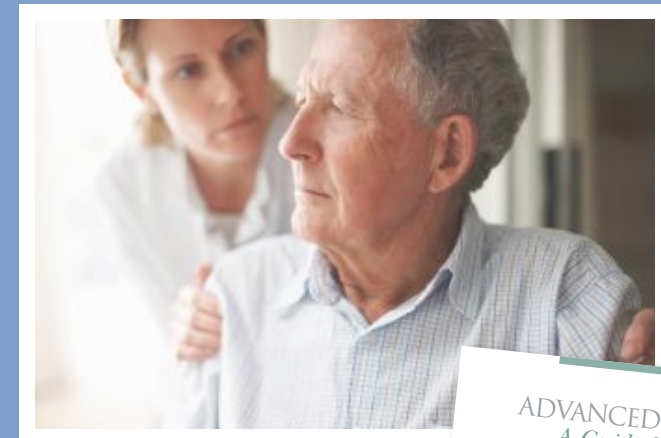


How to Talk to Families About Advanced Dementia

A Guide for Health Care Professionals

Companion to **ADVANCED DEMENTIA**, *A Guide for Families*



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a generous gift from an anonymous donor.*

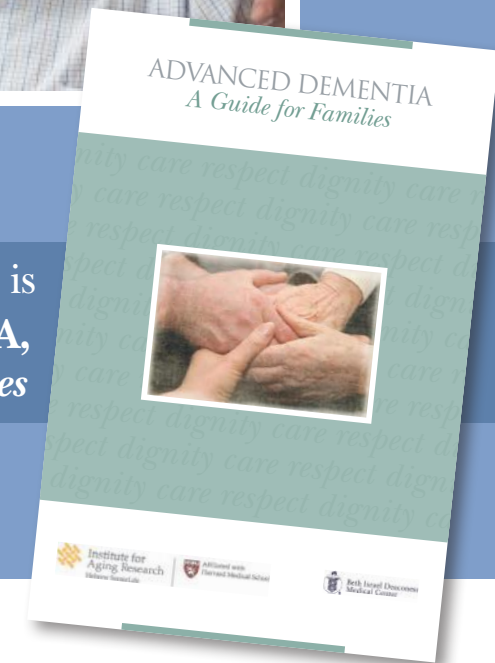
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Anne Mahler, MS, RN

Clinical Nurse Specialist, Palliative Care, Hebrew SeniorLife

Also included is
ADVANCED DEMENTIA,
A Guide for Families



The Power to Redefine Aging.



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COMPANION TO

ADVANCED DEMENTIA *A Guide for Families*

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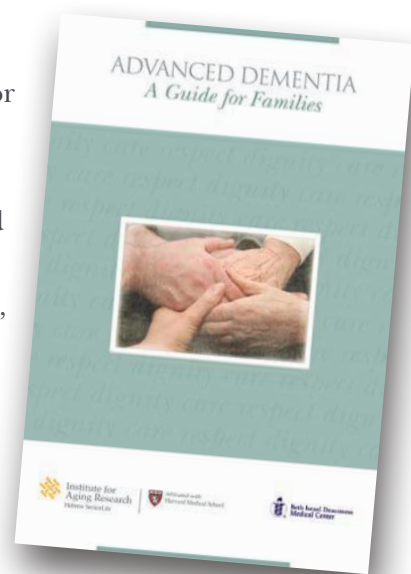
Institute for Aging Research, Hebrew SeniorLife is an affiliate of Harvard Medical School.

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The purpose of this guide

This training guide, a companion training piece to the booklet “Advanced Dementia: A Guide for Families,” is a user guide designed for health care providers who support families making treatment decisions for patients with advanced dementia. The booklet was created by an interdisciplinary team of Boston-based geriatric and palliative care physicians, nurses, and researchers from Hebrew SeniorLife (HSL) and Beth Israel Deaconess Medical Center in 2011.

In 2012, HSL promoted a culture shift to more goal-directed care for residents with advanced dementia. The palliative care team promoted in-depth conversations, offering the booklet to family members serving as health care proxies for residents in its post acute and long term care units. The *How to Talk to Families About Advanced Dementia* guide was developed in order to train primary care providers, nurses, and nursing assistants to engage families in understanding the physical decline that comes with late stage dementia, and to help family members prepare for treatment decisions that lie ahead. The teaching guide will be used to create a 30-minute workshop for staff in order to provide skill building techniques and a greater level of comfort when talking to families.



Professional educators, nursing leaders and mentors in medicine, social work and other fields of practice can offer this training to interdisciplinary staff in health care settings serving patients with advanced dementia.

Topics of Discussion

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ADVANCED DEMENTIA: A Guide for Families is located at the end of the Professional Training Guide in its entirety

How to Use this Professional Guide

Each section of this training manual contains (a) information to aid health care providers in guiding family conversations and (b) examples of specific language that providers can use (shaded blue conversation box).

The left side begins with medical information and advice for decision-making challenges that arise from treatment of advanced dementia.

