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*Reference for CD provided at Staff Ombudsman Training, June 6, 2007.*
Trainer’s Notes

End-of-Life Care in Nursing Homes

The State LTC Ombudsman Program provides this packaged information on CD as a resource for Continuing Education as well as In-Service to facility staff. It contains PowerPoints, documents, forms, and resources. Use the items in entirety, by sections, or whatever way works for your program. More information on each section follows:

PowerPoint show and presentation. The presentation file includes some Notes. A basic outline includes:

1. Kind of Death
   a. Seneca quote
   b. Personal perspectives - discussion

2. Summary of Brown University Report
   a. Key findings
   b. Training recommendations
   c. Policy issues

3. Resident Wishes outlines agenda for the rest of the presentation/show
   a. Advance care planning
      i. Means planning ahead for how you want to be treated if you are very ill or near death
      ii. Five-step process
         1. Thinking about what you would want to happen if you could not talk or communicate with anyone
         2. Finding out about what kind of choices you will need to make if you become very ill at home, in a nursing home or in a hospital
         3. Talking with your family and doctor about how you want to be treated
         4. Filling out papers that spell out what you want if you are in an accident or become sick
         5. Telling people what you have decided

4. Advance Directives
   a. Types
   b. Frequently Asked Questions

5. Nursing home care planning
   a. Comprehensive vs. Palliative
   b. Cure vs. Comfort
   c. Hospice
6. Ethical issues (interspersed throughout)
   a. *For Discussion* - Mr. Garcia
   b. *For Discussion* - Mrs. Chen

7. Memorials & Acknowledgements
   a. “I Remember” ideas throughout (commercial breaks)
   b. Some ideas are from TMF Health Quality Institute pilot on Person-Directed Care, [www.tmf.org/nursinghomes/providers/index.htm](http://www.tmf.org/nursinghomes/providers/index.htm)

8. Video alters view about terminal care
   a. Visual and verbal vs. Verbal only
   b. Research findings from *Report in Archives of Internal Medicine*
   c. Video is for research only and cannot be downloaded

9. Resources
   b. *Alternatives to Guardianship under Texas Law*, Texas legal Services Center
      i. Explains advance directive documents
      ii. Discusses other documents that allow people to state their wishes and to help avoid guardianship

10. Experiences
End-of-Life Care in Nursing Homes

Office of the State LTC Ombudsman
Texas Department of Aging and Disability Services
A man’s life should satisfy other people, his death only himself, and whatever sort he likes best.

Seneca
(4 BC - 65 AD)
What is a good death from your perspective?

- In your sleep?
- During favorite time of day, e.g., sunrise?
- In the hospital?
- At home?
- Surrounded by family and friends?
- Cryonics until a cure through future medical technology?
- ___________?
End-of-Life

- Early 1900s, most people died at home usually from infectious disease.

- In 1999, deaths occurred
  - 51% in hospitals
  - 22% in nursing homes
    (People ≥85 years old, 43% died in NHs)

- In 2001, about 1 in 4 American adults died in a nursing home - a proportion that has been increasing in recent years.

*End of Life in Nursing Homes: Experiences and Policy Recommendations*
End-of-Life

Today, most die in hospitals or nursing homes after a lengthy experience with one or more chronic conditions.

Despite the growing importance of nursing homes in caring for the dying, little is known about the experiences or care of terminally ill people in nursing homes.
Brown University Report

- 54 in-depth telephone interviews with relatives and others close to people who lived in a NH or ALF during the last month of their lives
- Nov. 2001 – Oct. 2002 (1-2 years after the death)
- Decedents
  - 83.9 years: average age
  - 70.4% women
  - 77.4% white
- Median length of NH stay: 6-12 months
Key Findings

- Professional caregivers of dying people insufficiently recognize
  - symptoms
  - needs
  - illness trajectories

- Low expectations of NHs and experiences with poor-quality care turn many family members into vigilant advocates for their dying relatives

Result: opportunities missed for
- advance care planning
- palliative intervention
Key Findings

- Physicians are viewed as “missing in action.”

- Family members report a need for more and better-trained staff.
Key Findings

- Rules reinforce task-focused care rather than person-centered care
- Hospice services often enhance end-of-life care
- Referral is frequently made late in the illness or not at all preventing people from receiving the full benefit of such services
Training Recommendations

- Educate health professionals
- Train physicians in end-of-life care
- Train NH staff and administrators
- Inform the public about end-of-life care
- Develop new knowledge and improved practices
Policy Issues

- Examine quality of end-of-life care
- Study viability of using Medicare’s skilled-care benefit
Policy Issues

- Include the right to hospice care in the Patients’ Bill of Rights

- Add content on pain management, fluids and hydration, and other aspects of end-of-life care to CMS Survey Manual
Policy Issues

- Identify and disseminate best practices, policies, and procedures to enhance collaboration between NHs and hospice providers
Resident Wishes

- Advance care planning
- Nursing home care planning
  - Cure vs. Comfort
  - Routine vs. Palliative
- Ethical issues – For Discussion
- Memorials & Acknowledgements
"I remember ...

Place a single flower on the bed

Share memories with family, friends, and staff

Add photos to a memory book
For Discussion

What if Mr. Garcia who lives in Live Oaks nursing home decides to stop eating?

- He is losing weight.
- He does not complain of pain or hunger.
- His daughter is Power of Attorney.

What do you think will happen?

What is important to consider?
~ Advance Care Planning ~

Planning ahead for how you want to be treated if you are very ill or near death.

