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Vulnerable Populations

All Michigan residents are vulnerable at the end of life. These are some of the reasons:

- They have an affliction that most cultures and families do not want to face, so they may be isolated in a conspiracy of silence.
- Their physicians may continue to battle disease long past the point when the afflicted person would surrender.
- Many doctors delay informing the person that the end of life approaches. They lack the right words, and they fear that they will destroy the person's hope.
- Most health care settings and health professionals are not geared to acknowledge end of life, so they do not recognize or address the special needs of patients and families. Very few hospitals have teams that specialize in caring for persons nearing the end of life.
- Medicare and other health insurance plans block access to hospice care—the health care team that does talk with, treat, and support dying persons and their families—with eligibility rules that discourage referrals.

For many Michigan residents who are nearing the end of life, this momentous transition is marked by unnecessary suffering for themselves and their caregivers. Some populations are considered to be especially at risk. Their vulnerability lies in a combination of factors—age, medical condition, place of residence, place of death, lack of access to hospice—that increase their susceptibility to needless suffering. This section provides a brief overview of several vulnerable populations and their end of life issues.

The Extent of the Problem

The populations listed below are those identified as vulnerable by interviewed hospice contacts. Many are underserved by hospice for various reasons. The list is not exhaustive, and the groups are not mutually exclusive. Many individuals belong in several categories.

Michigan's three critical end of life needs are problems for every population, but the information that follows illuminates a few of each group's unique concerns. Table 8.1 lists each vulnerable population, the number of mentions by 57 hospice contacts, and the number of deaths and estimated hospice recipients per group. Discussions of each group follow.

Vulnerable Population	No. of Mentions by Hospice Contacts	No. of Decedents in Group	Estimated No. of Hospice Recipients
Frail elderly at home	21	15,775 Persons age 65+ died at home	Unknown
Culturally diverse groups	19	12,698 Black 964 Hispanic 809 Other	2,793 (22%) Black Unknown Unknown
Marginalized groups	15	Unknown	Unknown
Children with life-limiting illnesses	9	1485 Age 0-14	147 Age 0-17
Persons with degenerative conditions	8	1946 Alzheimer's 1296 Parkinson's 239 ALS 42 Huntington's	Unknown
Nursing home residents	7	21,219	4,998 (24%)
Persons with AIDS and other non-cancer diagnoses	2	237 AIDS 26,447 Heart disease 4,389 Chronic lung 1,606 Kidney disease	118 (50%) AIDS 3,587 (14%) Heart Unknown 1,176 (73%) Kidney

Source: 2002 Michigan Resident Death File, Vital Records and Health Data Development Division, Michigan Department of Community Health; Michigan Hospice and Palliative Care Organization, Michigan Summary Report from 2002 National Data Set

The Underserved Groups

Frail Elderly at Home

Four of every ten hospice contacts voiced concern about elderly people who live alone or with an equally elderly caregiver spouse. They may have adult children who are distant or working and not available for 24-hour care. This is an issue in both rural and urban areas. Hospice contacts had these concerns:

- Many of these people have an income just above the Medicaid level and cannot afford private help or nursing home fees. They are reluctant to spend down their assets to qualify for Medicaid and leave their spouse impoverished. Those who can afford a nursing home often face a waiting list.
- Frail older adults may not be safe living alone, but there is a shortage of support services to help them. In one area, Meals on Wheels funding was exhausted by July.
- In the northern parts of the state, some of the elderly live in areas so remote that a four-wheel-drive vehicle is required to reach them year-round.
- Some of these isolated elders have been clients of the mental health system. They have alienated their natural support system and mistrust helpers in general.
- The well-being of the elderly caregiver is a primary concern. It is not uncommon for a hospice to admit the caregiver spouse shortly after the patient dies.

Culturally Diverse Groups

One third of hospice contacts expressed concern about underserving culturally diverse populations despite well-intended outreach efforts. In 2002, there were 13,507 nonwhite decedents in Michigan. Of those, 88 percent (12,698) were African American. Only an estimated 22 percent used hospice services, well below the 34 percent rate for white decedents. (Estimates for numbers served are not available for other ethnic groups.)

Numerous studies have found that African Americans and Hispanics are more likely than white persons to be under-treated for pain during hospital stays and in emergency rooms, outpatient clinics, and nursing homes (Crawley, 2001; Rallying Points, 2002).

Yet they fail to adequately use hospice and palliative care services (Robert Wood Johnson Foundation, 2004).

Scholars have studied roadblocks to access more for African Americans than for other groups. While diversity among blacks limits generalizations, researchers report these barriers:

- Tendency to see suffering as an expected part of life's continual struggle and to endure it as a noble spiritual commitment (Barrett & Heller, 2001; Crawley, 2001; Crawley, Payne, Bolden, Payne, Washington, & Williams, 2000);
- Preference for hospitalization and life-saving interventions (Blackhall, Frank, Murphy, Michel, Palmer, & Azen, 1999; Cort, 2004; Hopp & Duffy, 2000);
- Lower likelihood than whites of completing an advance directive, appointing a health advocate, or discussing preferences with others (Hopp & Duffy, 2000);
- Mistrust of the health care system and dismay at the lack of ethnic diversity among hospice staff (Reese, Ahern, Nair, O'Faire, & Warren, 1999);
- Preference for family over individual decision-making (Barrett & Heller, 2001);
- Reluctance to accept caregiving help from strangers (Cort, 2004); and
- Lack of knowledge and understanding of hospice (Cort, 2004; Crawley et al., 2000; Reese et al., 1999).

Input from hospice contacts echoes these barriers. They observed that African Americans as a group tend to embrace hospice less readily than other ethnic groups do. Their specific insights are that African Americans:

- Expect to suffer and accept it;
- Prefer to be hospitalized at the end of life;
- Favor resuscitation and other aggressive treatment; and
- Prefer to receive care from their own support networks.

National caregiver surveys report a higher prevalence of family caregiving among African Americans, Hispanics, and Asian Americans than among whites (AARP, 2001; National Alliance for Caregiving & AARP, 1997). Also, African American families are more likely to expect the responsibility and find it to be less of an intrusion that white caregivers do (White, Townsend, & Stephe, 2000).

Marginalized Groups

Persons with persistent mental illness, persons with developmental disabilities, and persons who are incarcerated face unique challenges at the end of life. But they also share troublesome problems with end of life decision-making. The end of life issues pertinent to each group are described below.