The right side (in shaded blue box) offers language that can be used when talking to families about goals of care and treatment choices.

The guide gives a brief review of the course of advanced dementia along with the most up-to-date treatment options.



The goal of this guide is to teach staff how to create an environment which will:

- Prepare families to be health care proxies in the role as decision-maker.
- Help families identify goals of medical care in accordance with patients' previously stated wishes.
- Plan proactively around options for care before a crisis in health status arises.

Tips for providing training workshops for staff:

- A family guide **SHOULD NOT** be handed casually to a family member, but is best accompanied by a thoughtful conversation with a health care provider.
- A hand-out for staff that includes all of the 'language' sections of the training booklet is extremely valuable.

- Staff is encouraged to practice the language or discuss specific cases within their care. This promotes lively discussion and helps maintain attention and interest.
- When advanced dementia is defined early in the training, it is helpful to use an example of a patient on the particular unit who met the criteria for advanced dementia
- One concept that proves particularly helpful is that families should be encouraged to “take the helicopter up” to consider the over-arching goal of care, rather than focusing on highly specific treatment options. This approach encourages the family to articulate the main goal, which then guides the treatment decisions as the disease progresses.

Explaining the Purpose of the Conversation

Language for Family Conversations:

“The purpose is to help us provide the best medical care for your father. We want to make sure you have the guidance you need to make the best decisions on his behalf. Our goal is to understand his preferences for his health care or your best judgment about what that would be now.”

Defining Dementia

- Broad term for diseases of the brain that cause memory problems and affect thinking and behavior
- Most common types: Alzheimer's, vascular, Parkinson's and Lewy body

What is Advanced Dementia?

Advanced dementia (AD) is the final stage of dementia.

- Dementia gets worse over time.
- Usually reaches final stage 3-6 years after being diagnosed.
- Typical features of advanced dementia include:
 - profound memory deficits such as inability to recognize family members.
 - speech limited to less than 5 words.
 - total functional dependence, incontinence of stool and urine
 - inability to ambulate independently.
- **Most common medical complications:** eating problems and infections – nearly 90% of patients with advanced dementia will develop eating problems. When eating problems begin, it often means that the end of life is near. Almost one half of people with AD experience fever and infections.



Dementia is a **terminal illness**. This means that people with AD commonly die from complications caused by the disease. It may help to imagine a person with widespread advanced cancer. If a person with cancer has pneumonia in their last few weeks of living, the cause of death is still the cancer. In the same way, the bodily functions and defenses of the person with AD are weakened. While they may develop pneumonia, the underlying illness leading to complications and death is advanced dementia.

Language for Family Conversations:

“As you know, your mom has had dementia for a long time and is now in the final stages of this condition. Over time, dementia affects not just the brain, but the whole body. So in addition to serious memory problems, mom is now unable to move around without help and she depends on others for care.”

“Some problems are very common in advanced dementia. For example, most residents with advanced dementia have eating problems and experience infections.”

“Patients with advanced dementia commonly die from this disease. In other words, just like widespread cancer, dementia is a terminal illness.”

Determining the Primary Goal of Care

What is the resident's main goal for their medical care? In lieu of the resident being able to make their own decision, the responsibility of the health care proxy is to try to decide what the resident would want for himself

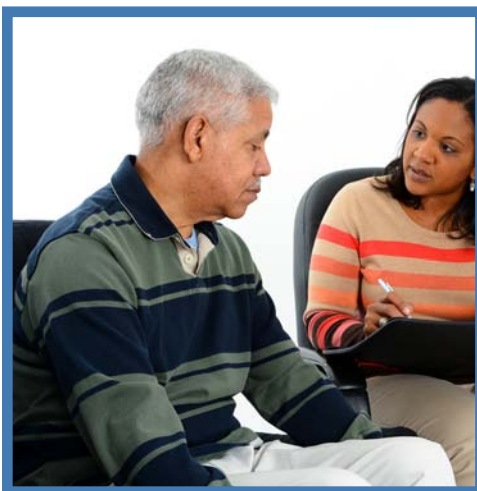
Choices: comfort, living longer, or something in between

• Comfort as goal

The focus is on keeping the resident as comfortable as possible, even if that means not providing medical treatments that could possibly help him live longer. If opting for comfort, the person usually does not want a feeding tube or a breathing machine. They would not want to be revived or hospitalized. Focus of comfort care includes treatments that aim to maximize the physical, emotional, and spiritual well-being of the resident. It does NOT mean that attentive care for the patient is halted.

• Living longer as goal

In this case, the most important goal is to extend life as long as possible, even if treatments cause discomfort. These patients would usually want to be hospitalized for aggressive treatment of a sudden illness. They often chose to be fed through a tube and if needed, would want CPR performed



• Something in between as goal

The person would want certain types of care, including some that may cause discomfort, if it would help them get back to their previous level of functioning. Antibiotics would be used to treat infections with the goal of bringing the person back to baseline.

Language for Family Conversations:

“Decision-making can be clearer if we have an understanding of what your mother would want as her main goal of medical care. You can focus on comfort or living longer as the main goal. Sometimes residents wish to focus on a goal that is somewhere in between.”

