In any given year, nearly one in twenty people in the United States experiences mental illness. While mental illness is not a "terminal diagnosis", serious mental illness is associated with premature death.

Of all diseases, only cardiovascular conditions have a higher morbidity than mental illness.

Despite higher relative mortality among the mentally ill, little has been studied or written about advance care planning (ACP) or end-of-life (EOL) services for persons with serious mental illness.

Basic information about the circumstances of death (where it occurs, who are the caregivers, primary diagnoses, and symptoms), preferences for care, or the availability of hospice/palliative care has not been gathered for this population.

This kind of information is essential for designing sensible processes, procedures, and guidelines for end-of-life care for the mentally ill.

Narrow WE: Revised Prevalence Estimates of Mental Disorders in the United States. Arch Gen Psychiatry 2002; 59:115-123
Mechanic D: Removing barriers to care among persons with psychiatric symptoms. Health Aff (Millwood) 2002; 21:137-147
End-of-Life Care for Persons with Serious Mental Illness

This project was developed at the Massachusetts Department of Mental Health, Metro Suburban Area, to enhance care for dying people with long standing severe psychiatric illness (often referred to as “clients” or “consumers”).

The team worked with researchers at the University of Massachusetts and Dartmouth–Hitchcock medical center to develop methods to evaluate:

1. The capacity of a severely mentally ill person to complete a health care proxy (the legal advance directive in MA), and,
2. A questionnaire to document the person's end of life preferences.

The project fostered a professional exchange of training and teamwork between regional Hospice/Palliative Care workers and the State Mental Health inpatient and residential facilities. Hospice staffs learn about the needs of people who are seriously mentally ill, while mental-health clinicians become familiar with hospice and the techniques of high-quality end-of-life care. Client care is improved by the involvement of Hospice/Palliative care workers that consult or provide direct care services in the client's “home” setting, wherever that may be.

This presentation is part of a wider effort to bring quality end-of-life care to dying persons who have serious mental illnesses. We are grateful to the © EPEC Project (Education for Physicians on End-of-Life Care) for permission to reproduce some of the material presented here.

© EPEC Project (Education for Physicians on End-of-Life Care), The American Medical Association and The Robert Wood Johnson Foundation, 1999

Emanuel LL, von Gunten CF, Ferris FD. The Education for Physicians on End-of-Life Care (EPEC) curriculum, 1999
Objectives

This Presentation will:

- Describe the current state of dying in America
- Introduce key concepts of End-of-Life Care (EOL)
- Review the principles of Bereavement
- Introduce the challenges of providing quality EOL Care for persons with Serious Mental Illness (SMI)
- Provide resources for further learning

The objectives for mental health professionals (psychologists, case managers, social workers, psychiatrists, mental health workers, etc) outlined above were developed from questionnaires that asked them about experience and comfort with End-of-Life Care.

This presentation sets a context by outlining how people currently die in the United States and contrasts this with data with the way they would like to die. In doing so, it highlights how the current system fails to meet the expectations and needs of patients and families who are living with advanced life-threatening illness.

We introduce the key elements of quality care at the end of life and highlight the special challenges to overcome in providing comprehensive end-of-life care to persons with severe mental illness with terminal disease.

Lastly, we will provide information for easily accessible resources which explore each of these areas in greater detail.
How Americans Died in the Past

Early 1900’s

- Average life expectancy 50 years, high childhood mortality, few adults lived into their 60’s
- Death common from infectious disease and accidents
- Medicine focused on care and comfort
- Sick cared for at home
- Death - a tangible, common part daily life

In the early 1900s, average life expectancy was 50 years. Childhood mortality was high. Those who became adults could expect to live into their 60s.

In those days, only a few people lived to the ages that we regard as normal today. Historically, up until the development of antibiotics in the mid-20th century, people typically died young, often of infectious diseases or accidents.

As only very few remedies were available to extend life, physicians were primarily experts in caring and comforting the ill person. Sir William Osler (1849-1919) a famous physician, sums up the doctor’s job as follows: “The physician needs a clear head and a kind heart; his work is arduous and complex, requiring the exercise of the very highest faculties of the mind, while constantly appealing to the emotions and higher feelings.”

While customs and traditions varied across cultures, most cared for their sick at home with support from their physician, if one was available.
Medicine's Shift in Focus

- Improvements in sanitation, public health, and antibiotics results in longer lives.

- Average life expectancy increases to 76 years. (73 men, 79 women).

- Death becomes hidden and viewed as the Enemy.

- Medicine adopts a sense of failure when the patient died.

During the second half of the 20th century, the age of science, technology, and communication shifted the values and focus of society on many levels. Authorities suggested that we had become a “death-denying” society—valuing productivity, youth, and independence while devaluing age, family, and interdependent caring for one another. At the same time, new science and technology offered the potential of medical therapies previously unknown. Physicians who humbly provided comfort in the face of terminal illness were slowly replaced by a “modern health care system”.