Persons with Serious Mental Illness

In 2003 there were 140,157 individuals with persistent mental illness who received treatment from community mental health services programs. According to statistics from the Bureau of Community Mental Health Services (2004) in the Michigan Department of Community Health:

- At least 58 percent had incomes below federal poverty thresholds.
- 22 percent represented diverse racial/ethnic groups.
- 8 percent were age 65 and over; 57 percent were age 27 to 64 years.
- 66 percent lived in private residences, 7 percent lived in foster care or group homes, 2 percent were homeless, and 2 percent were in jail or prison,
- Data on the number and cause of deaths are not captured at the state level and difficult to extract at the local level.

According to stakeholders in the mental health system, persons with persistent mental illness face these issues at the end of life:

- Premature death
Mortality rates for adults are at least twice those of same-age peers, and life expectancies are shorter by about a decade (Felker, Yazel, & Short, 1996; Foti, 2003). While causes of death are not reported, one stakeholder observed that violence, suicide, and chronic disease are most common. Most older clients die from the latter.

- Lack of caregiver support
People who lose touch with their families and friends during years of mental illness may be isolated at the end of life. For those who live in group settings, the staff and housemates become their support system. Some group homes are set up for medically frail clients; in others the staff members need training to provide care. Many clients remain in the service net until they die. If they become too ill to stay in one setting, they are transferred to a more suitable level of care. With the move, they lose their familiar support system.
- Fragmented care
Persons with serious mental illness face a lifetime of fragmented care as mental health providers, physicians, and Medicaid health plans struggle to coordinate services. They do have the advantage of individual case managers who work to keep physicians updated. Often geriatric clients are sprinkled among case managers' caseloads rather than concentrated with a particular one.
- Compromised pain and symptom control
The opioids and other drugs needed to relieve pain and distressing symptoms may interact adversely with medications used to treat mental health conditions. Also, some mental health clients have a history of alcohol or other substance abuse. These factors complicate palliative treatment and may result in less than optimal symptom management.
- No health advocate
It is not standard practice for case managers to assist clients with advance care planning. Many persons with serious mental illness have no appointed health advocate because their capacity to make such decisions is doubted. For them, end of life decision making ends up in the hands of family or public guardians. Confusion about guardianship laws in Michigan causes many public guardians to avoid decisions about withholding or withdrawing life-sustaining treatment. Stakeholders observed that this leads to unnecessary overtreatment of persons with guardians.

According to stakeholders, there is no formal protocol for addressing end of life needs in the community mental health system. The model of care is somewhat crisis-oriented, and treating the mental illness is the primary focus until a more urgent need arises.

- Persons living in a community setting are likely to be assigned to Assertive Community Treatment (ACT) if they become medically unstable with frequent hospital admissions. The ACT team provides multidisciplinary evaluation, treatment, and support to help the person stabilize. The ACT team may be involved with end of life cases as well.
- Stakeholders reported that end of life needs are managed in a compassionate and person-centered manner. Case managers try to keep their clients in place to die. They may invite hospice to help as necessary and as desired by the client.

Persons with Developmental Disabilities

Developmental disabilities include mental retardation, cerebral palsy, autism, and other severe impairments that manifest before age 22 (Last Acts, 2001, November). In 2003 there were 26,846 individuals with developmental disabilities who received support from community mental health service programs. According to statistics from the Bureau of Community Mental Health Services (2004):

- At least 66 percent had incomes below federal poverty thresholds.
- 17 percent represented diverse racial/ethnic groups.
- 6 percent were age 65 and over; 61 percent were age 27 to 64 years.
- 50 percent lived in private residences and 33 percent lived in foster care or group homes. Less than 1 percent were homeless or in jail or prison.

According to stakeholders, persons with developmental disabilities stay in the service net until they die. Most of them are Medicaid recipients, and they each have a nurse care manager assigned to coordinate their treatment plan. Services may include care for the client and respite for the family. Care managers make home visits to monitor the client's status. According to stakeholders and hospice contacts, persons with developmental disabilities face these issues at the end of life:

- Longer life expectancy
The life expectancy of persons with developmental disabilities “exploded in the last half of the 20th century” (Last Acts, 2001, November). Many now live into their 70's and 80's and die of the same chronic diseases as

everyone else. With 61 percent of the population in the 27 to 64 age group, this portends a much higher prevalence of older persons with developmental disabilities and end of life issues in coming decades.

- **Fear of discrimination in treatment decisions**
Persons with disabilities constantly face discrimination and devaluation because of their functional limitations. In the context of end of life treatment decisions, this raises concern about denial of life sustaining treatment because of the disability. Many persons with developmental disabilities have family or public guardians and health advocates. According to one stakeholder, guardians and CMHSP providers both are obligated to sustain life as long as possible.
- **Inadequate pain assessment**
Some persons with developmental disabilities cannot express themselves well orally and therefore cannot easily report pain and other symptoms. It is the responsibility of caregivers to observe behavior and interpret its meaning.
- **Unresolved grief**
When parent caregivers age and finally die, persons with developmental disabilities feel intense grief. Loss of a parent caregiver also means a change of living environment—sometimes moving in with a sibling, sometimes moving to a group home. These major life changes are losses that need to be grieved, yet others may overlook this need if the person cannot easily verbalize grief.

As persons with developmental disabilities live longer, some live in the same group home with the same housemates and staff for 15 to 20 years. They become family. When a resident dies, both the housemates and the staff are bereaved and need to work through their grief. Once again, the need may be overlooked in clients who cannot easily verbalize their feelings.

- **No health advocate**
When a person with a developmental disability has no health advocate, the responsibility for end of life decision making falls onto family or public guardians. The confusion about guardianship laws in Michigan causes many guardians to avoid decisions about withholding or withdrawing life-sustaining treatment. This may lead to

life-prolonging treatment regardless of the person's condition. According to hospice providers, neither the guardian nor the family has any clout against the system on behalf of the client.

Incarcerated Persons

Across the United States, prison populations are growing and inmates are aging. As a result, the number and rate of inmate deaths are steadily increasing (Linder, Enders, Craig, Richardson, & Meyers, 2002). This is true in Michigan. Between 1990 and 1998, the prison population grew by 33 percent. But the proportions of inmates aged 40 to 59 and 60+ more than doubled (Firestone & LaRoux, 2000).