“If comfort is the main goal of care, the most important thing is attending to her physical and emotional symptoms and to keep her as comfortable as possible, even if that means not providing all possible medical treatments that could help her to live longer. If the main goal is to live longer, treatments will be offered to extend life as long as possible, even if that requires procedures that may also cause discomfort.”

“Something in between means that your mother would want certain types of care, including those that may cause some discomfort, if it might help her to get back to a previous level of functioning.”

“At this time, do you have a sense of what your mother would want as her primary goal of care?”

Approach to Eating Problems

The topic introduces the idea that feeding problems are expected in advanced dementia

- Close to 90% of residents with AD have eating problems. When eating problems start, it often means the end of life is getting closer. If the family member knows ahead of time that this could happen, it is possible to plan ahead so things go more smoothly when the problem arises. Causes of eating problems: brain's control of muscles and nerves involved in chewing and swallowing is lost; unable to feed themselves; may forget to swallow.
- Difficulty chewing and swallowing leads to one of the most common complications in AD— aspiration.
- Steps in working with eating problems: The first step requires a basic medical assessment (rule out a dental problem, a new infection, or a stroke). The resident's goal of care should guide whether an aggressive diagnostic assessment is necessary. Other simple steps with feeding include offering favorite foods, reducing portion size and changing food textures.

Treatment options

• Continued feeding by mouth

- **advantages:** this is the way most people eat; staff or family help the resident to eat and there is social engagement during feeding; the resident is the guide as to how much she eats; continues with treatments to maximize comfort; the resident can still taste food.

- **disadvantages:** a large amount of time is required to carefully hand-feed the resident, and food and fluid intake will vary over time.

• Tube-feeding

- **advantages:** when food is placed directly into stomach via tube, the resident is definitely receiving food in consistent amounts.

- **disadvantages:** best evidence tells us that **tube feeding has NOT shown**

to help people with advanced dementia live longer or improve their quality of life; it has not been shown to prevent or reduce aspiration or to increase comfort; tube fed patients with AD often continue to lose weight; there may be diarrhea; some residents may need to be restrained or receive sedating medications so as not to pull out the feeding tube; the resident misses out on the enjoyment that comes with tasting food and from the social interaction during mealtimes.

Is the resident going to starve to death? No. It's important to remember that eating less is expected as end of life approaches with advanced dementia. It is a natural part of the disease process. When they stop eating and die, it is their dementia that is causing the body to slowly shut down.

Language for Family Conversations:

“Eating problems are expected in the end-stage of dementia. When eating problems start, it often means that the end of life is getting closer. This is a natural part of the process of any terminal illness, including advanced dementia.”

“ We do not know exactly how your mother feels. However, the best evidence suggests that even when she is eating and drinking very little, she does not appear to sense hunger or thirst.”

“When eating problems start, we recommend that someone helps your mother to eat, which usually means feeding her by hand. She should be the guide as to how much or how little he or she wants to eat, based on your mother's comfort. At this stage, the total amount of calories is less of a concern.”

Approach to Decisions about Hospitalizations

Importance of thinking about hospitalizations

People with advanced dementia can and do get acutely ill. Infections are most common, but patients can also have other medical conditions such as GI bleeding, a stroke or a heart attack. When these illnesses occur, families are faced with a decision about whether to hospitalize the patient or not.

- **Advantages:** access to treatments such as surgery and ICU interventions such as ventilators.
- **Disadvantages:** Going to the hospital can be traumatic and frightening to a person with advanced dementia. A patient may not understand what is happening and the actual transfer can be uncomfortable as well. There are likely to be treatments or tests that are burdensome or painful. Being cared for by unknown people can make the patient upset and agitated. Hospital providers cannot offer the day-to-day care in the same way that the resident is accustomed to receiving. In addition, the resident is at risk of infection, bed sores and delirium.

How to decide

Consider the primary goal. If it's comfort, hospitalization is almost never the right choice for the resident with advanced dementia. The vast majority of medical problems that a person might experience can be treated more comfortably in the nursing home (an exception may be a hip fracture).

If primary goal is living longer, then hospitalization is the right choice if the treatment needed can only be found at the hospital. However, the chance of survival from an illness such as pneumonia is the same whether treated in the nursing home or in the hospital.

Planning ahead is vital to ensure that the staff knows the family's wishes. If the family's goal is comfort and they do not want their loved one going out to an acute care hospital then a "do not hospitalize" order must be put in place so that family and staff are all on the same page.

Language for Family Conversations:

"Like all older patients, even those with advanced dementia, your mother can get acutely sick. When these illnesses occur, a decision will need to be made about whether or not to hospitalize her."

"In general, hospitalization can be a traumatic and frightening experience for patients with advanced dementia. This may be the case with your mom. The transfer to the hospital can be difficult and acute care often involves treatments that are uncomfortable. The hospital is also a very busy place, and being cared for by unfamiliar nurses and physicians can be scary to her."