Improved sanitation, concerted efforts by public health, and the development of a wide range of antibiotics and other medical interventions increased life expectancy to an average of 76 years by 1995 (79 years for women compared with 73 years for men), and every year these statistics have continued to improve.

New medications and therapies have changed the way that illness is experienced. This shift in focus is so complete that death became the enemy and medicine “waged war” against it. Some medical organizations promised that even the most serious illnesses can be crushed. Meanwhile physicians and health care workers learned that they are failures if they cannot rescue a patient from death.
Dying in America Today

Modern Health Care:

- Few cures
- Lots of chronic illness, prolonging the dying process

Hercules fighting the Angel of Death

Death cannot be conquered—we all die. Technologically complex health care systems and biomedical sciences can cure only a few illnesses. Their recent contributions have allowed persons with chronic long-term illnesses to live longer, and extend the process of dying.
How We Die...

- <10% sudden, unexpected

- >90% protracted illness with differing trajectories

A few of us (< 10%) will die suddenly of a myocardial infarction, an accident, or another unexpected event, like a heart attack.

Most of us (> 90%) will experience a protracted course of illness before we die...
Sudden Death, Unexpected Cause

< 10%, MI, Accident, etc.

This graph shows the trajectory of those who die rapidly following a heart attack, or a terrible traumatic accident.
Steady Decline, Short “Terminal Phase”

Some of us die following a protracted terminal illness characterized by a predictable steadily declining course and a short “terminal” phase. This happens in certain malignancies such as inoperable brain tumors or other aggressive cancers.
The vast majority of people die following a slow decline punctuated by exacerbations and partial remissions (improvements) of their illness. Hence, over time the person does increasingly poorly. Toward the terminal phase a medical crisis occurs that is not remediable. This pattern is commonly seen in illnesses like COPD, congestive heart failure, emphysema, and dementia. About 90% of us die following a course like this.

Because the progression toward inevitable death is so long for most of us, there is ample time to think about what is coming and to prepare for it. People can do this by expressing their wishes or preferences. A large study conducted in 1995, called the "SUPPORT STUDY" looked at how well dying patient's wishes were followed.
The SUPPORT Study

A Controlled Trial
to Improve Care of Seriously Ill Hospitalized Adults

Study to
Understand
Prognoses and
Preferences for
Outcomes and
Risks of
Treatments

S U P P O R T

JAMA 1995;274:1591-1598

In 1995, the Journal of the American Medical Association, published the results of a very large study known as the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. It is usually referred to as the “SUPPORT” Study. The SUPPORT Study was the largest, two-phase clinical study on how seriously ill and dying patients are cared for in the United States. It was conducted in five major hospitals and examined the care received by nearly 10,000 patients.

The findings were very distressing.

For example,

The SUPPORT Study found that:
- 38% of dying people spent 10 or more days in intensive care units,
- 50% of dying hospitalized people experienced moderate or severe pain at least half of the time during the last few days of life,
- and 47% of the physicians did not know their patients’ preferences regarding Do Not Resuscitate Orders (DNR).

The SUPPORT study also showed that DNR orders were not written until a day or 2 before the person died, showing that there was little if any advanced care planning at the terminal phase of the patients’ illness.

Dying Experience of Older Patients

SUPPORT Study

- Most elderly and seriously ill patients died in acute care hospitals, even if they wanted to be home ...
- Pain and other symptoms were common and distressing to patients.
- Family members believed that patients preferred comfort measures only, but “high tech” life-sustaining treatments were used anyway.

Ann Intern Med 1997;126:97-106

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Pain & Suffering

- People are afraid of dying in pain.
- People are afraid of dying alone.
- Uncontrolled pain and loss of control are the primary source of fear and fantasies among the terminally ill.
- These fears fuel suicidal ideation and attempts.

Other studies have shown that patients and families worry that the symptoms (especially pain), won’t be managed and that they will lose independent functioning and control. They worry about who will provide care, how they will pay for it, what dying will be like, and whether there is an afterlife.

Several studies indicate that most patients who are living with a life-threatening illness can expect to experience multiple physical symptoms as well as psychological, social, spiritual, and practical problems, often all at once.

Most of these problems add to a patient’s and family’s sense of suffering and reduce their independence and quality of life, particularly if they are present for a long time. For many people, the loss of independence is devastating and a source of significant suffering.

When experiencing prolonged suffering and unmanaged symptoms, people vary in their ability to develop strategies for coping with their illness, disability, loss of control, and lack of ability to do meaningful things. Some patient’s suffering is so devastating that they plan to suicide or seek assistance to die prematurely by physician-assisted euthanasia.

Persons with serious mental illness who are in pain, hopeless, guilty, depressed, psychotic, or who have a history of suicide attempts, or a family member who committed suicide, are at HIGH RISK for suicide in this setting.
Patients want to die at home...