- Sometimes when people are in an accident or have an illness that will cause them to die, they are not able to talk or let others know how they feel.
- Texas law allows you to tell your doctor how you want to be treated by using an advance directive.
Five-Step Process

1. Think about what you would want to happen if you could not talk or communicate with anyone.
Five-Step Process

2. Find out about what kind of choices you will need to make if you become very ill at home, in a nursing home, or in a hospital.
Five-Step Process

3. Talk with your family and doctor about how you want to be treated.
Five-Step Process

4. Fill out papers that spell out what you want if you are in an accident or become sick.
Five-Step Process

5. Tell people what you decided.
Advance Directives

- **Consent to Medical Treatment** — For a person who has not issued a directive and needs medical care.

- **Directive to Physicians and Family or Surrogates** — It is designed to help you communicate your wishes about medical treatment at some time in the future when you are unable to make your wishes known because of illness or injury.

- **Medical Power of Attorney** — Except to the extent you state otherwise, this document gives your named agent authority to make any and all health care decisions for you in accordance with your wishes when you are no longer capable of making.

- **Out-of-Hospital Do Not Resuscitate**

- **Procedure when person has not executed or issued a directive and is incompetent or incapable of communication**
Advance Directives FAQs

For more details on advance care planning, the Department of Aging and Disability Services provides questions and answers through the following:

- [Frequently Asked Questions in English](#)
- [Frequently Asked Questions in Spanish](#)
For Discussion

Mrs. Chen wants to revoke her Power of Attorney (PoA).

- She lacks capacity to consent to another PoA.
- She has no person to ask to serve as PoA.

What should the Ombudsman consider?
"I remember ..."

Write a poem or story about the person

Play his or her favorite music
Care Planning

Comprehensive Care Plans

- Measurable short-term and long-term objectives and timetables to meet resident needs:
  - Medical needs
  - Nursing needs
  - Mental health needs
  - Psychosocial needs

- Identified in comprehensive assessment
Care Planning

Palliative Care Planning

- Developed only at the request of resident, legal representative, or surrogate decision maker for residents with
  - Terminal conditions
  - End stage diseases
  - Other conditions for which curative medical interventions are not appropriate

- Must have goals that focus on maintaining a safe, comfortable, and supportive environment in providing care to a resident at the end of life
Care Planning

Comprehensive care plans should be made available to ALL direct care staff.
"I remember ..."

Nursing homes can create ~

A culture that considers death a natural part of life and create ways to acknowledge and honor it

An opportunity for staff to be with the dying person

A relationship with religious professionals who can provide support on an organizational basis
Hospice

Care for people who are terminally ill.

- A team of specially trained professionals who provide
  - Pain management
  - Emotional and spiritual support

- Tailored to the individual’s needs and wishes
Hospice

Focus is on Caring, not Curing.

- Recognizing the tremendous toll that illness takes on family members, the hospice team also comforts and supports the resident’s loved ones
  - during the illness
  - through bereavement counseling
"I remember …"

Establish a comfort service for families that includes a cart, refreshed frequently with small snacks, beverages etc. Include a CD player with music, hand cream, appropriate books, freshening wipes, and religious items if desired.
Memorials
Acknowledgements

Determine what is meaningful in each nursing home; get input from

- Residents
- Staff

Consider using some “I Remember” memorials

Identify other local acknowledgements
Video Alters Views about Terminal Care

End-of-life care decisions can be abstract exercises - hard to envision hypothetical scenarios.

- Researchers sought to determine whether using **video images WITH verbal descriptions** would change people's minds about future care.

- They used a two-minute video of an elderly woman with advanced dementia being cared for in a nursing home by her two daughters.

- Harvard Medical School physicians produced video.

- Middle-aged patients (120) at clinics at two Boston teaching hospitals viewed the video.
Before viewing

50% would choose "comfort care," that includes painkillers and oxygen but not hospitalization or high-tech interventions to prolong life

21% opted for life-prolonging medical measures at any cost, e.g., CPR

18% picked limited intervention, which includes artificial feeding and antibiotics

11% were unsure

Black and Latino patients were more likely to opt for more aggressive levels of care
After viewing

89% chose comfort care

All who had initially opted for life-prolonging treatment
  - changed their preferences or
  - became uncertain about what they wanted

Differences related to ethnicity disappeared

SOURCE: Report in Archives of Internal Medicine
RESOURCES

- DADS Joint Training on End of Life
  [link](www.dads.state.tx.us/providers/training/jointtraining.cfm)
  empower caregivers with knowledge / resources necessary to provide compassionate, respectful care for resident’s final season of life

- On Our Own Terms – Moyers on Dying (PBS)
  [link](www.pbs.org/wnet/onourownterms)

- Texas Partners for End-of-Life Care
  [link](www.txpec.org)

- Respecting Choices [link](www.gundluth.org/eolprograms)
  “Let’s Talk, Texas!” pilots at Methodist Hospital, Houston and Baylor All Saints Medical Center, Ft. Worth
RESOURCES

- Advance Care Planning document
  www.dads.state.tx.us/providers/NF/advancedplanning/index.html

- Advance Directive forms

Experiences

What have you experienced or seen that influenced respectful care at the end of someone’s life?
ADVANCE CARE PLANNING

What is advance care planning?

“Advance care planning” means planning ahead for how you want to be treated if you are very ill or near death. Sometimes when people are in an accident or have an illness that will cause them to die they are not able to talk or to let others know how they feel.

Advance care planning is a 5-step process.

- Thinking about what you would want to happen if you could not talk or communicate with anyone
- Finding out about what kind of choices you will need to make if you become very ill at home, in a nursing home or in a hospital
- Talking with your family and doctor about how you want to be treated
- Filling out papers that spell out what you want if you are in an accident or become sick
- Telling people what you have decided

QUESTIONS AND ANSWERS ABOUT ADVANCE CARE PLANNING

If I get too sick to say what kind of help I want from doctors or nurses, what can I do?