"It is important to consider whether hospitalization can meet the main goal of your mother. Most illnesses can be treated more comfortably in the nursing home, where the staff would know your mother better than a strange new staff."

Approach to Treatment Decisions about Infections

Infections are common with advancing dementia. Most patients with AD get infections, and this is often a sign that the end of life is near. Pneumonia and UTIs are most common.

In advanced dementia the body's defenses that fight off bacteria are weakened. The patient may also have problems with swallowing, which can cause food or saliva to be aspirated, potentially causing a pneumonia.

Pneumonia occurs in about 40% of patients with advanced dementia who are near the end of life. People with advanced dementia who are treated with antibiotics may live a few months longer than those untreated, but may also suffer more discomfort. Research also finds that people treated with antibiotics in nursing homes do just as well as those treated in hospitals.

Treatment options :

Symptom management: the treatment focuses on the relief of discomfort but does not try to stop the infection itself. Antibiotics, hospitalizations and tests are avoided. Most of the uncomfortable symptoms can be relieved with simple measures such as Tylenol, oxygen to reduce shortness of breath, and pain medication.

Antibiotics: They may be given by mouth, injected into the muscle or into the vein. The main advantage is that the resident's infection may get better. The disadvantage is that they may cause discomfort or side effects such as severe diarrhea. Some tests to monitor antibiotics may be uncomfortable.

Aligning treatment choices with goals of care: If comfort is the primary goal, then symptom management without antibiotics is preferable. If living longer remains the primary goal, then antibiotics are recommended. Hospitalizations may still be avoided.

Language for Family Conversations:

“Two of the most common infections that your mother can experience are pneumonias and urinary tract infections. This is often a sign that the end of life is near.”

“One of the main decisions to be made in terms of treating infections is whether or not to start antibiotics. It is important to make sure that your treatment choice for your mom aligns with your choice in the goal of care. Generally, if that goal is comfort, it may not be necessary to use antibiotics for her.”

“It is important to realize that antibiotics are often prescribed for suspected infections in the urine without a clear diagnosis. This is not appropriate. It is best to use antibiotics only when an infection is definite, because giving antibiotics has side effects that can be harmful to your mother.”

When to Refer to Palliative Care or Hospice

- **Hospice:** provides care to patients who have a terminal illness and who are no longer receiving curative treatments.

All care is focused on achieving the best patient comfort, providing strong family support, and helping the patient to live as well as possible for the remainder of his life.

- **Palliative Care:** provides care to patient at any time during a person's illness, not just in the final stages, even if the patient is continuing to receive aggressive, curative treatments.

The focus is on symptom management and on helping the family to clarify the goals of care.

It is important to note that **patients with advanced dementia can receive hospice OR palliative care.**



Language for Family Conversations:

“Hospice and palliative care both involve a team-oriented approach to care for patients, such as your mother, with serious illness. Both focus on symptom control, communication, support for you and your family, and quality of life.”

Palliative care is a medical specialty that provides information, emotional and spiritual support as you and your family work to clarify the goals of treatment. Specialists can help you understand the prognosis and treatment options. The team can then help you make choices about the goal of care if you are undecided or if there are disagreements about this in the family.”

“Hospice provides care to patients who have a terminal illness such as your mother who we know is suffering with advanced dementia. This would be when your mom is no longer receiving curative treatments. For example, when a decision is made to no longer hospitalize mom when an infection or other illness arises, hospice can provide the medical care needed to her comfortable at home or in the nursing home.”

ADVANCED DEMENTIA

A Guide for Families



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The purpose of this guide

is to provide information to the family members and individuals responsible for

making health care decisions for patients with advanced dementia. The guide is organized into 10 sections. The topics and contents for these sections were developed by health care professionals, including geriatricians, nurses, palliative care specialists, and medical researchers, based on their clinical experience and the latest research in the field of advanced dementia. Family members of patients with advanced dementia have also contributed to the guide in order to reflect their viewpoints and concerns.

The guide covers issues that most commonly confront decision-makers caring for patients with advanced dementia. The guide is meant to serve as a resource to provide support when sensitive and challenging decisions must be made. The information is intended to complement and encourage, but not replace, counseling by the patients' direct health-care providers. A section has been provided at the end of the guide for notes and questions that a health-care provider and support team can answer.

Finally, every patient is different. The information in this booklet provides general guidelines to complex decisions, which must be adapted to each individual situation. On behalf of the authors, we hope you find this guide to be a useful tool.

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Section 1

What is Advanced Dementia?

What is “dementia”?

Dementia is a broad term for diseases of the brain that cause memory problems and affect other aspects of thinking and behavior. The most common type of dementia is Alzheimer’s disease. Other causes of dementia include: vascular disease (recurrent strokes), Parkinson’s disease, and Lewy body disease.

What is “advanced dementia”?

Although there are different causes for dementia, all types of dementia get worse over time. Advanced dementia refers to the final stage of the disease. The final stage comes at different times for everyone. On average, patients reach the advanced stage of dementia anywhere from 3-6 years after they are first diagnosed. The length of time people live with the advanced stage is also different for everyone and can range from months to years.