- 90% report wanting to die at home
- But deaths in institutions are increasing:
  - 1949 --- 50%
  - 1958 --- 61%
  - 1980 to present --- 74%

Barriers to dying at home:

- lack of familiarity with the dying process
- lack of adequate supports
- lack of insurance coverage

Ninety percent of the respondents to a Gallup survey commissioned by the National Hospice Organization (NHO) in 1996 stated that they wanted to die at home or in a familiar setting.

However,

- By 1949, 50% of deaths in America occurred in institutions;
- As of 1958, this had increased to 61%;
- Since 1980, it has remained at around 74%;
- In 1992, 57% of Americans died in hospitals, 17% died in nursing homes, and only 20% died in their own homes.

As care for patients with life-threatening illnesses shifted to institutions, people became increasingly unfamiliar with the dying process, especially at home. Today, only a minority of people have ever witnessed someone die. Most nonprofessionals have never seen a dead body except, perhaps, at a funeral parlor.

The lack of direct, real experience with death leaves many people emotionally vulnerable and unprepared to help a family member who wants to die at home, be at home.

Gaps between Fears and Desires

Patients are afraid of...

- dying in an institution
- dying on a machine
- dying in discomfort
- being a burden

Patients desire to die...

- not on a ventilator
- with family/friends
- in comfort
- at home

Despite research, nonprofit organizations, and medical interventions (Bill Moyer's "On Dying" for example) there remains an enormous gap between how and where people want to die and how and where people actually die.

As we shift to caring for terminally ill patients at home, many families remain concerned about their capacities to be successful. Meanwhile, dying still occurs in hospitals, although often not until closer to the final terminal stage.

Improving Care at the End of Life

- End-of-Life Care
- Palliative Care
- The continuum of prolonging life while supporting a death with dignity

Before applying this information to the care of a terminally ill mentally ill person, there are a few definitions and concepts that mental health caregivers need to be aware of.
End-of-Life Care
refers to the “reliable, skillful, and supportive care” of “people with advanced, potentially fatal illnesses and those close to them.” (Institute of Medicine, 1997)

Palliative Care
refers to the comprehensive management of physical, psychological, social, spiritual and existential needs of patients, in particular those with incurable, progressive illnesses.

Palliative care affirms life and regards dying as a natural process that is a profoundly personal experience for the individual and family.

Supportive care extends to family and those closest to the patient.

The goal of palliative care is to achieve the best possible quality of life at the end-of-life through relief of suffering, control of symptoms and restoration of functional capacity while remaining sensitive to personal, cultural and religious values, beliefs and practices.
(Last Acts, 1997)

More recently, palliative care programs and consult services have been developing across the US to provide the expertise and standards of practice developed by hospice to patients who have needs for symptom control and supportive care earlier in their illness. Designed to improve the quality of patients' lives while they fight their disease, good palliative may increase life expectancy in the occasional patient.

Last Acts Task Force, in formulating its Precepts of Palliative Care (1997)
Palliative Care

Palliative Care

- Affirms life, regards dying as a normal process
- Neither hastens nor postpones death
- Provides relief from pain, other symptoms
- Integrates psychological and spiritual care
- Interdisciplinary team approach
- Support system for the family during illness and into bereavement

WHO 1990

Palliative care is the thoughtful total care of patients whose disease is not curable. Control of pain, other discomforts, and attention to psychological, social and spiritual problems is paramount.

Palliative care seeks to achieve the best quality of life for patients and their families.

Death is viewed as a natural part of the life cycle. Practitioners seek neither to hasten nor postpone death, but to provide comfort and supportive care while the patient’s illness runs its natural course.

The family is the “unit of care”. In this context, the word family refers broadly to “whoever matters to the patient.” Empowerment of the family is emphasized. The patient and family members are included in all decision-making. Initial and ongoing evaluations help the patient and family define their evolving needs, set realistic goals and make informed treatment choices.

The primary focus is on life and living, not death and dying. Interventions are directed to the relief of suffering and doing whatever is possible to enhance the quality of life, one day at a time. Pain and other distressing physical symptoms are actively addressed, and psychological, social and spiritual support is offered.

Opportunities for continuing growth in this phase of life are seen when dying patients speak of hope, dignity, meaning, purpose, forgiveness, reconciliation, and life completion.

Support for survivors continues beyond death of the patient into the bereavement period.

This graph shows how (1) curative therapies and (2) life-prolonging therapies wane over time while (3) symptom control and supportive care increase (e.g. PALLIATIVE CARE) as the illness progresses toward the end of a person's life. At the terminal phase Palliative Care and Hospice Interventions are primary through the process of death. Following the person's passing, those remaining need help grieving and bearing the pain of bereavement.

Comfort-oriented symptom control and supportive care increase over time, maximizing as dying culminates in death. Often people receive this care at home through a hospice program.

For biological family, "family" as defined by patient, and "peers", "friends" or "roommates" anticipatory grief for the impending loss begins before death.