The number of deaths in Michigan prisons averaged 105 per year between 1995 and 2000 (Michigan Department of Corrections, 2001). In the course of those six years, causes of death changed as follows:

- The proportion of deaths due to cancer almost doubled, from 17 percent to 32 percent.
- The proportions of deaths due to cardiovascular disease grew by half, from 19 percent to 29 percent.
- HIV-related deaths dropped from 24 percent to 4 percent of the annual total.
- Homicides and suicides fell from 10 percent to 4 percent of deaths.

Compared to the general population, prison inmates are more likely to have one or more of these characteristics: minority race, low income, poor prior health care, mental illness, history of substance abuse and other risky behaviors. As a result, they tend to age more rapidly and their life expectancy tends to be reduced (Cohn, 1999). Health care costs for older inmates are high.

According to Byock (2002), inmates dread the prospect of dying in prison. They fear spending their final hours alone and in agony. These are some of the end of life issues they face:

- Inmates mistrust attempts to limit curative treatment (Last Acts, November 2001).
- Some medications, particularly opioids, may be dispensed with restrictions. Some may not be available at all (Linder et al., 2002).

- Family members often live far away and are unwilling to serve as advocates. Advance directives are rare (Last Acts, November 2001).
- Security concerns block access to hospice and other compassionate care (Cohn, 2002; Last Acts, November 2001).

United States Supreme Court rulings have established prisoners' rights to quality care (Linder et al., 2002). But efforts to improve end of life care for prisoners encounter little public support (Cohn, 2002). There have been standards for prison hospice since 2000, and at least 14 states have had formal programs in place since 1988 (Ratcliff & Cohn, 2000). Hospice contacts in the Marquette and Jackson areas were not aware of any hospice programs in Michigan prisons. Efforts by a community outreach group in Marquette had been rebuffed by the warden there because of security and liability concerns.

Uninsured Persons

Six hospice contacts singled out persons who have very low incomes and do not qualify for Medicaid as a vulnerable population. They fall into the gap where access to health care and support services is very difficult.

Nearly one third of Hispanics and 20 percent of blacks lack health coverage. The majority of uninsured persons are young adults (aged 18 to 24) who have lower paying jobs and cannot afford health insurance. As a result, uninsured persons and their families tend to seek treatment only after symptoms become serious (American Public Health Association, n.d.). Their demographic characteristics suggest that when they do face death, it is likely to be in a hospital. Hospice services are paid through fundraising donations.

Homeless Persons

Illness, severe poverty, and inadequate access to health care lead to shorter life expectancy and higher mortality rates among homeless persons. The health problems most frequently observed include mental illness and addictions, traumatic injuries, tuberculosis and HIV infection, and other complex medical problems (Cheung & Hwang, 2004).

For a homeless person with chronic disease, the end of life course is likely to include repeated emergency department visits and hospital admissions. For many, the personnel at shelters, soup

kitchens, and other service agencies become support systems (Alexander & Schietinger, 2003). Even so, treatment plans often are unworkable (O'Connell, 2004). These are key issues:

- Clinicians may neglect management of pain in people with a past history of substance abuse.
- Taking medication as prescribed is a concern. At some shelters, staff set out clients' pills each day.
- Since there is danger of pain medicines being stolen or lost, they may be prescribed in small amounts.
- Finding a homeless person for follow-up can be difficult. Some hospice contacts reported that they had tried and failed.

When a hospice receives the occasional referral for a homeless person, the team visits the client wherever he lives. One team cared for a man who lived in a refrigerator box under a freeway overpass. He preferred that setting to a nursing home, because that was where his support system was. The hospice team honored his wishes.

Children with Life-Limiting Illnesses

Of the 87,534 deaths in Michigan in 2002, just 1,485 (2 percent) occurred in children through age 14. Table 8.2 shows major causes of death by age category.

Age	Cause of Death	No.	%
<1	Infant Mortality (Perinatal Conditions, Congenital Anomalies)	753	71%
	Accident/Homicide/SIDS	167	16%
	Heart/Cancer/All Other	134	13%
	Subtotal	1054	
1-4	Accident/Homicide	64	42%
	Heart/Cancer/All Other	87	58%
	Subtotal	151	

Age	Cause of Death	No.	%
5-14	Accident/Homicide/Suicide	133	47%
	Heart/Cancer/All Other	147	53%
	Subtotal	280	
0-14	Infant Mortality	753	51%
	Accident/Homicide/Suicide/SIDS	364	25%
	Heart/Cancer/All Other	368	25%
	TOTAL	1485	

Source: 2002 Death File, Vital Records and Health Data Development Division, Michigan Department of Community Health

In addition, data reported by the Michigan Child Death State Advisory Team (2004) indicate that causes of death in the 15 to 18 year-old group for 2001 were:

- 74 percent accidents, homicide, and suicide; and
- 26 percent other causes.

These data begin to reveal some of the unique issues related to deaths of children:

- Seven of ten deaths in the population of children aged 0 to 14 years happen within the first year of life. Miscarriages and other fetal deaths are not counted, because they are not reported on death certificates.
- Infant mortality due to prematurity, low birthweight, congenital anomalies, and other perinatal conditions causes 71 percent of deaths before age one and 51 percent in children overall.
 - Most of these deaths occur within 28 days of birth, often in neonatal intensive care units.
 - Hospitals were the location for 88 percent of deaths during the first year of life in 2002.
 - Feudtner, Silveira, and Christakis (2002) examined 19 years of data in Washington state and found the same pattern—that infants with complex chronic conditions died predominantly in hospitals.

- Traumatic and sudden deaths account for 25 percent of mortality through age 14 and 74 percent among 15 to 18 year-olds.
- Only 25 percent of deaths in children are caused by heart disease, cancer, and other illnesses. These children are the most likely candidates for hospice care. Feudtner et al. noted a rising trend of home deaths for those who died of chronic diseases at age one and beyond.