What are typical features of a patient with advanced dementia?

Over time, dementia affects not just the brain but the entire body. Although everyone is different, patients with advanced dementia often have such serious memory problems that they may not even recognize close family members. At the most advanced stages, patients with dementia are unable to move around on their own, and depend on others for all their care needs. They usually cannot speak more than about 5 words.

What are the most common medical complications that occur in someone with advanced dementia?

Eating problems and infections are the most common complications in advanced dementia. Close to 90% of patients with advanced dementia will develop problems eating. When problems with eating begin, it often means that the end of life is near (*see Section 4*). Almost half of patients with advanced dementia experience infections or fevers. The most common type of infection is pneumonia (*see Section 5*).

Is advanced dementia a terminal illness?

Yes, dementia is a terminal illness. This means that patients with advanced dementia commonly die from complications caused by this disease. Some people have a hard time understanding that dementia is a terminal illness. It may help to imagine a patient who died with widespread cancer. If this patient had pneumonia or eating problems in the last few weeks of life from the weakened state caused by the cancer, most people would still consider cancer the underlying cause of death. In the same way, the bodily functions and defenses of patients with end-stage dementia are weakened. As a result, they often get pneumonia or eating problems near the end-of-life, but advanced dementia is still the underlying major illness leading to these complications and death.



Section 2

Determining the Primary Goal of Care

What is meant by the term “goal of care”?

We use this term to describe what the patient wants as the main goal of their medical care in a given situation.

What are the choices?

Generally, patients either focus on *comfort* or *living longer* as the main goal of care. Sometimes patients wish to focus on a goal that is somewhere *in between* these two choices.

What does it mean when “comfort” is the goal of care?

When comfort is the main or primary goal of care, it means that the focus is on keeping the patient as comfortable as possible, even if that means not providing medical treatments that could help him or her live longer. People who choose comfort as a goal of care do not wish to be fed through a tube or placed on a breathing machine. They don't want medical staff to try to revive them if their heart stops beating or they stop breathing. *Comfort care* means they do not want to be resuscitated. Most people would also not want to be hospitalized unless the hospital is the only place that can provide the care needed to make them comfortable.

Comfort-focused care includes many types of treatments that aim to maximize the physical, emotional, and spiritual well-being of the patient (*see Section 8*). Comfort-focused care does **not** mean medical treatment is stopped.

What does it mean when “living longer” is the main goal of care?

This means the most important goal of the patient's care is to extend life as long as possible, even if that requires treatments that may also cause discomfort. Usually people who choose *living longer* as the goal would want to be hospitalized for aggressive treatment of a sudden illness (such as a severe infection.) They would choose to be fed through a tube if they had serious eating problems. They would want medical providers to try to revive them if their heart stopped beating or be placed on a breathing machine if they stopped breathing. *Living longer care* means they would want to be resuscitated. Patients who choose living longer as a goal still receive treatment to reduce their suffering.

What does it mean if the goal of care is in between “comfort” and “living longer”?

This means that the patient wants certain types of care, including those that may cause some discomfort, if it might help him or her get back to a previous level of functioning. An example may include giving intravenous antibiotics to treat pneumonia in someone with advanced dementia. The antibiotics will not treat the dementia, but they might allow the person to get back to where they were before the pneumonia started.

Who decides the primary goal of care?

If possible, the patient decides the primary goal of care. But patients with advanced dementia are unable to make medical decisions.





the closest family member or to an appointed guardian.

Therefore, their health care proxy – the person they chose to make medical decisions for them – decides on the goal of care. If there is no designated proxy, this responsibility often falls to

How does the health care proxy decide the goal of care?

The job of the health care proxy is to try to decide what the patient would want for him/herself. The first step in this process is to consider any written or oral *advance directives* the patient communicated when he or she was mentally competent and able to do so. An advance directive refers to any instructions about health care that a person might have prepared. A living will is one type, but in some cases, a person may have described their wishes in conversation. Advance directives should always be respected.

If there are no clear advance directives, the health care proxy should use *his/her best judgment* about what the patient would want based on what is known about the patient's philosophy and beliefs. If the proxy feels he or she cannot judge what the patient would want, the proxy should then choose what he or she believes to be in the patient's *best interests*. Best interests usually means choosing what most people would want in the patient's situation.

Section 3 Basic Approach to Decision-Making

Who makes medical decisions for a patient with advanced dementia?

The designated health care proxy makes medical decisions for the patient with advanced dementia. If there is no designated proxy, this responsibility often falls to the closest family member or to an appointed guardian. However, to make an informed decision, the proxy needs information from the professionals caring for the patient and to communicate effectively with the patient's care team.

Here are some basic steps that can help someone who is trying to make a decision for a patient with advanced dementia. To illustrate the steps, we present the case of Mrs. S. – a 90-year-old patient who lives in a nursing home and who has advanced dementia. Mrs. S. has been hospitalized with a skin infection from a leg ulcer. Her daughter is her designated health care proxy.