Bereavement support is needed by all and is available before and for some time after the death. This service is most often provided by Hospice/ Palliative caregivers in the person's geographical region.
How to Help when Someone has died, or
The Principles of Bereavement

Grappling with Grief:

- Is about finding new ways of holding on to an important relationship.
- Is about “reworking” the people we love into our lives in new and different ways after they die.
- Is not about “moving on” or “letting go.”

“Looking for loved one”
The Principles of Bereavement

- The relationship is now entirely in our internal world, rather than in the external world.

- Life has changed, and our sense of self must be reconstructed.

- Assumptions about the world can be shattered (for example - that the people we depend on will always be there, or that life is predictable.)

“What was, still is”
# Grief, what it can look like…

- **Physical**
  - sleep disruptions, decreased appetite, tightness in the throat/chest, palpitations, shortness of breath, dry mouth, nervous tension

- **Emotional**
  - shock and disbelief, sadness, anger, guilt, fear, anxiety

- **Psychological**
  - concentration, focusing, and memory problems

- **Spiritual**
  - sense of meaninglessness, hopelessness and helplessness, questioning prior religious beliefs, anger at God

The intensity of feelings and the lack of familiarity of the feelings can often leave a person questioning themselves, feeling like they don’t "belong in their own skin", or wondering if they are "going crazy"

While physical symptoms are very typical, especially in the early weeks or first couple months, symptoms such as chest pain should always be checked by a physician to be sure there are no other physical problems that require treatment occurring.

Physical symptoms, difficulty concentrating and focusing are usually the most pronounced soon after a death, and generally diminish over the first couple months.

Although intellectually, a person can understand the reality and permanence of a death from the time they are given the news, emotionally "knowing" the reality takes much longer. It is common for the intensity of feelings to increase over the first few months as the death seems more real, and as time goes by with the person absent from the world.
Support for the grieving person (Do’s and Don'ts)

Although you are not able to take away a bereaved person’s pain, you are able to help them.

**DO:**
- be available to listen to their story over and over again
- remember that grieving is a process that can take a very long time
- know that the work of grieving takes time
- be willing to listen and to try and understand their experience as they struggle to develop a new, coherent, story line for their life that no longer includes this important person in their external world.

Frequently, one of the most difficult things for someone who is grieving is how isolated, or alone they feel, and they struggle with the overwhelming feelings of loss. You can be sure that many people, in response to their own feelings of helplessness, are giving the message that they should somehow start feeling better.

By focusing on understanding, and helping "hold" the pain of a person who is grieving, you are focusing on what you can do, which is to lighten the load, rather than what you can not do, which is make a loss not painful.
Support for the grieving person (Do's and Don'ts) cont'd

Supporting someone who is grieving over time can be difficult because you can’t change the cause of their pain and it is hard to tolerate feeling helpless.

- **DON'T:**
  - Try to minimize the person’s feelings by offering platitudes such as “he’s in a better place,” or “God only gives people what they can handle.”
  - try to explain away their feelings, “her suffering is over,” “time heals all wounds,” or “you need to be strong for...”

It is often tempting to respond to the intensity of someone else’s pain by trying to “fix it.” Frequently, people who are grieving are given all sorts of advise on how to manage their grief by looking at things differently, or by doing things differently (“get out more,” “you’re going at too fast a pace, you’re running away from your feelings”, etc.) For the most part, all this accomplished is giving the bereaved the messages that you don’t understand, don’t want to hear it, or that they are somehow inadequate.

Making efforts to minimize the pain are usually in response to your own needs rather than in response to the needs of the grieving person.
Remember that...

- Change always involves loss
- Grief follows all losses, not only death
- Recent loss conjures up feelings from past losses
- Death heightens awareness of our own vulnerability and mortality
- Other stressors will exacerbate the intensity of the grief process
### Grief

- no distorted sense of self
- guilt is focused on the loss often stated as “I should have...,” “If only I had...”
- pain is experienced as related to the loss rather than as meaningless or as part of a generalized hopelessness
- preoccupation with the deceased rather than self

### Depression

- sense of self worthlessness
- guilt related to feelings of personal inadequacy or badness
- emotional pain is generalized and experienced as meaningless
- pervasive sense of hopelessness and helplessness
- preoccupation with self and own pain

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**Distinguishing Grief from Depression**

There are many similarities in presentation between grief and bereavement, especially the extreme sadness, a sense of hopelessness and helplessness, a belief that life will never feel good again. However, there are also some very clear distinctions, which are outlined above.

Vegetative signs- insomnia, poor appetite, poor concentration, difficulty focusing, little pleasure in usual activities- are not helpful criteria for assessment, since they are common in normal grief, especially during the first couple months following a death.

Intensity of affect increasing over the first few months is common, as the loss seems increasingly real and permanent, and as social supports diminish as time goes on. People often fear that they are “doing worse after initially coping well” and benefit from information and support on the normal grief process.
Distinguishing Grief from Depression... con't

As the weeks go by after the death, the bereaved will begin getting messages from others around them that they should be "moving on," or feeling better more quickly than they typically do, leaving them increasingly isolated, which is likely to exacerbate rather than help diminish despair.