Putting your wishes in writing makes sure that everyone knows what you want. There are two ways to do this. One is a form called the “Directive to Physicians, Family and Surrogates”. This form tells doctors, family members or other people who are close to you the type of help you want when you are sick.

The other form is a “Living Will”. This form also puts in writing how you want to be treated. Both forms can also include written instructions on thing that you do NOT want done to you.

Do I have to fill out these forms?

No. No one can make you fill out these forms. But without them the people helping you will not know what you want if you can’t tell them.

Can I change my mind about what I say on the forms?

Yes. You can change your forms at any time you want. If you change your mind, you can mark out what you wrote before and write what you want now instead. Make sure you write very clearly. It may be a good idea to fill out a new form and throw away the old form. That way no one will make a mistake when they are trying to help you.

It is also a good idea to tell your family and doctor that you have changed your wishes.

Remember, these forms can only be used when you can’t tell people what you want. If you are awake and able to say what you want, then that is the only thing that matters.
Can someone speak for me if I am not able to say what I want?

Yes. You can fill out a form called a “Medical Power of Attorney”. This form lets you name someone to speak for you. The person you name is called an “agent” on the form. You can choose anyone you want to be your agent. It does not have to be a member of your family. But remember, it is always important for your family and agent to know what you want before something happens to you.

If you don’t name someone to be your agent, then state law has a set of rules for how decisions will be made for you.

Do I need a lawyer to fill out any of these forms?

No. You can fill them out yourself. You can ask a lawyer to help you, but you do not have to. If you need help understanding the forms, most nursing facilities and hospitals will have people who can explain them. Once you have filled out the forms, all you have to do to make them legal is sign them. You do not need a notary public.

Do doctors, nurses and hospitals have to follow my instructions?

Yes. Health care professionals cannot ignore your wishes. If a doctor, nurse, hospital or nursing facility is not able or not willing to follow your instructions they must transfer you to someone who will.

Other Questions about Hospitals and Nursing Facilities

and Treatment at the End of Life

Sometimes people have questions about when it makes sense for them to move from a nursing facility to a hospital. The following information tries to answer some of those questions.

If I am in a nursing facility and get very sick, should I stay where I am or go to the hospital?

This is a choice you will have to make after you talk to your doctor or family members. If you can get the care you need where you are, it is often safer and more comfortable to stay in the nursing facility. Moving to the hospital can cause problems because the people working there do not know everything about you. Sometimes this leads to problems with medications, pressure sores and infections. Ask your doctor if there are things you need that the nursing facility can’t give you. Make sure you understand all the risks in moving or staying where you are.
What is an Out-of-Hospital Do Not Resuscitate Order (OOHDNR)?

This form is for use when you are not in the hospital. It lets you tell health care workers, including EMS workers, NOT to do some things if you stop breathing or your heart stops. If you don’t have one of these forms filled out, EMS workers will ALWAYS give you CPR or advanced life support even if your advance care planning forms say not to. You should complete this form as well as the Directive to Physicians and Family or Surrogates and the Medical Power of Attorney form if you don’t want CPR.

What is Cardiopulmonary Resuscitation (CPR)?

You have probably seen this on TV. CPR is pressing on your chest to keep blood flowing and assistance with breathing, such as mouth-to-mouth assistance. Sometimes electrical shocks are used to help start the heart. CPR is only used for short periods until a person can get to the hospital.

Does CPR always work?

No. It depends on other things, including your overall health and your age. Everyone is different. It does not work very well for most people who have a life-threatening illness or are over 80. You should talk about CPR with your doctor and discuss what is best for you and what best fits with your personal values and goals.

What is Artificial Respiration or Ventilation?

This means getting assistance with breathing when you can’t breathe on your own. A tube is put into your nose or mouth or into your windpipe. If this tube is needed for more than a few weeks, a surgeon will probably need to put the tube directly into your throat. Doing this causes problems with talking, eating and drinking. The tube is also attached to a machine, which makes it harder to move around.

Eating, Drinking and Pain During a Terminal Illness

What is Artificial Nutrition and Hydration?

These are medical treatments that allow a person to get food and water when they cannot eat or drink. Fluids can be given through a needle placed in a vein (IV). This is usually done for only a few days because of the risk of infection and because it is hard to keep the needle in place. Sometimes food and water are given through a tube that goes down the nose and throat into the stomach. If the tube needs to be in place for a long time it is placed directly into the stomach by a surgeon.

These different kinds of tube feeding are different from ordinary eating and drinking because they don’t let the person taste or feel food and liquids like they are used to doing. Also, the person is not in control of their food or liquid intake. Doctors and nurses decide how much food and water they should have in this way.
Do Artificial Nutrition and Hydration Make People Live Longer?

Sometimes, but not always. How effective these kinds of treatment are depends on other medical problems. When a person with a terminal illness can’t eat or drink it usually means that the body has stopped working like it should and it will not improve. If this is the case, tube feeding alone will not make the person healthy again. It may even make the person uncomfortable during their final days.

What about Pain and Comfort?

If a person has a medical problem that will cause them to die and they don’t want artificial treatment, they can still be comfortable. Making people comfortable during the final part of their life is called “palliative care”. Even if there is no cure for a condition, doctors can treat pain, nausea and discomfort. Comfort should always be part of the treatment plan that a doctor discusses with a patient or family.