Step 1: Clarify the clinical situation:

The proxy needs to have a clear understanding of the patient's medical conditions – both those that have been going on for a long while (chronic conditions) and those that may have just come on (acute conditions). The proxy needs information on how these conditions are likely to affect the patient. In our example:

Mrs. S's major **chronic medical condition** is advanced dementia. In the nursing home, she cannot care for herself or speak meaningfully with others. She no longer recognizes her daughter. Her dementia will not get better even if the infection is treated. Her leg ulcer is due to poor blood circulation. She has had it for 12 months. Her **acute medical condition** is a skin infection around her leg ulcer, which is causing redness, swelling, and some pain. This is the third

time in 3 months she has been treated with antibiotics for a skin infection related to the ulcer. Each time, the redness only gets a little better and then worsens again.

Step 2: Determine the primary goal of care:

The proxy should decide whether comfort, living longer, or something in between (middle of the road) is the main goal of care.

Before she became ill with advanced dementia, Mrs. S did not talk much about her feelings. She had a very independent personality. She once mentioned that if she was very sick and could not think or care for herself, she would not want “heroic” measures to keep her alive. Her daughter is quite certain that her mother would choose comfort as the main goal for her health care.

Step 3: What are the treatment options – risks and benefits of each option?

The proxy must understand what the treatment choices are and the risks and benefits of each option. Although it is usually not possible to say exactly what will happen with each choice, the proxy should be informed of best available evidence regarding the treatment options. As many proxies do not have formal medical training or prior experience with these choices, the patients’ health care providers should help the proxy understand this information.

The doctors say there are 3 options for Mrs. S. No matter which option is chosen, Mrs. S. will receive treatment for pain.



Treatment Options

1. *Comfort-focused care approach:* The first treatment option is to focus on comfort. This means Mrs. S. would return to the nursing home where she would receive all treatments needed to keep her comfortable, such as pain medications or oxygen. She would continue to be cared for in the nursing home and not return to the hospital if her condition worsened.
2. *Living longer approach:* The second option is to use all available treatments to try to keep Mrs. S. alive as long as possible. This includes looking at the underlying problem of the leg ulcer. The doctors feel that blockages in the arteries are causing the ulcer. Because the ulcer is likely to continue to cause problems, they would recommend an amputation of the leg above the knee to prolong Mrs. S.’s life as long as possible.
3. *Middle-of-the-road approach:* The third option would be to try another course of intravenous antibiotics for several weeks. This would involve putting a special catheter (small tube) in a vein in Mrs. S.’s arm (PICC line) to deliver the drugs, but Mrs. S. could return to the nursing home once the catheter is in place.

Summary of treatment options, with risks and benefits

OPTION	RISKS/CONS	BENEFITS/PROS
Comfort-focused care	May die sooner Ulcer still present	Will be comfortable Can go back to nursing home
Living longer (amputation)	Risks of surgery Pain following surgery Prolonged recovery in hospital or rehabilitation unit	May prolong life Treats underlying problem (ulcer)
Middle-of-the-road	Risks of prolonged antibiotics (such as diarrhea) Need to keep intravenous line in place Ulcer probably will not heal despite treatment of the infection	Can go back to nursing home

Step 4: Which treatment option is closest to the primary goal of care?

After reviewing the treatment options and risks and benefits of each option, the health care proxy decides which approach is closest to the patient’s goal of care.

Mrs. S.’s daughter feels confident that her mother would want her treatment directed toward comfort. Therefore, she thinks she will choose the comfort-focused care approach.

Step 5: Seek input from others, if necessary.

These decisions are difficult. Although the proxy has the right to make the final choice, he or she may find it helpful to get input from others: another friend or family member who knows the patient well, a health care professional, clergy member, social worker, etc. Other sources of valuable information may include printed materials or online resources (see Section 10: Resources).

Mrs. S.’s daughter is quite sure she will choose the comfort care approach. However, before making a final decision, she wants to have a better understanding of what comfort care involves and how it will be provided in the nursing home. To get this information, a meeting is arranged with the hospital’s Palliative Care Service. The Palliative Care team explains the type of care Mrs. S. will receive and arrangements are made for specialized services, including pain management and hospice care at the nursing home.

Section 4

Approach to Eating Problems

Step 6: Reassess as the clinical situation evolves.

Sometimes a decision is made to take a particular approach, but as time goes by and new information is available or the patient's status changes, the proxy may want to start from step 1 again to see if the decision would be the same.

In our example, suppose Mrs. S.'s daughter had chosen another course of intravenous antibiotics (middle-of-the-road-approach) for her mother but the antibiotics did not help. Mrs. S.'s daughter may want to go back to the beginning and reconsider which option is now best. She may want to change her mind and choose either comfort care or surgery (the "living longer" approach). Health care proxies should understand that it's always okay to go back and reconsider a decision, especially if time goes by, the situation changes, and/or new information is available.



Are eating problems in advanced dementia common?

Yes. Close to 90% of patients with advanced dementia have eating problems. When eating problems start, it often means that the end-of-life is getting closer.