References


Risk Factors for Complicated Mourning

- Prior history of depression or other mental illness
- Multiple losses
- Sudden or traumatic death of the loved one
- An ambivalent relationship with the loved one

F. Kahlo, artist.
Red flags... when to get help

- Suicidal ideation or plan
- Withdrawal from social supports
- Marked behavioral or personality changes
- Alcohol or substance abuse
- Risk taking behavior

The capacity people have to tolerate intense pain, make sense out of horrendous losses, and reconstruct a world that has meaning and holds joy is remarkable. However, there are times when the demands of grieving exceed a person's ability to cope, and more intervention is required. When there are signs that a person is having trouble managing, additional support should be sought, through psychotherapy, medication evaluation, or, in the event of suicidal risk, the person should be evaluated for hospitalization.
Consumers speak...

“People don’t realize how many losses consumers have.”

“A lot of our friends die. Our friends are our family. We need help to deal with that.”

Remember that many persons with serious mental illness experience the loss of friends at an early age. As a group, they die younger than their counterparts in the general population, and therefore have more exposure to death.

* A MA DMH consumer

End-of-Life Care for Persons with SMI

Special Challenges

- Little is known about end-of-life care for persons with SMI
  - Specific literature scarce
  - Tools not tested in this population

- Advance Care Planning is complicated
  - Capacity assessment issues
  - Legal guardianship issues

- Shortage of persons to designate as Health Care Proxies

Healthcare systems across the US are improving care for the dying. Today we see higher rates of learning about a patient’s end-of-life care preferences, advocacy for the principles of palliative care, and the development of tools to measure progress promoting excellence in end-of-life care.

Despite these impressive gains, interest in improving care at the end of life for persons with serious mental illness has been largely ignored. In fact, most academic end-of-life care studies have specifically excluded persons with mental illness.

This project, “End of Life Care for Persons with Serious Mental Illness” began by asking questions and gathering data regarding preferences and capacities of persons with serious mental illness. Data has been collected and aggregated. We expect to learn about the circumstances of their deaths, their preferences for care, their capacity to participate in advance care planning, and the success of hospice/palliative care interventions with them.

Because advance care planning for persons with SMI is complex these patients are vulnerable and underserved with regard to quality end-of-life care. Their "families" and loved ones have few, if any, resources to guide them through the clinical and legal processes associated with individualized advance care planning, a process complicated by issues regarding capacity assessment and guardianship status. For example, In Massachusetts, any person who has been adjudicated incompetent by a court and has a guardian (substitute decision maker) is excluded (by law) from designating a health care proxy. Meanwhile, the Health Care Proxy is the only legal form of an Advance Directive recognized in Massachusetts.

At the same time, competent persons with SMI also experience difficulties when selecting a Health Care Agent. This is because most people select a family member to be their Agent. However, persons with SMI may be estranged from their family of origin, or may prefer to select a residential staff member or their case manager. As the law specifically excludes persons who own or have financial interests in the setting where a person with SMI lives, these potential proxies are not available. In addition, the Departments of Mental Health may exclude case managers or other contracted staff from acting as a patient’s health care proxy, even though these persons may know the patient best and the patient may feel most comfortable with them.

2. Massachusetts General Laws Chapter 201D: Health Care Proxies, 1990
Consumers speak...

“I worry about what kind of death I’ll have.”

“Will people know if I’m psychotic or just think I’m delirious?”

“Who will know when I need my medications?”

Fears about terminal illness and death are common among persons with serious mental illness. Anxieties about proper treatment and communication issues are frequently based upon earlier unpleasant and often stigmatizing experiences with the health care system.

Despite this, persons with SMI want to discuss their EOL preferences and have the capacity to do so. (see Health Care Preferences Questionnaire)

*This quote came from a MA Department of Mental Health Client.

Palliative Care for Persons with Serious Mental Illness

- “Family” may be other clients, staff, members of the mental health service provision team

- Needs to occur “at home”

Palliative Care for Persons with Serious Mental Illness

As noted earlier, palliative care embraces the patient and his/her entire natural family in making decisions and participating in the plan of care. Persons with severe and persistent mental illness may not have been living with or in frequent contact with natural family members.

In fact, for many persons with SMI, the “family unit” is the staff and other clients who reside with them. “Home” may mean the person’s unit at a state mental hospital, a long-term VA facility, or a psychiatric-community based residence. “Home” translates to whatever setting the person feels is most familiar where s/he is surrounded by friends and “family.”

In this context, the word “family” refers broadly to “whoever matters to the patient.” Family members usually provide some/all of the dying person’s physical health needs and empowering them is emphasized. Initial and ongoing evaluations help the patient and “family” define their evolving needs, set realistic goals, and encourage the patient to describe his/her end-of-life preferences.