The pain of losing a child begins well before death occurs. Parents report that the time of crisis is when a child is diagnosed with a life-limiting illness. Support needs to start then (“Federal Study,” 2001; Last Acts, August 2002). These are other end of life issues that children and their parents face:

- Reluctance to give up
Children often have long and unpredictable disease trajectories (“Federal Study”). Their physiologic resiliency makes predictions about survival difficult. This creates a high tolerance for burdensome treatment that offers only a small chance for benefit. No one wants to give up too soon (Rushton & Catlin, 2002).
 - Children with complex chronic conditions may survive several nearly fatal episodes. This leads the family and health care providers to resolutely favor life-prolonging therapy. They hope for yet another astonishing recovery. One research team studied deaths in 60 children’s hospitals during three years. They found that mechanical ventilation was provided at some point for 66 percent of neonates, 40 percent of infants, 36 percent of children, and 36 percent of adolescents (Feudtner, Christakis, Zimmerman, Muldoon, Nef, & Koepsell, 2002).
 - When to stop treatment is a tough issue. Hospice contacts noted that parents and grandparents do not accept death and want everything done. The child dies in the hospital getting treatment.
- Significant suffering
In their efforts to cure them, parents and physicians often do not grasp the degree of suffering that children endure (Field & Behrman, 2003). For example:

- One research team found that 89 percent of children suffered a lot or a great deal from at least one symptom in their final month—most commonly pain, fatigue, or shortness of breath. Only one in four families reported that attempts to manage the symptoms were successful (Stephenson, 2000).
- Children with cancer struggle with painful procedures and untreated symptoms even though physicians have the capability to relieve their suffering. Dying newborns have similar problems (Rushton & Catlin, 2002).
- Limited and late access to palliative care
Even well-established pediatric palliative care programs report low referral volumes and short lengths of service. However, infants with palliative care consults had fewer blood draws, central lines, endotracheal tubes, feeding tubes, and x-rays. Fewer received CPR, and they spent fewer days in intensive care units. There were more referrals to chaplains and social work for emotional support (Pierucci, Kirby, & Leuthner; 2001). The American Academy of Pediatrics (2000) recommends that children receive simultaneous curative and palliative care beginning from the initial diagnosis of a life-limiting illness.

Caregiving at home can be frightening for parents, given complex care and high stakes. Children often receive more high tech treatment (Huff, 2002) and need more frequent home visits (“A model,” 2002). According to the National Hospice and Palliative Care Organization (2000), children in hospice programs use twice the nursing hours that adults do. Parents need access to 24-hour support. One program noted that no family refused a palliative care consult when the primary physician suggested it (Pierucci et al., 2001).

- Profound grief
Families experience deep and lasting grief when a child dies. This is especially true when the death is traumatic.
 - Certain types of death are associated with grief that is more pathologic or prolonged. These include unexpected, sudden or untimely death; death that is horrific or painful; death that is violent or stigmatized (homicide, suicide, or AIDS); death involving multiple losses; and death of a child

(Green, Krupnick, Stockton, Goodman, Corcoran, & Petty (2001).

- Traumatic grief is a critical risk factor for risky health behaviors and long term mental and physical health impairment (Prigerson et al, 1997).

Parents, siblings, and others often need bereavement support beyond the traditional 13 months offered by adult-focused programs (“Don’t try,” 2001).

Persons with Degenerative Conditions

As the population ages, a growing number of people decline with slowly progressive functional limitations and the resulting medical complications. They commonly are disabled for many years:

- They may have mental impairment due to Alzheimer’s disease or related dementias.
- They may have physical impairment due to neurological disorders like Parkinson’s disease, Huntington’s disease, and Amyotrophic Lateral Sclerosis (ALS).
- They may have both mental and physical impairment, as in some persons with Parkinson’s disease or Huntington’s disease.

An estimated 200,000 Michigan residents have Alzheimer’s disease (Michigan Dementia Coalition, 2003). While only 1,946 death certificates listed this diagnosis as the underlying cause of death in 2002, substantial numbers of other decedents had some form of dementia. This is particularly true for those aged 85 and older. Table 8.3 shows place of death for persons with selected degenerative conditions.

Diagnosis	Place of Death			
	Hospital	Nursing Home	Home	Other
Alzheimer’s disease N=1,946	9%	75%	16%	0%
Parkinson’s disease N=1,296	23%	58%	18.5%	0.5%
Huntington’s disease N=42	21%	57%	19%	3%
ALS N=239	23%	23%	51%	3%

Source: 2002 Death File, Vital Records and Health Data Development Division, Michigan Department of Community Health

With the notable exception of those with ALS, most persons with degenerative conditions spend their final days in nursing homes.

People who decline slowly from these causes share common challenges at the end of life:

- Loss of ability to care for themselves
This has two primary implications at the end of life:
 - Assisting with basic activities of daily living becomes a full time endeavor as decline progresses. Their needs exceed the capability of solo family caregivers and also of most nursing facilities at current staffing levels.
 - The pace of decline may be marked by plateaus at levels of very intense need for assistance. These persons may not meet guidelines for hospice eligibility and their families often cannot afford private help.
- Gaps in the service net
According to hospice contacts, people with degenerative conditions have nowhere to go. They have the same intensity of need as terminal patients who decline more rapidly. Yet hospice contacts report that Medicare denies hospice claims because the patients do not decline quickly enough.
- Exhausted caregivers
Hours of daily intensive caring and the anguish of watching their loved one deteriorate take a toll on family caregivers. The role is a risk factor for physical and mental health problems, especially for older spouses. The toll is greater when caring includes coping with challenging psychiatric behaviors due to dementia. It is often those symptoms that drive caregivers to place their loved ones in nursing homes. Families are not aware of the kinds of help available or where to find help when they need it. In many communities, respite and other support services are in short supply.
- Compromised pain and symptom control
Discomfort becomes difficult to assess when persons with degenerative conditions lose the ability to communicate verbally. Then pain and other symptoms can only be expressed through facial expressions, oral outbursts, and

other behaviors. The result is that pain is under treated in these patients (Michel, Pautex, Zekry, Zulian, & Gold, 2002).