Decisions related to eating problems are the most common decisions faced by family members of patients with advanced dementia. Knowing that eating problems are likely in the future makes it possible to plan ahead, which can help make things go more smoothly when eating problems do occur.

What causes eating problems in patients with advanced dementia?

There are several causes. In order to chew and swallow, many muscles and nerves must work together in an effective way. In someone with advanced dementia, the brain signals that control this complex activity are affected by the disease and no longer work as they should.

Aspiration is one of the most common eating problems in advanced dementia. Aspiration occurs when food goes "down the wrong way" and into the lungs instead of the stomach. Aspiration can be uncomfortable for the patient and causes pneumonia to develop in the lungs.

Patients with advanced dementia also sometimes have chewing problems that cause them to hold food in their mouth or spit it out. Finally, many of these patients are simply not able to perform the physical task of feeding themselves.

What are the first steps in dealing with eating problems in someone with advanced dementia?

When eating problems first occur, a basic medical evaluation should be done to see if there is something new that is causing the problem. Sometimes sudden eating problems can be caused by a new infection, a stroke, constipation, dental issues, or medication side effects. The patient's goal of care should guide the degree to which any new medical problems are evaluated and treated (see Sections 2 and 3).

Simple steps that can help increase food intake include: offering favorite foods, reducing portion sizing, and changing food textures (for example, ground foods). Consulting with a nutritionist, speech/swallowing therapist, or occupational therapist might also be helpful. Often, patients with advanced dementia need help from another person with feeding at each meal.

What if these initial approaches don't help?

The health care proxy should discuss the eating problem with the patient's care providers. The basic approach to decision-making outlined in Section 3 should be followed. The key steps are to establish the goal of care, understand the treatment options, and decide which option fits in with the primary goal.

What are the treatment options for eating problems in advanced dementia?

There are 2 options:

1. Continued feeding by mouth, or
2. Placement of a feeding tube



What is continued feeding by mouth?

Feeding by mouth is the way most of us eat. In the case of a patient with advanced dementia, someone helps the patient to eat, which usually means feeding the patient by hand. The patient should be the guide as to how much or little he or she wants to eat, based on comfort. At this stage, the total amount of calories eaten is less of a concern. Signs that the patient is comfortable and wants to eat generally include: opening the mouth readily for the next bite and chewing and swallowing the food steadily. Signs that the patient is not comfortable or does not want to eat include not opening the mouth, coughing, holding food in the mouth, or spitting food out.

The patient gets treatments to maximize comfort (for example, pain medications) and may continue treatments for other medical conditions. **Advantages** of continued feeding by mouth include the ability of the patient to still taste food, the focus on comfort, and the social engagement with the people feeding the patient. Potential **disadvantages** include the time required to carefully hand-feed the patient and the fact that the food and fluid intake will vary over time.

What is tube-feeding?

When a patient is tube-fed, liquid food is placed directly into the stomach through a tube. The most common way this is done in advanced dementia is by using a PEG tube. PEG stands for “percutaneous endoscopic gastrostomy,” which refers to the procedure used to place the tube. A PEG tube is placed through the skin of the belly and into the stomach as part of a short hospital procedure. Liquid food is then delivered through the PEG tube each day. The main **advantage** of tube-feeding is that the patient is definitely receiving food in consistent amounts. However, there are several **disadvantages**. According to the best available evidence, tube-feeding has not been shown to help people with advanced dementia live longer or to improve their quality of life. It has not been shown to prevent or reduce aspiration (food going down the wrong way) or increase comfort. Tube-fed patients with advanced dementia often continue to lose weight due to the advanced stage of their disease. Other disadvantages include the risks that go with the PEG tube insertion (such as infection), diarrhea from the liquid food, the possible need for restraints or sedating medications so the patient doesn’t pull out the tube, and frequent hospital transfers for treatment when the tube gets blocked or comes out of place. Finally, tube-fed patients miss out on the enjoyment that comes with tasting food and the social interaction with caregivers during mealtimes.

Do patients with advanced dementia feel hunger or thirst if they are not tube-fed?

We do not know exactly what patients with advanced dementia feel. However, the best evidence suggests that even when they are eating and drinking very little, patients with advanced dementia do not sense hunger or thirst.

Is the patient going to ‘starve to death’ without tube-feeding?

No. It is very important to remember that eating less is expected as the end-of-life approaches in *any* terminal illness, including advanced dementia. This is a natural part of the disease process. When patients with advanced dementia stop eating and then die, it is their dementia that is causing the weakening of their body and their death, **not** the lack of food.

How do I make sure that the plan for feeding is in line with the goals of care?

If comfort is the main goal of care, then continued hand-feeding rather than tube-feeding makes sense. If living longer is the goal of care, it is tempting to think that tube-feeding is the logical choice. But, as noted previously, research has not shown that patients with advanced dementia who receive tube feeding live longer or experience less suffering. In fact, because no clear benefit of tube-feeding in advanced dementia has been shown, and because patients with this condition who develop eating problems are near the end of life, most experts do not think that feeding tubes should be used for this condition.