THE IMPORTANCE OF ADVANCE CARE PLANNING

Everyone is going to die sometime, but not everyone gets to choose how they are treated at the end of their lives. Taking the time to do advance care planning can help family members and medical staff act for you. They will be faced with hard decisions near the time of your death. Having an advance care plan lets you make sure that you are treated according to your values and wishes regardless of whether you can speak for yourself.

ADDENDUM

Sources to get Advance Directive documents and information:

Area Agencies on Aging, 800-252-9240
Internet: www.dads.state.tx.us/news_info/publications/handbooks/index.html
• Consent to Medical Treatment — For a person who has not issued a directive and needs medical care. Does not include withholding or withdrawing life sustaining treatment. PDF in English / PDF in Spanish
• Directive to Physicians and Family or Surrogates form — This is an important legal document known as an Advance Directive. It is designed to help you communicate your wishes about medical treatment at some time in the future when you are unable to make your wishes known because of illness or injury. PDF in English / PDF in Spanish
• Medical Power of Attorney form — This is an important legal document. Except to the extent you state otherwise, this document gives the person you name as your agent the authority to make any and all health care decisions for you in accordance with your wishes, including your religious and moral beliefs, when you are no longer capable of making them yourself. PDF in English / PDF in Spanish
• Out-of-Hospital Do Not Resuscitate Information & Form — PDF in English
• Procedure When Person Has Not Executed or Issued a Directive and Is Incompetent or Incapable of Communication — PDF in English / PDF in Spanish
Note: May include withholding or withdrawing life sustaining treatment.
Frequently Asked Questions about Advance Care Planning

What is Advance Care Planning?

Advance care planning means planning ahead for how you want to be treated if you are very ill or near death. Sometimes when people are in an accident or have an illness that will cause them to die they are not able to talk or to let others know how they feel. Texas law allows you to tell your doctor how you want to be treated by using an advance directive. Chapter 166 of the Texas Health and Safety code is the state law on advance care planning through advance directives. Chapter 166 explains advance directives, includes forms to use for advance directives and states how medical decisions can be made when a person does not have an advance directive.

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Do I have to fill out this form?

No. No one can make you fill out the form. But with it the people helping you will know what you want if you can’t tell them.

Can I change my mind about what I say on the form?

Yes. You can do that at any time you want. If you change your mind, you must make out a new form and throw away the old one rather than make changes to the old form. That way no one will make a mistake when they are trying to help you.

It is also a good idea to tell your family and doctor that you have changed your wishes.

Remember, this form can only be used when you can’t tell people what you want. If you are awake and able to say what you want, then that is the only thing that matters.

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Yes. You can fill out a form called a Medical Power of Attorney. This form lets you name someone to speak for you. The person you name is called an agent on the form. You can choose anyone you want to be your agent. It does not have to be a member of your family. But remember, it is always important for your family and agent to know what you want before something happens to you.

If you don’t name someone to be your agent, then state law has a set of rules for how decisions will be made for you.
What are the rules?

Do I need a lawyer to fill out any of these forms?
No. You can fill them out yourself. You can ask a lawyer to help you, but you do not have to. Once you have filled out the forms, all you have to do to make them legal is sign them in front of the proper witnesses. You do not need a notary public.

Do doctors, nurses and hospitals have to follow my instructions?
Yes, unless they inform you in advance that they cannot. If they do not intend to honor your wishes, they are required to give you a reasonable opportunity to or assist you to transfer to a physician or health care provider who will comply with your wishes. Health care professionals cannot simply ignore your wishes.

Other Questions about Hospitals and Nursing Facilities and Treatment at the End of Life

Sometimes people have questions about when it makes sense for them to move from a nursing facility to a hospital. The following information tries to answer some of those questions.

If I'm in a nursing facility and get very sick, should I stay where I am or go to the hospital?
This is a choice you will have to make after you talk to your doctor or family members. If you can get the care you need where you are, it is often safer and more comfortable to stay in the nursing facility. Moving to the hospital can cause problems because the people working there do not know everything about you. Sometimes this leads to problems with medications, pressure sores and infections. Ask your doctor if there are things you need that the nursing facility can't do for you. Make sure you understand all the risks in moving or staying where you are.

What is an Out-of-Hospital Do Not Resuscitate Order (OOHDNR)?
This form is for use when you are not in the hospital. It lets you tell health care workers, including Emergency Medical Services (EMS) workers, NOT to do some things if you stop breathing or your heart stops. If you don't have one of these forms filled out, EMS workers will ALWAYS give you CPR or advanced life support even if your advance care planning forms say not to. You should complete this form as well as the Directive to Physicians and Family or Surrogates and the Medical Power of Attorney form if you don't want CPR.

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These are medical treatments that allow a person to get food and water when they cannot eat or drink. Fluids can be given through a needle placed in a vein (IV). This is usually done for only a few days because of the risk of infection and because it is hard to keep the needle in place. Sometimes food and water are given through a tube that goes down the nose and throat into the stomach. If the tube needs to be in place for a long time, it is placed directly into the stomach by a surgeon.

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Do Artificial Nutrition and Hydration Make People Live Longer?
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What about Pain and Comfort?
If a person has a medical problem that will cause them to die and they don’t want artificial treatment, they can still be comfortable. Making people comfortable during the final part of their life is called palliative care. Even if there is no cure for a condition, doctors can treat pain, nausea and discomfort. Comfort should always be part of the treatment plan that a doctor discusses with a patient or family.

The importance of Advance Care Planning
Everyone is going to die sometime, but not everyone gets to choose how they are treated at the end of their lives. Taking the time to do advance care planning can help family members and medical staff act for you. They will be faced with hard decisions near the time of your death. Having an advance care plan lets you make sure that you are treated according to your values and wishes regardless of whether you can speak for yourself.
My Personal Directions
for Quality Living

Name:
Date:

To My Caregivers (paid and unpaid):

I am recording my personal preferences and information about my self, in case I need long-term care services in my home or in a long-term care facility. I hope this information will be useful to those who assist me. Please always talk to me about my day-to-day life to see what it is that I want and enjoy. However, the information below may provide some help in understanding me and in providing my care.