The psychiatric team is knowledgeable regarding psychiatric symptoms and treatment but may need consultation from hospice/palliative care specialists particularly regarding pain management. Such consultations work best when the psychiatric team has a constructive relationship with their local Hospice/Palliative care providers that is supported by a contractual agreement. In this way, the person with serious mental illness and terminal illness (SMITI) is able to remain “at home”, surrounded by “family”, free of pain, and under the care of a knowledgeable interdisciplinary team.
Palliative Care for Persons with Serious Mental Illness

- Pain, psychological and spiritual care is addressed
- Requires an interdisciplinary team approach
- Support system for the “family” during illness and into bereavement

**Palliative Care for Persons with Serious Mental Illness ... con’t**

When a SMITI person is dying at a group home, for example, the entire staff and the other patients would be involved. Community meetings can be devoted to thoughts and feelings about having a dying person remain on the unit, how to help him or her bear the burden, what “saying goodbye” feels like, how to manage subsequent grief and bereavement, what volunteers might do for the dying person (read, play music, sit with them, plan funeral arrangements,) etc.

The facility’s spiritual leader or an outside consultant could be invited to speak with the patient and the unit.

Opportunities for continuing growth in this phase of life are embraced by persons with SMITI and help them redefine hope, feel an inner resolute dignity, meaning, and purpose, voice forgiveness, reconciliation, and say goodbye.

Support for survivors continues beyond death of the patient into the bereavement period.


See “Administrative issues” on this website (www.promotingexcellence.org/mentalillness) for an example of a contractual agreement between a state psychiatric hospital and a local Hospice/Palliative Care Provider.
Consumers speak...

“I know my death will be medically complicated because of all the medications I’ve been on.”

“I already have irreversible kidney damage from Lithium.”*

Further complicating our patients' (consumers', clients') health status is the common use of numerous medications simultaneously, sometimes from the same class, and usually over extensive periods of time.

In some instances either the long-term use of a medication or its combination with other medications can result in irreversible side effects. Psychiatric patients are often aware of these problems, and worry that about their fragile health status.

*A MA DMH consumer

How to Help Persons with SMI Prepare for the Future

- Document Preferences for End-of-Life Care
- Assist in their process to complete an advance care directive
- Use the TOOLS described next
Assessment Tools

- The Healthcare Preferences Questionnaire (HCPQ)
- Competence Assessment Tool – Health Care Proxy (CAT-HCP)

The Healthcare Preferences Questionnaire (HCPQ) and the Competence Assessment Tool – Health Care Proxy (CAT-HCP) - presented next - have been designed to test the hypotheses that persons with serious mental illness are emotionally able and cognitively capable of considering and specifying 1) advance care preferences, and 2) a health care agent.

Foti ME. Do It Your Way. Journal of Palliative Medicine, 2003
The Healthcare Preferences Questionnaire (HPQ) is a 21-page survey instrument designed to learn about end-of-life care preferences among the severely mentally ill, as well as their comfort related to questions about death and dying. It includes: the “SF-12”, a standard health status research questionnaire; elements derived from the American Health Decisions publication The Quest to Die with Dignity®; three scenarios describing decision points in critical health care situations (pain, paralysis, and psychiatric emergency); an assessment of the patient’s spiritual beliefs and values; and queries regarding emotional discomfort experienced while completing the questionnaire.

Foti ME. Do It Your Way. Journal of Palliative Medicine, 2003
Healthcare Preferences Workbook

- Watch for a publication on Results of the Health Care Preferences Questionnaire
- Remember that Persons with Serious Mental Illness have Preferences and can articulate them
- Download the current version of the Advance Directives section of our “Do It Your Way” Medical and Psychiatric Care Preferences Workbook
- Contact us for the entire workbook.
The Competence Assessment Interview – Health Care Proxy (CAT-HCP) is a research tool that uses the MacArthur Competence Assessment Tools (MacCAT) format to specifically evaluate a subject’s capacity to select a health care proxy.

- It is a modification of other Capacity Instruments developed to assess competence:
  - to consent to Treatment
  - to participate in Research
  - to participate in forensic assessments

The Competence Assessment Interview – Health Care Proxy (CAT-HCP) is a research tool that uses the MacArthur Competence Assessment Tools (MacCAT) format to specifically evaluate a subject’s capacity to select a health care agent.

The MacArthur Competence Assessment Tools (MacCAT) are instruments with demonstrated reliability and validity that measure decisional capacity. These instruments guide an interview that assesses a person’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 alternatives; and to communicate a choice.

The CAT-HCP an Overview

Do people with serious mental illness have:

- The Capacity to
- Understand and Appreciate the
- Benefits and Risks of
- Selecting a Healthcare Proxy???

In some states, selecting a health care proxy (also called a Health Care Agent; a person to speak for you if you are unable to make or communicate your own health care decisions) is the legal form of an advance directive. To select a health care proxy in MA (a right), the person has to be 18 years of age and competent. Any person who has a guardianship (substitute decision maker) is not able to select a health care agent according to the law.

