduct a sustained and comprehensive effort to educate consumers about their right to informed choice about treatment options;
- Alert physicians to their statutory mandate to ensure informed choice; Provide continuing education to build clinicians' skills; and
- Monitor outcomes and share best practices statewide.