I want my caregivers to know:

The way I like to awaken & begin my day:

The way I relax and prepare to sleep at night:

Activities I enjoy:

Things that I would like to have in my room:
Foods that I enjoy:

For comfort:

For fun:

Other:

Things I do not like:

I become anxious when:

Things that calm or soothe me:

Things that make me laugh:

Religious preferences:

Other:
At the end of my life, I would like:

For more information about me please talk to:

This form was developed by the National Citizens’ Coalition for Nursing Home Reform to encourage communication between those of us who might need care and those who will be providing the care. Please adapt this tool to express your personal preferences, requests and wishes. Be sure to give a copy to your family members and/or trusted friends and talk with them about what you have written.

National Citizens’ Coalition for Nursing Home Reform
1828 L. Street NW, Suite 801
Washington DC 20036
http://nursinghomeaction.org
My Personal Directions for Quality Living

Name: Alice H. Hedt
Date: June 16, 2005

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I am recording my personal preferences and information about myself, in case I need long-term care services in my home or in a long-term care facility. I hope this information will be useful to those who assist me. Please always talk to me about my day-to-day life to see what it is that I want and enjoy. However, the information below may provide some help in understanding me and in providing my care.

I want my caregivers to know:

I have led an active and busy life, raising three children (born in four years) and working as an advocate for nursing home residents. My family and friends are very important to me. I enjoy traveling and talking with people who have different life experiences and viewpoints. I have been married for over 30 years. I particularly enjoy singing in choirs and spending time outdoors by water or in the mountains.

The way I like to awaken & begin my day:

I enjoy (need 😊) coffee and like to start my day quietly, read the paper, have a quiet devotion time, and then have breakfast while watching the news on TV.

The way I relax and prepare to sleep at night:

I am a terrible sleeper. Don’t worry if I am up several times, reading, puttering and checking e-mails.

Activities I enjoy:


Things that I would like to have in my room:

My favorite reclining chair– it has heat and vibrates, and an afghan. Pictures of where I have traveled. The books I have had with me all of my adult life. I would very much like a window with a bird feeder and flowers. Art posters on the wall – Matisse, O’Keefe
Foods that I enjoy:

For comfort: mashed potatoes and gravy, macaroni and cheese (home-made); egg biscuits

For fun: watermelon, white sheet cake with vanilla icing, caramel ice cream sundaes - the ones from MacDonald’s are cheap and good; caramel corn

Other: I enjoy most ethnic foods, especially Thai, Mexican and Vietnamese; I like to drink different kinds of green tea and Merlot.

Things I do not like:

Crafts. Food that is really spicy. Prejudice. Chin hairs – please pluck mine!

I become anxious when:

I feel pressured to do things that I don’t think I should do.

Things that calm or soothe me:

Talking with close friends; music; massage; talk radio (especially the game shows)

Things that make me laugh:

Children – especially my granddaughter and God children; old movies; funny stories.

Religious preferences:

While I have been a Lutheran my whole life and my husband is a Lutheran minister, I am very open to most spiritual experiences and worship opportunities.

Other:

I like lotions and soaps that smell good, especially lavender. I enjoy all kinds of music and I like projects – coordinating activities, etc. I prefer sleeping on my left side and need a pillow that is comfortable to me because I have some neck pain. I need my glasses.
At the end of my life, I would like:

To have a few family and friends with me. I do not want to be alone when I die. It would be very nice if someone would read hymns, psalms, and poetry to me. Please see my living will and advanced directives. I would like for Pastor Wiggins to provide spiritual support if he is available.

For more information about me please talk to:

My husband Fred; my children – Matt, Melissa and Bethany; my friends, especially Beverly, Sue, Rosemary, Marj, Elma, Sarah, Cilla and Nancy.

This form was developed by the National Citizens’ Coalition for Nursing Home Reform to encourage communication between those of us who might need care and those who will be providing the care. Please adapt this tool to express your personal preferences, requests and wishes. Be sure to give a copy to your family members and/or trusted friends and talk with them about what you have written.

National Citizens’ Coalition for Nursing Home Reform
1828 L. Street NW, Suite 801
Washington DC 20036
http://nursinghomeaction.org  202-332-2275
Agonizing Schiavo Case Shows Need to Put Medical Wishes in Writing

BY BRUCE BOWER, TEXAS LEGAL SERVICES CENTER

Love within families is a complex fabric woven from pride, tenderness and countless other shades of human emotion. It’s a tough love, too, reinforced with unbreakable threads of trust and mutual responsibility. Most of us will do whatever it takes to avoid letting family down.

So imagine the special sadness of failing them, not through betrayal or weakness, but omission.

The Terri Schiavo case in Florida epitomizes all that family caregivers dread. Ms. Schiavo has been in a coma since a 1990 heart attack. Husband Michael says that, well before her heart attack, she told him to refuse offers of artificial life support if she ever became unable to make her own medical decisions. Nothing was ever put in writing, though.

Without taking sides in this wrenching struggle, we can agree this is all about Terri Schiavo and her right to direct her own health care. The trouble is, as she lies in her hospital bed with tubes nourishing a robust body that houses a lifeless cerebral cortex, there’s little hope she can ever make those calls on her own.