Among people with serious mental illness, guardianships are common. In some Institutions of Mental Disease (State Hospitals) 40-60% of patients have guardianships. This means that they cannot select a health care agent legally.

Our hypothesis is that psychiatric patients with serious mental illnesses (psychotic disorders, for example) with or without guardianships, do have the capacity to understand, appreciate, reason through and choose a health care agent if they desired to do so.

The CAT-HCP results will enlighten us about this question. In the meantime, it is important to educate every psychiatric patient about advance directives and health care proxies. See next slide for information about educational materials.
Toolkit for Innovation and Improvement

- **Do It Your Way –**
  Patient Guidance Brochure and Preferences Workbook

- **The Healthcare Preferences Questionnaire (HCPQ)**

- **CAT-HCP** (Capacity to select a health care agent)

- **The Deceased Client Profile (DCP)**

Available at: www.promotingexcellence.org

**Do It Your Way – Patient Guidance Brochure and Workbook**
This informational brochure was developed to reach as many clients as possible with information about the use of a Health Care Agent. The brochure explains the processes involved in selecting a health care agent.

The "Do It Your Way" – Mental and Physical Healthcare Preferences Workbook is composed of three sections: Wellness Maintenance and Symptom Response; In Crisis; and Advance Care Planning.

The Healthcare Preferences (HCPQ) and CAT-HCP are presented in preceding slides. More information about each of these will be forthcoming through the published literature.

The Deceased Client Profile (DCP) is a form that collects mortality data for quality assessment and improvement activities such as the evaluation of end-of-life care services and planning long-range wellness initiatives. It records the manner and cause of death, medical and psychiatric diagnoses, medications, medical visit history, location of death, hospice/palliative care involvement, and advance directives.

More information and downloads are available at: www.promotingexcellence.org/mentalillness

Or, by contacting:
Mary Ellen Foti, MD
Westborough State Hospital
P.O. Box 288 - Lyman Street
Westborough, MA 01581

Phone "Kathy at": 508 – 616 – 3509
Email: maryellen.foti@dmh.state.ma.us
What you can do
As Mental Health Provider

- Become aware of Palliative Care and Hospice (PC & H) programs serving your area (go to www.nhpco.org)

- Invite local PC & H providers to present Education Programs in your facility on the:
  - scope of their services
  - eligibility criteria for referrals

- Develop a collaborating working relationship for delivering end-of-life care to persons with serious mental illness in your community

Mental health providers can use reciprocal education activities to develop collaborative working relationships with the hospice and palliative care teams serving patients in their area.

Local palliative care and hospice providers can present basic information about the services offered and eligibility criteria for referral, as well as case presentations and group discussions about end-of-life issues and the principles of palliative and hospice care.

Mental health providers can offer perspectives to palliative and hospice care providers on how to communicate comfortably with persons with mental illness and present case studies involving terminally ill patients with serious mental illness.

Presentations can be extended to area medical professionals, mental health advocacy groups, family and consumer groups and other stakeholders in the community.
Compassion is most important and as long as one’s in good hands it doesn’t matter if it is family. It can be anyone as long as love leads.

Carrie Phipps

In Conclusion...

• Patients with serious mental illness have the right to participate in Advance Care Planning and access quality end-of-life care.

• Integrated service delivery models can be established to ensure access to for persons with serious mental illness.

• Ongoing research and assessment will identify unique end-of-life care issues for this population and contribute to appropriate and compassionate care for them.

• Working collaboratively with persons with serious mental illness and including their voices in the nation’s end of life care discussion will provide additional dimension and depth to this critical conversation.

“In God’s Hands” was the winning logo image of a contest held early in this project. Many consumers participated and the works were showcased in a publicly attended Art Show at Medfield State Hospital. To view more of the logo submissions, go see Art Contest on this SITE at www.promotingexcellence.org/mentalillness
EOL Resources available Online

- **PEELC** - Promoting Excellence in End-of-Life Care  
  www.promotingexcellence.org

- **EPEC Project** - Education for Physicians on End-of-Life Care  
  www.EPEC.net

- **EPERC** - End-of Life/Palliative Education Resource Center  
  www.eperc.mcw.edu/start.cfm

- **CAPC** - Center to Advance Palliative Care  
  www.capcmssm.org/

- **ELNEC** – End of Life Nursing Education Consortium  
  www.okabced.org/ELNEC.htm

There is a growing body of resources related to end-of-life care online. Many of the resources mentioned here will provide links to other resources directed to health care professionals as well as to the general public.

**PEELC - Promoting Excellence in End-of-Life Care** - www.promotingexcellence.org  
Provides information and tools used by innovative demonstration projects in providing hospice and palliative care to special patient populations and in challenging clinical settings.

**EPEC Project - Education for Physicians on End-of-Life Care** - www.EPEC.net  
Provides teaching modules, handouts, PowerPoint slides, and facilitator’s guides designed to educate all physicians on the essential clinical competencies required to provide quality end-of-life care.