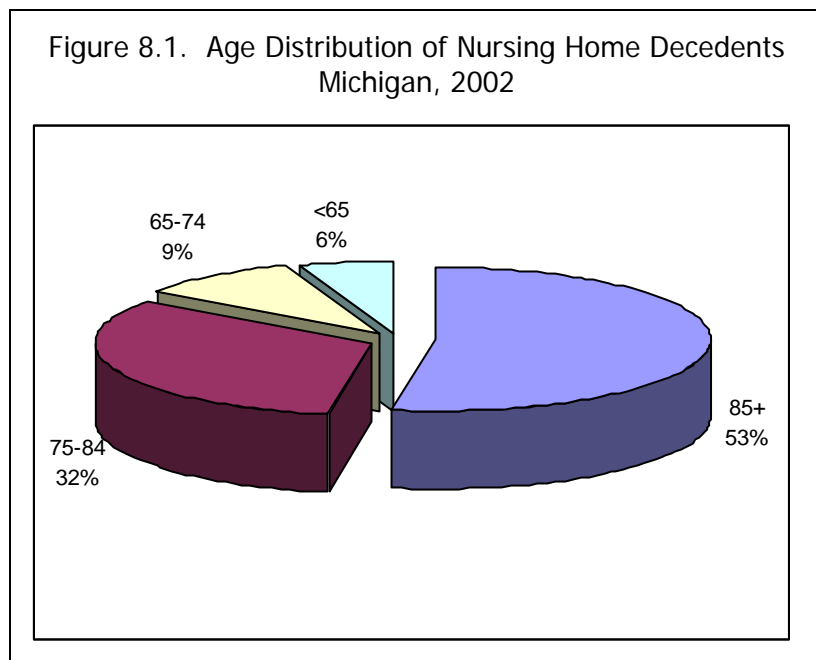
- Difficult treatment decisions
Even though many families aim to allow a natural death, making treatment choices is an emotional and guilt-ridden burden for them. These are some difficulties they face:
 - Families may have no idea where the person is on the slope of decline. They do not see dementia as a terminal illness (Forbes, Bern-Klug, & Gessert, 2000).
 - They are not aware that persons with late stage disease rarely rebound to prior levels after an acute illness (Calne & Kumar, 2003).
 - In the absence of a clear understanding of the patient's condition, families feel compelled to treat acute infections and other serious complications that may lead to a natural death (Forbes et al.).
 - Whether or not to insert a feeding tube when the person becomes unable to eat or drink is a particular concern (Hoefler, 2000; Kolata, 2004).

If there is no family advocate and a public guardian is assigned, the guardian is likely to approve all treatment.

- Lack of access to hospice and palliative care
Hospice is not widely recognized and not often used by families of persons with dementia (Jennings, 2003) and other degenerative conditions. One prime reason is the Medicare six-month rule for eligibility.
 - The long, slow decline makes it difficult for physicians to predict the timing of death for these persons. As a result, they may be uncertain about when to refer to hospice.
 - Likewise, some hospices are reluctant to accept these individuals until the illness is very advanced. Hospice contacts commented that persons with dementia often are not referred until very late. Some are unresponsive. Before that they do not meet all of the guidelines for eligibility.

Nursing Home Residents

More than 21,000 people died in Michigan nursing homes in 2002. They represent the state’s oldest, most debilitated, and most vulnerable citizens. Figure 8.1 shows that more than one half were aged 85 and older; one third were aged 75 to 84.



Source: 2002 Death File, Vital Records and Health Data Development Division, Michigan Department of Community Health

Table 8.4 shows the functional limitations of the oldest nursing home residents nationally (Krauss & Altman, 1998). For most limitations the prevalence is very similar for both age groups.

Limitation	75-84 yrs	85+ yrs
Needs help with 3+ ADLs	85%	85%
Totally dependent in:		
Bathing	48%	47%
Toileting	38%	38%
Dressing	36%	36%
Mobility	31%	30%
Transferring	28%	28%

Limitation	75-84 yrs	85+ yrs
Incontinent of both bladder and bowel	38%	38%
Some form of memory loss	71%	76%
Both long term and short term memory problems	53%	57%
Disoriented to time, place, and person	51%	45%
Problem understanding others and being understood	45%	46%
Alzheimer's disease or related dementia	50%	54%

Residents in nursing homes face these issues as they near the end of life:

- Compromised pain and symptom control
National data indicate that 30 percent of nursing home residents die within one year of admission (Parker-Oliver, Porock, Zweig, Rantz, & Petroski, 2003). Yet researchers consistently report that:
 - Pain is not well managed;
 - Symptoms are not treated properly; and
 - Emotional and spiritual needs are ignored (Bernabei et al., 1998; Teno, Bird, & Mor, n.d.).

Other research findings are congruent:

- A 1999 study found that nearly 41 percent of terminally ill residents in Michigan nursing homes suffered with serious pain daily.
- Teno, Clarridge, and colleagues (2004) interviewed bereaved family members whose relatives received end of life care in a nursing home. They reported no or inadequate help with pain (32 percent), shortness of breath (24 percent), and emotional support (56 percent).

- Miller, Gozalo, and Mor (2000b) found that nursing home residents on hospice care were twice as likely to receive strong pain relievers for their daily pain compared to other residents with pain.
- Limited access to hospice
Several hospice contacts commented that nursing home residents are underserved because many facilities balk at contracting with them. A national study supports their impression. The findings showed that 60 percent (± 5 percent) of Michigan nursing homes had no hospice recipients. Only one in 20 facilities had 5 percent or more of their residents on hospice (Petrissek & Mor, 1999).

Parker-Oliver and colleagues (2003) suggest that nursing home residents are not referred for hospice because end stage disease is not recognized or acknowledged. Just 4 percent of 9,615 persons admitted to Missouri nursing homes in 1999 were designated as end stage on the MDS intake assessment. Only half of them received hospice care.

- The hospice and non-hospice residents were clinically and functionally similar, and the two groups had nearly identical lengths of stay before death (median 30 vs. 36 days).
 - The hospice residents were more likely to have cancer (67 percent vs. 48 percent) and to be assessed as having moderate or severe pain (95 percent vs. 78 percent).
 - The researchers concluded that dying residents are likely to receive appropriate end of life care only if they are recognized as dying.
- Continued rehabilitation
Both stakeholders and hospice contacts noted that nursing home personnel try to rehabilitate dying patients who likely would prefer palliative care. Murphy, Hanrahan, and Luchins (1997) found that 90 percent of families wanted a palliative approach for their relatives with dementia, but only 13 percent were aware that it was possible.

Nursing home regulations and assessment tools focus on maximizing residents' function. This means exercise to prevent problems of immobility and enough food and fluids to prevent weight loss. From a palliative care perspective,

this is not always the goal for those at the end of life.

- A hospice team would expect fatigue and lack of appetite and provide comfort care.
- But nursing home teams may feel compelled to maintain a focus on restorative care (Evans, 2002).

The MDCH has distributed process guidelines for pain management and end of life care in nursing homes, but many facilities are not equipped to implement them.

- Grief support overlooked
Families feel considerable anguish about nursing home placement and the difficult treatment decisions that follow (Forbes et al., 2000). Residents, including those with severe dementia, suffer emotionally as well (Michel et al., 2002). While some facilities offer comfort carts and companions to support patients and families during a death vigil, bereavement support afterward is not part of standard nursing home care. According to Murphy and colleagues (1997), the needs of surviving family members often go unaddressed.