The Texas Department on Aging (TDoA) and Legal Hotline for Texans urge all Texans to assure their loved ones never face such a snarl. If you’re 60 or older you can contact a benefits counselor at your local area agency on aging (AAA) for free advice and access to legal documents that spell out all your preferences in advance.

Widely available legal tools such as Out-of-Hospital Do-Not-Resuscitate Orders, the Living Will (known in Texas as the “Directive to Physicians), the Medical Power of Attorney, and the Designation of Guardian Before Need Arises let you specify:

- Whether you want emergency personnel to resuscitate you
- How far doctors should go to save or sustain your life
- Forms of treatment or medication you don’t want to receive
- Who will be your designated legal proxy or guardian if you become incapacitated

Most advanced planning documents can be prepared free of charge. Check with your AAA to learn whether or not they offer this service. Either way, it’s a more than fair exchange for the power you have to assure that someone who shares your personal value system is making medical decisions on your behalf.

Don’t wait until the need arises; incapacitation often is sudden and unexpected. Worried that you’ll change your mind after the papers are completed? Don’t be. You can change the documents at any time.

Before you call your AAA be sure to consult with your physician. He or she can give you the rundown on commonly used resuscitation techniques and life-sustaining treatments. This will help you make a more informed decision.

After you sign the legal documents, give copies to your physician to add to your medical records. Copies should go to the person or persons you’ve named as decision-maker and agent. Keep the originals and at least one copy of each document.
Whom should you designate? That’s your call. Most typical are family members, friends, spouses and attorneys. Just be sure the person knows you well enough to fully understand and be able to attest to your beliefs and preferences. (Important: never assume that familiarity with your wishes guarantees willingness to carry them out.)

To reach your nearest AAA, call 1-800-252-9240 and ask for a benefits counselor. Even if you’re under 60, you can still get advice and check resources from the Legal Hotline for Texans at www.tlsc.org/hotline.html or 1-800-622-2520. Your doctor may be able to help you obtain the documents.

Procrastination can be forgivable, even endearing, in some life situations. But not when it brings pain and unnecessary stress to the people you love. Do right by them and specify in writing all of your life- and health-care preferences.

Do it today.

BRUCE BOWER IS AN ATTORNEY FOR THE TEXAS LEGAL SERVICES CENTER, WHICH OPERATES THE LEGAL HOTLINE FOR TEXANS.

Advance Planning Documents

Advance Directives allow each person to state the kind of medical care you want or don’t want at a future time when you cannot communicate your wishes. When you complete these documents, discuss your wishes with the person(s) named as your agent.

In Texas, the following resources are available:

- DIRECTIVE TO PHYSICIANS AND FAMILY OR SURROGATES FORM
- MEDICAL POWER OF ATTORNEY FORM (formerly Durable Power of Attorney for Health Care)
- OUT-OF-HOSPITAL DO NOT RESUSCITATE INFORMATION & FORM
- PROCEDURE WHEN PERSON HAS NOT EXECUTED OR ISSUED A DIRECTIVE AND IS INCOMPETENT OR INCAPABLE OF COMMUNICATION
  - May include withholding or withdrawing life sustaining treatment.
- CONSENT TO MEDICAL TREATMENT
  - For a person who has not issued a directive and needs medical care.
  - Does not include withholding or withdrawing life sustaining treatment.

Access forms at www.dhs.state.tx.us/providers/ltc-policy/AdvanceDirectives/index.html
All are available in English and Spanish (Out-of-Hospital is English only).

Alternatives to Guardianship Under Texas Law from the Texas Legal Services Center is an excellent resource to learn the purpose of these documents. For a copy, contact your local AAA or go to http://tlsc.org/hotline.html and select the brochure from the list.

OMBUDSMEN: Check Nursing Facility Requirements 19.419 to see the rules that nursing homes must follow regarding Directives and Medical Powers of Attorney.
GUARDIANSHIP

Ensuring rights. When a resident becomes incapacitated and is no longer able to participate in care planning, the nursing home (NH) must involve the person authorized to make decisions on the resident’s behalf. This person may be a guardian, a person designated in an advanced directive or a health care agent under a medical power of attorney. If no one has been appointed to make a resident’s decisions, a surrogate decision-maker can be used in accordance with Health and Safety Code 313 - Consent to Medical Treatment Act.

Under Texas law, if an adult patient in a hospital or residents in a nursing home is comatose, incapacitated or otherwise mentally or physically incapable of communication, an adult surrogate from the following list may consent to medical treatment on behalf of the patient:

- the patient’s spouse
- an adult child of the patient who has the waiver and consent of all other qualified adult children of the patient to act as the sole decision-maker
- a majority of the patient’s reasonably available adult children
- the patient’s parents or
- the individual clearly identified to act for the patient by the patient before the patient became incapacitated, the patient’s nearest living relative, or a member of the clergy

If a resident (who doesn’t have capacity to make his own medical decisions) doesn’t have a surrogate decision-maker, the NH may make a referral via an informational letter to the court that has guardianship jurisdiction in the county where the NH is located. The attending physician, nurse practitioner, director of nurses or his/her assistant, administrator, social worker, advocate, ombudsman or any other interested professional can make this referral.

It is important to note that sending an informational letter to a court is not the same as filing for guardianship. Under Texas Probate Code Section 683, once the matter is referred to the court it is the duty of the court to determine if a guardianship is necessary. Each county uses its own informational letter form. The court may also request that the NH complete a Capacity Assessment for Self Care and Financial Management form for its use.


In the end, it’s not the years in your life that count – it’s the life in your years.

~ Abraham Lincoln
Advance directives

Advance directives are legal documents that allow you to convey your decisions about end-of-life care ahead of time. They provide a way for you to communicate your wishes to family, friends, and health care professionals, and to avoid confusion later on.