**EPERC - End-of Life/Palliative Education Resource Center** - www.eperc.mcw.edu/start.cfm  
A central repository for peer-reviewed educational training materials and information about end-of-life issues.

**CAPC - Center to Advance Palliative Care** - www.capcmssm.org  
A resource to hospitals and health systems interested in developing palliative care programs.

**ELNEC – End of Life Nursing Education Consortium** - www.okabced.org/ELNEC.htm  
Is a comprehensive, national education program to improve end-of-life care by nurses.
EOL Resources available Online

- **AAHPM** - American Academy of Hospice and Palliative Medicine  
  www.aahpm.org

- **NHPCO** - National Hospice and Palliative Care Organization  
  www.nhpco.org

- **IICN** - Inter Institutional Collaborating Network on End-of-Life Care  
  www.growthhouse.org/iicn.html

- **City of Hope, National Medical Center**  
  http://mayday.coh.org

- **Toolkit of Instruments To Measure End-of-Life Care**  
  www.chcr.brown.edu/pcoc/toolkit.htm

**AAHPM - American Academy of Hospice and Palliative Medicine**  
Organization for physicians dedicated to the advancement of hospice/palliative medicine, its practice, research and education.

**NHPCO - National Hospice and Palliative Care Organization**  
Nonprofit membership organization representing hospice and palliative care programs and professionals in the United States.

**IICN - Inter Institutional Collaborating Network on End-of-Life Care**  
A shared online EOL community linking major organizations internationally.

**City of Hope, National Medical Center**  
A central source for collecting a variety of materials including pain assessment tools, patient education materials, quality assurance materials, end-of-life resources, research instruments and other resources.

**Toolkit of Instruments To Measure End-of-Life Care**  
Bibliography of instruments to measure the quality of care and quality of life for dying patients and their families.
Online Mental Health Resources

- NMHA - National Mental Health Association  
  www.nmha.org
- APA - American Psychiatric Association  
  www.psych.org
- NAMI - National Alliance for the Mentally Ill  
  www.nami.org
- NASMHPD - National Association of State Mental Health Program Directors  
  www.nasmhpd.org

NMHA - National Mental Health Association - www.nmha.org
Nonprofit organization addressing all aspects of mental health and mental illness.

APA - American Psychiatric Association - www.psych.org
A is a medical specialty society ensuring humane care and effective treatment for all persons with mental disorder, including mental retardation and substance-related disorders. Its vision is a society that has available, accessible quality psychiatric diagnosis and treatment.

NAMI - National Alliance for the Mentally Ill - www.nami.org
Nonprofit, grassroots, self-help, support and advocacy organization of consumers, families, and friends of people with severe mental illnesses, such as schizophrenia, major depression, bipolar disorder, obsessive-compulsive disorder, and anxiety disorders.

National Mental Health Consumers' Self-Help Clearinghouse - www.mhselfhelp.org
A consumer-run national technical assistance center serving the mental health consumer movement by connecting individuals to self-help and advocacy resources, and offering expertise to self-help groups and other peer-run services for mental health consumers.

NASMHPD - National Association of State Mental Health Program Directors - www.nasmhpd.org
Organization reflects and advocates for the collective interests of State Mental Health Authorities and their directors at the national level, analyzes trends in the delivery and financing of mental health services, and builds and disseminates knowledge and experience reflecting the integration of public mental health programming in evolving healthcare environments.
Online Bereavement Resources

- Association for Death Education and Counseling, www.adec.org
- Grief Net. Grief Network www.griefnet.org
- NCDE - National Center for Death Education www.mountida.edu/ncde
- Gift From Within www.giftfromwithin.org
- SAVE: Suicide Awareness \ Voices of Education www.save.org

The Association for Death Education and Counseling is a multidisciplinary professional organization dedicated to promoting excellence in death education, bereavement counseling and care of the dying. Based on theory and quality research, ADEC provides information, support and resources to its multicultural membership and, through them, to the public. The website includes a list of additional resources.

Grief Net is a place that offers the opportunity to communicate with others via e-mail support groups about death, grief, and major loss, including life-threatening and chronic illness.

The National Center for Death Education offers professional education on death, grief and loss through onsite and online courses, as well as an extensive thanatology library housed at Mount Ida College in Newton, MA. Contact: ncde@mountida.edu.

Gift From Within is an international private, nonprofit organization dedicated to those who suffer post-traumatic stress disorder (PTSD), those at risk for PTSD, and those who care for traumatized individuals. A member of the International Society for Traumatic Stress Studies (ISTSS) this organization offers resources not only trauma survivors and family members but also for educators, clinicians, volunteers, therapists, doctors, nurses and other professional helpers.

Suicide Awareness \ Voices of Education provides education and information about suicide and suicide prevention, as well as outreach and grief support for those who have lost loved ones to suicide. Includes the CDC's most recent statistics on death by suicide, frequently asked questions about suicide, book reviews, and other resources about suicide.