Persons with Non-Cancer Diagnoses

In Michigan in 2002, more than half of all deaths were attributed to chronic, non-cancer causes. Among the leaders were:

- Heart disease (26,447 deaths, 30.2 percent);
- Stroke (5,740 deaths, 6.6 percent);
- Chronic lung disease (4,389 deaths, 5.0 percent);
- Diabetes (2,753 deaths, 3.1 percent); and
- Kidney disease (1,606 deaths, 1.8 percent).

Along with the 237 AIDS cases, these few chronic causes accounted for more than 41,000 deaths. People who reach the end of life with these conditions face similar challenges:

- The course of the disease is unpredictable. It is difficult to predict when death will occur.
- Patients do not recognize the condition as life-limiting or terminal. Physicians are reluctant to be candid too soon (Hanratty et al., 2002). Many wait for the patient to ask. As a result, people lack information about the disease and their treatment choices. Advance care planning is uncommon.

- There is no clear terminal phase or transition point between curative and palliative treatment (Gibbs, Addington-Hall, & Gibbs, 1998).
- Patients suffer considerably, but their pain and symptoms are not well recognized. As a result, they are under treated. Patients may accept the discomfort as a sign of old age (Gibbs, McCoy, Gibbs, Rogers, & Addington-Hall, 2002).
- The course of decline is punctuated by acute episodes that require inpatient treatment to prevent death. During hospital stays, patients receive invasive interventions as needed to survive the episode (Ward, 2002).
- Compared to most cancers, the pattern of decline with non-cancer diagnoses often is marked by longer periods of progressive functional disability. Caregivers become exhausted (Emanuel et al., 1999; Murray, Boyd, Kendall, Worth, Benton, & Clausen, 2002).
- No health professional is responsible for managing overall care, explaining the significance of the multiple admissions, or assuring informed choice about treatment.
- Compared to persons with cancer, their access to hospice and palliative care is limited and late.

Described below are issues that are particularly relevant to heart failure, chronic lung disease, end stage kidney disease, and AIDS.

Heart Disease

Heart failure is the only major cardiovascular disease with rising incidence, prevalence, and mortality. Both incidence and prevalence increase substantially over the age of 75 (Gibbs et al. 1998). With the aging population and changes in cardiac death rates, epidemiologists predict a dramatic increase in the number of individuals living with compromised heart function over the next few decades (Bonneaux, Barendregt, Meeter, Bonsel, & van der Maas, 1994). In Michigan, deaths from congestive heart failure increased as a percentage of both total and heart disease deaths between 1990 and 2002.

Despite therapeutic advances, quality of life with chronic heart failure is poor. Discomfort and distress are often worse than in cancer (Gibbs et al., 2002), and suffering intensifies at the end of life (Gibbs et al., 1998).

People with failing hearts have particular problems with unmanaged symptoms, lack of knowledge and choice, and unpredictable death.

- **Unmanaged symptoms**
People with heart disease report a wide range of very distressing symptoms. They include pain (reported by 50 percent), shortness of breath (43 percent), depression (59 percent), and anxiety (45 percent). Many suffer with these symptoms for six months or more before they die. The symptoms become more prevalent and more intense in the final days before death (Gibbs et al., 2002; Stewart & McMurray, 2002).
- **Lack of knowledge and choice**
Unlike cancer, the diagnosis of heart failure does not begin with bad news, and physicians struggle with when to bring up palliative care (Hanratty et al., 2002). Murray and colleagues (2002) report these findings from interviews of people with heart failure:
 - They had little understanding of their condition and prognosis.
 - Without chest pain, they did not connect symptoms like shortness of breath to their heart.
 - They did not realize that they could die from their heart ailment.
 - Most did not feel involved in decision making—“it just happens. They decide and that’s that.”
- **Unpredictable death**
Because heart failure follows a variable clinical course, it may be more difficult to predict death than in other chronic diseases (Cowie, 2003).
 - As many as one half of patients die suddenly (Cleland, Massie, & Packer, 1999), and the odds of doing so are high in earlier stages of the disease. So far there is no marker to determine who is at risk (Gibbs et al., 2002).
 - At the other extreme, people with late stage disease often recover and even improve after inpatient treatment for acute episodes. These individuals have a high chance of being readmitted within three to six months (Gibbs et al., 2002).

Chronic Lung Disease

People with chronic obstructive pulmonary disease (COPD) have a progressive, debilitating terminal illness. The end of life often includes respiratory failure. Current medical care for people with end-stage COPD and acute respiratory failure involves invasive treatment. Compared to patients with cancer, they are more likely to die in a critical care unit on a ventilator with poor control of pain and other symptoms (Claessens, Lynn, & Zhong et al., 2000).

While doctors can predict that this may happen, they are less able to forecast the timing. The course of the disease is unpredictable. If a patient with marginal lung function avoids acute illness, survival can be unexpectedly prolonged. Given adequate treatment, a person with COPD may die of another cause before experiencing respiratory failure (Abrahm & Hansen-Flaschen, 2002). Discussed below is the end of life issue that particularly stands out for people with chronic lung disease:

- Lack of communication and informed choice
Given the unpredictable course of COPD, physicians hesitate to bring up end of life concerns early, and patients and families remain uninformed.
 - Studies show that only a small proportion of people with moderate to severe COPD have discussed end of life issues with their physicians. Oxygen-dependent COPD patients in focus groups ranked communication with the physician as a top need. One participant first learned that his disease could not be reversed during a presentation in a pulmonary rehab program. This was true for the other rehab patients as well (Curtis, Wenrick, Carline, Shannon, Ambrozy, & Ramsey, 2002).
 - Other studies indicate that most people with COPD welcome frank discussions and guidance from their physicians (Abrahm & Hansen-Flaschen, 2002; Simonds, 2003). This is especially important since they and their caregivers may face decisions about using mechanical ventilation for acute episodes of their illness or for long term support.

End Stage Renal Disease

Most people with end stage kidney disease have greatly shortened life expectancies. Only 39 percent of all dialysis patients survive for five years once the treatment begins. Of those aged 65 and

over, only 18 percent survive five years on dialysis. Life expectancy also is shortened by frequent comorbid conditions like hypertension, heart failure, and peripheral vascular disease. (“ESRD Workgroup,” 2003).