- **Consent to Medical Treatment** — This form is for a person who has not issued a directive and needs medical care. Does not include withholding or withdrawing life sustaining treatment. [PDF in English](#) | [PDF in Spanish](#)

- **Declaration for Mental Health Treatment** — This document allows you to make decisions in advance about mental health treatment and specifically three types of mental health treatment: psychoactive medication, convulsive therapy, and emergency mental health treatment. The instructions that you include in this declaration will be followed only if a court believes that you are incapacitated to make treatment decisions. Otherwise, you will be considered able to give or withhold consent for the treatments. [PDF in English](#) | [PDF in Spanish](#)

- **Directive to Physicians and Family or Surrogates Form** — This form is designed to help you communicate your wishes about medical treatment at some time in the future when you are unable to make your wishes known because of illness or injury. [PDF in English](#) | [PDF in Spanish](#)

- **Medical Power of Attorney Form** — Except to the extent you state otherwise, this document gives the person you name as your agent the authority to make any and all health care decisions for you in accordance with your wishes, including your religious and moral beliefs, when you are no longer capable of making them yourself. [PDF in English](#) | [PDF in Spanish](#)

- **Out-of-Hospital Do Not Resuscitate Information & Form** — This form instructs emergency medical personnel and other health care professionals to forgo resuscitation attempts and to permit the patient to have a natural death with peace and dignity. This order does NOT affect the provision of other emergency care including comfort care. [PDF in English](#)

- **Procedure When Person Has Not Executed or Issued a Directive and Is Incompetent or Incapable of Communication** — This form is used if an adult qualified patient has not executed or issued a directive and is incompetent, or otherwise mentally or physically incapable of communication. In that case, the attending physician and the resident's legal guardian or an agent under a medical power of attorney may make a treatment decision that may include a decision to withhold or withdraw life-sustaining treatment from the resident. [PDF in English](#) | [PDF in Spanish](#)
In the early 1900s, most people died at home usually from infectious disease. Today, most die in hospitals or nursing homes (NHs) after a lengthy experience with one or more chronic conditions. In 1999, 51 percent of deaths occurred in hospitals and 22 percent in NHs. For people age 85 or older, 43 percent died in NHs.

Even though more people are dying in NHs, researchers from Brown University found that NHs too often are ill prepared to address the needs of dying residents and their families. Intensive interviews with surviving family members provide an intimate perspective on the experience of dying in a NH. Their stories tell the anguish of needless suffering from inadequate pain management and unnecessary hospital transfers as well as the frustration of the lack of physician involvement and effective, sensitive palliative care. There were moments of pride in helping a dying relative and gratitude toward staff who provided an extra level of care and support.

INTRODUCTION

In 2001, about one in four American adults died in a NH - a proportion that has been increasing in recent years. Despite the growing importance of NHs in caring for the dying, little is known about the experiences or care of terminally ill NH residents.

PURPOSE

To identify policy issues and to make recommendations for educational initiatives and policy change, researchers describe end-of-life care in NHs from the perspective of bereaved family members or others close to the decedents. The report focuses on the:

- Experiences of people dying in NHs, including
  - symptom management
  - decisions regarding care
  - communication with physicians and other care providers

- Experiences of family members, including
  - their communications with care providers
  - expectations and perceptions of NH care
  - their perceptions of the burden of providing care and support to a loved one at the end of life
Perceptions family members have of the professionals providing care, including
- problems with sharing information
- decision-making processes
- sensitivity to the needs and dignity of the patient
- caregiver support

Experiences of decedents receiving hospice services in NHs, including
- respondents' perspectives on electing hospice care for their dying relatives
- coordinating hospice and NH services
- satisfaction with care

METHODOLOGY

Researchers drew primary data from 54 in-depth telephone interviews with relatives and others close to people who had lived in a NH or assisted living facility during the last month of their lives. Interviews conducted from November 2001 - October 2002 (one to two years after the death).

Decedents:
- average age was 83.9 years
- 70.4 percent women
- 77.4 percent were white

Median length of NH stay: Six months to one year

The report focuses on the in-depth qualitative interviews, but information from the matched quantitative interview for each decedent was used to
- clarify trajectories of care, diagnoses, and other factors
- describe the population more fully
- make comparisons with other decedents in the larger sample

Researchers also used review of relevant literature and expert consultations to develop recommendations.

KEY FINDINGS

Experiences of Dying in a NH

1. Professional caregivers insufficiently recognize symptoms, needs, and illness trajectories of dying people with the result that opportunities for palliative intervention and advance care planning are missed.

Illness trajectories of terminally ill residents vary considerably and may be difficult to predict. Some
- are recognized as terminally ill at admission
- may live in a nh for some time before identified as having a terminal prognosis
- transition to terminal phase that is indistinguishable from a long, slow decline in function

Respondents reported inadequate communication with staff, extra caregiving burdens, inappropriate treatments or transfers, incorrect or late decisions, and
unnecessary suffering. Pain is not properly identified and treated, dyspnea (difficulty breathing) is poorly managed, and emotional suffering is not addressed.

Experiences of Family Members

2. Low expectations of NHs and experiences with poor-quality care turn many family members into vigilant advocates for their dying relatives.

Some family members report feeling grateful for excellent end-of-life care for their loved ones, but many do not always trust staff to provide competent, compassionate care. Out of concern for their relatives’ well-being, many family members act as advocates to shield them from harm and ensure basic care. Despite considerable burden, many family members and friends report feeling substantial gratification from providing the care.