Despite the short life expectancy, a culture of death denial prevails in dialysis units among clinicians, patients, and families. Dialysis patients initially may not comprehend the life-limiting nature of their disease. For about 20 percent of them, death comes after a decision to stop dialysis. Caregiver support, advance care planning, and stopping treatment are key end of life issues for this population. Since many dialysis patients are people of color, sensitivity to cultural diversity in end of life decision-making and closure also is important (“ESRD Workgroup,” 2003).

AIDS

Dramatic advances in treatment of HIV infection in the United States have transformed AIDS from a disease with a short and fatal course to a manageable and unpredictable chronic illness. Selwyn and Forstein (2003) note these key issues for people with late stage disease:

- Treatment is complex and quality of life is tenuous as people struggle with advanced symptoms of AIDS, toxic side effects of their drug therapy, and multiple comorbid conditions. Physicians now are focused more on treatment and less on end of life issues.
- There is a high prevalence of pain and other distressing symptoms that may be unrecognized or undertreated or both.
 - There is significant potential for drug interactions between palliative and HIV medications. Whether and when to discontinue AIDS therapy is a concern.
 - Access to pain medications may be a particular problem if the person has a history of substance abuse.
- AIDS and AIDS mortality are concentrated in culturally diverse and marginalized populations.
 - In Michigan in 2002, African Americans accounted for 160 (68 percent) of the 237 deaths due to AIDS. The vast majority of the deaths (96 percent) occurred in adults aged 25 to 64.

- People with AIDS are less likely to have engaged in advance care planning with their physicians or to have discussed their preferences about withholding or withdrawing treatment. There still is societal stigma associated with AIDS, and some patients may view palliative care as an attempt to withhold standard care.
- From the beginning, caregivers of persons with AIDS have carried a heavy burden of anger, anxiety, guilt, isolation, and exhaustion. These issues have intensified now that AIDS is a chronic disease.

Obstacles to Improvement

Policy Obstacles

Confusion about guardianship laws blocks public guardians from making treatment choices that may be in their wards' best interest. As a result, dying persons with public guardians receive aggressive life-prolonging interventions regardless of their condition.

Accreditation by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) is optional for nursing homes. So they are not required to meet JCAHO standards for pain assessment and management.

System Obstacles

For the seriously mentally ill and other marginalized groups, providers and researchers have not collected basic information about their causes and circumstances of death, preferences for care, or use of hospice services (Foti, 2003).

Service providers who work with or on behalf of vulnerable populations are not aware of their clients' end of life needs or their own potential role in meeting them. Few have processes for recognizing persons nearing the end of life, assessing their needs, and connecting them with helpful services.

There is no central source of information about the location and scope of grief support programs in Michigan communities and health care facilities.

Service providers may doubt the decision-making capacity of persons with impaired cognitive function due to mental illness, developmental disability, or dementia. As a result, these

individuals may not be offered the opportunity to engage in advance care planning or to state their preferences for end of life care.

Provider Obstacles

While nursing assistants in nursing facilities provide the most direct care for the state's most vulnerable end of life population, they have little or no training in palliative care and other end of life priorities.

Few nursing homes in the state allow their residents to have access to hospice on a regular basis. Research suggests that the nurses who assess each resident using the Minimum Data Set tool (MDS) may not identify persons nearing the end of life. This may cause staff to continue to provide restorative rather than palliative care. It also may block access to hospice support for the resident and family.

Physicians find it particularly difficult to discuss prognosis, raise end of life issues, and conduct advance care planning with patients when the disease course is unpredictable and the prognosis uncertain.

- This is a key issue for persons with chronic diseases other than cancer.
- The lack of communication hampers consumers' ability to make informed choices about treatment and blocks their access to hospice and palliative care.

Consumer Obstacles

End of life practices in the United States tend to be based upon a western model of individual autonomy and total disclosure of illness and options. To the extent that people from other cultures do not share these values, hospice and palliative care may not appeal.

Encouraging Factors

JCAHO Pain Standards

In 2001, JCAHO introduced new pain assessment and management standards for all direct-care-providing organizations, including nursing homes. The standards require:

- Screening of all patients for pain;

- Education on pain management for providers, patients, and families;
- Appropriate policies and procedures; and
- Ongoing quality management.

These JCAHO standards are consistent with palliative care initiatives and may provide a catalyst to improving care at the end of life (Evans, 2002). The Michigan Commission on End of Life Care recommended that the MDCH “adopt by regulation the requirement that all state licensed long-term care settings incorporate and comply with the JCAHO Long Term Care Pain Management Standards” (Michigan Commission on End of Life Care, 2002).

Innovative Programs

There have been promising efforts to reach out to vulnerable populations, both nationally and in Michigan.

National Models

Programs in Missouri and Massachusetts enable advance care planning for the adults with developmental disabilities and adults with serious mental illness.

- Special Neighbors
The Institute for Human Development at the University of Missouri at Kansas City and the Midwest Bioethics Center combined efforts to develop a person-centered approach to advance care planning for adults with developmental disabilities. The model involves several steps:
 - Methods include group discussions and support, a workbook called the *Health Preferences Journal*, role playing exercises, and hospital field trips to see people on life support.
 - The program coordinator leads individual participants and their family members through a process to define a desired future.
 - Participants and caregivers think through and record their responses to six typical end of life scenarios. They answer many questions about fears, pleasures, memories of grief, attitudes toward life-sustaining treatments, and other end of life issues.

- The entire group meets for discussion, and then individuals complete their advance directives. They are reviewed by their health advocates and other supporters.

The process takes time. But participants have demonstrated that they can make sound end of life treatment decisions as a result. They knew exactly who they wanted to serve as advocates, and they expressed many shared values. The model has been adopted by Special Neighbors, a residential services provider (Last Acts, 2001).

- **Do It Your Way**

The Massachusetts Department of Mental Health partnered with a hospice provider to assess the capacity of persons with serious mental illness to participate effectively in end of life care decisions. They designed two tools for advance care planning with this population:

- The Health Care Preferences Questionnaire allows clients to express their preferences for end of life treatment. It includes questions to capture values and health status, and three end of life vignettes and to assess treatment preferences.
- The MacArthur Competence Assessment Tools (MacCATs) guide an interview that assesses a client's ability to understand basic information; to appreciate its relevance to the person's own situation; to reason through the risks, benefits, and consequences of various choices; and to communicate a decision.