Professionals Who Provide Care to Dying Persons

3. Physicians are viewed as “missing in action.”

Respondents noted
- infrequent communication with physicians
- physicians were rarely seen in the NH
- dissatisfaction with level of attention and care provided by physicians

4. Family members report a need for more and better-trained staff.

Staff are often perceived as caring and compassionate but are also seen as overworked and lacking the training and time needed for compassionate care. Although sympathetic to problems faced by staff, respondents worry about their relatives’ safety and well-being.

Institutions That Shape the End-of-Life Experience

5. Regulations that reinforce task-focused rather than person-centered care add to the burden of residents and families.

Respondents reported that staff focused more on following rules (federal/state regulations as well as facility rules) than on the needs and preferences of individual residents. They attribute some problems to state and federal mandates and management constraints that discourage individualized and palliative care for dying people. Some reported unwanted transfers from one facility to another driven by facility policies and staff limitations rather than preferences or needs of the residents or their caregivers.

Hospice Care in NHs

6. Hospice services in NHs often enhance the end-of-life care of dying residents, but respondents report that referral is frequently made late in the illness or not at all, thereby preventing residents from receiving the full benefit of such services. Respondents sometimes report conflicts between hospice and facility staff.
Respondents reported that hospice services often help NHs provide better quality care to dying people. However, misunderstandings and conflicts about hospice care role, scope, and regulations were common among staff. Some respondents reported
- disappointment with the services delivered
- disagreements between hospice and NH staff over care responsibilities
- their family member would have been required to leave because hospice was not offered at their NH

TRAINING AND POLICY CONSIDERATIONS AND RECOMMENDATIONS

The experiences shared by family members suggest the need for improved end-of-life care. To achieve this goal, a sustained effort will be required on many fronts, including better education of health professionals, enhanced training of nursing home staff, policy changes, better public information about end-of-life care, and adequate financial support for training and staffing. Suggested recommendations follow:

Educate Health Professionals

1. Improve career education and continuing training of health professionals in the following areas:
   - care of dying patients, including managing physical symptoms (e.g., pain) and emotional distress
   - knowledge of illness trajectories and physical function to make more accurate prognoses
   - communication with dying patients and their families about individual preferences and expectations, and improved advance care planning consistent with these preferences

2. Advocate for federal funding to support career education and continuing training of health professionals in end-of-life care.

Train Physicians in End-of-Life Care

3. Use incentives under general medical education (GME) funding to improve physician training in end-of-life care. Such training might include:
   - internal medicine, family practice, pediatric, and obstetrics and gynecology residents follow a panel of patients, including terminally ill people, throughout residency
   - physician residents follow individual patients as they leave the hospital to enter a NH
   - GME funding to support training in palliative care and geriatric fellowships

Train NH Staff and Administrators

4. Provide education and mid-career training, e.g., End-of-Life Nursing Education Consortium Project, and develop career tracks in palliative care for nursing assistants to improve the following:
   - management of symptoms associated with dying
• communication with residents and family to clarify preferences and describe the dying process
• identification of decision points in the dying process
• focus on resident-centered care

5. Train and educate NH administrators to:
• improve understanding of quality assurance in end-of-life care
• clarify regulations and guidelines for Medicare/Medicaid hospice benefits
• enhance strategies for responding appropriately to family advocates
• encourage best practices in staff training, oversight, and retention, e.g., career-track incentives
• ensure that NH Administrator certification includes adequate content on end-of-life-care

Inform the Public about End-of-Life Care

6. Develop a public information campaign targeted to residents experiencing a terminal illness and their families. Educational materials and information provided would include:
• how to be an effective advocate for dying NH residents
• what end-of-life care in NHs entails
• what to expect when people in NHs die
• why one should consider the availability of hospice care when selecting a NH
• how hospices provide care and what Medicare/Medicaid hospice benefits include
• strategies to communicate effectively with physicians and other health care professionals
• educational resources to learn more about end of life care

Develop New Knowledge and Improved Practices

7. Develop and support centers of excellence for end-of-life care.
• use private/public partnerships to develop research and educational centers focused on improving symptom management and developing innovative models for caring for dying people
• advocate for federal funding to support such centers

Policy Issues

8. Create incentives (address disincentives) for physicians to regularly visit and care for dying patients in NHs

9. Increase reimbursements to NHs to enhance staffing and resources
• improve quality of care
• avoid unnecessary hospitalizations

10. Examine quality of end-of-life care to:
• improve strategies and methods to monitor quality
• understand unintended consequences of quality assurance strategies and measures
• encourage quality improvement organizations to conduct projects related to end-of-life care
• train surveyors to address quality of symptom control and end-of-life care
• resolve potential conflicts between goals of rehabilitation and maintaining function and goals of palliative care at the end of life

11. Study viability of using Medicare’s skilled-care benefit to address the end-of-life palliative care needs

12. Provide incentives (remove fiscal disincentives) for NHs to contract with Medicare-certified hospices and hold them accountable for achieving high-quality end-of-life care outcomes regardless of whether they contract with or fully use hospice or palliative care services

13. Identify and disseminate best practices, policies, and procedures to enhance collaboration between NHs and hospice providers

14. Include the right to hospice care in the Patients’ Bill of Rights

15. Add content on pain management, fluids and hydration, and other aspects of end-of-life care to the Centers for Medicare and Medicaid Services State On-Line Survey Manual

CONCLUSION

As increasing numbers of Americans spend their final hours in NHs, much more must be done to
• ensure appropriate and compassionate care
• improve the caregiving workforce
• reform policies and regulations that guide care in institutional settings

To improve end-of-life care in NHs, there needs to be a sustained effort on many fronts, including increased funding for adequate staffing and training.
Alternatives to Guardianship Under Texas Law
Legal Hotline for Texans