To enable their collaboration, hospice and mental health providers exchanged trainings to expose each other to typical issues they confront. A pilot of the tools with clients indicated that they can engage in end of life decisions and that their concerns are no different than anyone else's concerns. Another product of the collaboration is a Deceased Client Profile to track causes and circumstances of client deaths (Foti, 2003; Last Acts, 2001).

Michigan Innovations

Michigan providers have tried a variety of promising approaches to improve end of life services for marginalized groups and ethnic populations.

- One hospice contact in an area with many group homes has educated managers and staff to assess pain and symptoms and need for grief support. Hospice contacts have found group home managers to be positive learners and good end of life caregivers.
- Another hospice contact identified public guardians in her area and offered training about hospice services, how their wards could benefit, and when to call hospice.
- Advocates in one health system are working with the end stage congestive heart failure support group to facilitate advance care planning.
- A local hospital offered EPEC training for all health care providers in the community. Mental health case managers became more aware of end of life issues and now pursue advance care planning with their clients. Cross-training with nursing home providers about mental health issues led to improved understanding of each others' mandates and needs. This has helped them work together more effectively for clients.

Implications for Policy and Programs

Vulnerable populations suffer from the same critical end of life needs as the general population. However their needs are intensified because of their special challenges. Below are implications for policy and programs.

Target Greatest Need First

With limited resources, it is advisable to target a few top priorities and do them well. Begin with comprehensive interventions for the largest, most vulnerable group—nursing home residents.

Mobilize the MDCH

Every vulnerable population is served directly or indirectly by a unit of state government. Most of the units are located in the MDCH, particularly in the Public Health Administration.

They include:

- Division of Chronic Disease and Injury Control
- Division of HIV/AIDS-STD
- Children's Special Health Care Services Division

- Office of Minority Health and Multi-Cultural Services
- Office of Faith-Based Initiatives
- Office of Services to the Aging
- Bureau of Community Mental Health Services
- Bureau of Hospital, Center and Forensic Mental Health Services
- Bureau of Health Systems
- Medical Services Administration
- Michigan Developmental Disabilities Council
- Office of the Attorney General

Recommended actions for the MDCH are as follows:

- Alert relevant units to overall end of life needs as well as issues specific to their clients.
- Urge chronic disease programs to consider the needs of residents who develop and decline from the disease despite best efforts at prevention. Broaden the focus of programs to address end of life issues for persons with those diseases. The Cancer Control and Prevention Section does this; it may be an appropriate program element for other sections as well. If they do not embrace this responsibility, who will?
- Alert OSA to the end of life perspective on the needs of the frail elderly and their caregivers in the home setting.
- Define data needed to monitor end of life needs and services for marginalized groups.

Expand Access to Palliative Care

All vulnerable populations have unmet needs for pain and symptom management and limited access to hospice and palliative care. Recommended actions for the MDCH are the following:

- Explore the feasibility and value of seeking policy change to:
 - Mandate all healthcare settings to assess and manage pain according to the JCAHO standards; and
 - Require nursing homes to allow access to hospice.
- Assess the availability and scope of palliative care services in hospitals and other facilities. Assess their cultural competence.

- Assess the availability and scope of grief support services in hospitals, hospices, and communities. Include target groups for grief support. Inquire specifically about services for family survivors of deaths that occur mainly in hospitals—like trauma victims, fetal, and infant deaths.
- Provide technical assistance to MHPCO to identify and disseminate promising practices among member hospices to educate consumers, providers, caregivers, and nursing home staff.
- Identify and disseminate strategies to reduce cultural mistrust of palliative care and hospice.
- Support the efforts of the Michigan Alliance for Pediatric Palliative Services to meet the needs of dying children. Promote access to palliative care services in children’s hospitals.

Facilitate System Change for Informed Choice

Vulnerable populations are particularly likely to lack support for informed decision-making about treatment options.

Recommended actions for the MDCH are as follows:

- Promote adoption of model programs to make it easier for physicians to discuss prognosis and treatment choices with their patients. Focus on people with chronic and degenerative conditions and limited life expectancy.
- Seek clarification of guardianship laws.
- Promote training about end of life issues and decision-making for:
 - All actors in the guardianship system, including judges and other court personnel, guardians, families, and attorneys; and
 - Advocates for vulnerable populations. These include group home managers, mental health and disability case managers, nursing home personnel, and others who serve vulnerable populations.

It is critical for health care workers to remember that individual differences within ethnic groups are often greater than differences among groups (Koenig, 1997). A person-centered approach to decision-making is recommended.

Key Points

All special populations are vulnerable to unnecessary suffering and lack of informed choice. These populations include socially marginalized persons, the culturally diverse, children, and the very elderly—especially those with degenerative conditions or in nursing homes.

Some racial and ethnic groups do not embrace hospice and palliative care as readily as other populations. They may hold conflicting cultural values.

Persons with serious mental illness risk premature death and often lack money and family support. They face fragmented care and inadequate relief of pain and symptoms.

Persons with developmental disabilities risk inadequate pain relief if they cannot communicate their discomfort. Grief is a key issue when housemates or caregivers die. Life expectancy has increased markedly, so more will live to cope with aging and chronic disease.

The majority of childhood deaths are caused by infant mortality or trauma. Children need access to palliative services in hospitals, where they are most often treated. They endure much undertreated suffering. Their parents need decision-making and grief support from the moment of diagnosis.

Persons with degenerative conditions like Alzheimer's and Parkinson's diseases slowly lose function and often plateau with severe limitations. Overwhelmed caregivers lack access to support services and hospice. Pain is undertreated. Families face tough treatment decisions.

Nursing home residents aged 75+ are likely to have memory loss, problems communicating, and severe functional limitations. They have undertreated pain and low access to hospice care.

Persons with chronic diseases other than cancer have particularly low access to hospice because their disease course is unpredictable. They are prone to lack of knowledge and choice, unmanaged symptoms, and overwhelmed caregivers.

Many vulnerable persons are thought to be incapable of making treatment decisions. New programs demonstrate that with training and guidance, many ARE capable of choosing an advocate and expressing preferences for care. Their legal guardians avoid end of life decisions.

There is little data about end of life needs for many of these vulnerable groups and no formal programs to address those needs. Most of these groups are served directly or indirectly by units of state government, many within the Public Health Administration. Those units should champion improved end of life care for their clients and training for those who serve them.

Undertreated pain and lack of informed choice are issues for every vulnerable population. The MDCH should take steps to improve their access to palliative care and decision support.