Section 5

Approach to Decisions about Hospitalization



Who makes the decision about the approach to feeding problems? The designated health care proxy is responsible for making health-related decisions for the patient, including decisions about how to handle feeding problems. Usually, these decisions are best made with input from the patient's doctor. Refer to Section 3 for more information on factors that go into the decision-making process." (see Section 3: Basic Approach to Decision-Making).

What additional support would be helpful in making decisions about feeding problems in advanced dementia?

Many people facing this decision find it helpful to speak to other trusted people, such as those close to the patient who know their values, members of the clergy, and a variety of health professionals (such as nurses, social workers, etc.). The different insights and perspectives that these people bring can often help the decision-maker come to a conclusion that feels right. Written and online materials are also available (see Section 10: Resources).

Why is it important to consider decisions about hospitalization for patients with advanced dementia?

Like all older patients, those with advanced dementia get acutely sick. Infections are the most common acute illnesses in patients with advanced dementia, but occasionally they will get other sudden illnesses such as bleeding from the digestive tract, a stroke, a bone fracture, or a heart attack. When these illnesses occur, a decision may need to be made about whether the patient should be admitted to the hospital. There are special considerations for the patient with advanced dementia.

What are the disadvantages of hospitalization?

In general, hospitalization can be a very traumatic and frightening experience for patients with advanced dementia, as they will not be able to understand what is happening to them. The transfer to the hospital itself can be very uncomfortable. Once at the hospital, acute care often involves treatments and tests that are burdensome and painful. The hospital is a very busy place filled with unfamiliar faces and noises. Being cared for by unknown nurses and physicians can be scary. These providers will not be able to provide the routine day-to-day care in the same way that the patient is used to. Finally, hospitalized patients are at risk for infections, increased confusion, and bedsores.



What are the advantages of hospitalization?

The main advantage of hospital care is access to treatments that cannot be provided in other settings, such as surgery and intensive care (for example, breathing machines).

How do I decide if hospitalization is the right choice?

The first step is to consider the main goal of care and whether hospitalization will achieve that goal.

- *How do I decide about hospitalization if comfort is the primary goal of care?*

Hospitalization is almost never the right choice for patients with advanced dementia when comfort is the main goal. The vast majority of medical problems they experience can be treated more comfortably in the nursing home or home setting. There are exceptions, such as a hip fracture, when hospital-level care may be needed to achieve comfort.

- *How do I decide about hospitalization if living longer is the goal of care?*

If living longer is the main goal of care, then hospitalization is the right choice when the treatment needed to increase survival is only found in the hospital. However, as noted, the vast majority of acute problems that patients with advanced dementia get can be treated without hospitalization. For example, the survival of advanced dementia patients with pneumonia is the same whether they are treated in the hospital or nursing home.



Can I make the decision not to hospitalize my loved one with advanced dementia?

Yes.

How can I plan ahead to make sure hospitalization decisions go smoothly?

Before an acute illness occurs, it is important to talk to the primary care physician and other health care providers about the patient's goals of care and wishes about hospitalization. By having these conversations ahead of time, you can help make sure that the patient does not receive treatments he/she would not want. Many patients with advanced dementia have a "Do-Not-Hospitalize" (DNH) order. Even with this order, hospitalization can always be reconsidered for specific conditions, such as a hip fracture.

Section 6

Approach to Treatment Decisions for Infections

Are infections in advanced dementia common?

Yes, most patients with advanced dementia get infections and this is often a sign that the end of life is near. Pneumonia and urinary tract infections are the most common types of infections that occur in these patients.

Why do patients with advanced dementia get infections?

In advanced dementia, the body's defenses that usually fight off bacteria are weakened. Many patients with advanced dementia also have problems swallowing or clearing secretions in the throat, which can cause food or saliva to "go down the wrong way" into the lungs – a condition known as aspiration, which can cause pneumonia.

What are the treatment options for infections in advanced dementia?

There are two main options:

1. Symptom management, or
2. Antibiotics plus symptom management

What is meant by symptom management of an infection?

Symptom management means the treatment focuses on the relief of discomfort from infections but does not try to stop the infection itself. Antibiotics, hospitalization, and tests are avoided. Most of the uncomfortable symptoms from infections can be relieved with simple measures such as medication to reduce fever (such as acetaminophen), oxygen to reduce shortness of breath, and pain medication for discomfort. The main **advantage** of symptom management is that discomfort is relieved, and uncomfortable tests and treatments are avoided. The main **disadvantage** of symptom management alone is that a patient with an infection may get sicker without antibiotics.

If the patient can't speak, how will you know if he or she is uncomfortable or in pain?

Although we can never know for sure what a patient with advanced dementia is feeling, health care providers are used to watching for signs of discomfort in those who cannot speak for themselves. Some signs include agitation, restlessness, rapid breathing, or facial expressions suggesting discomfort, such as frowning. When these signs occur in someone with an infection, measures aimed at relieving discomfort can be provided.

What about antibiotics?

Antibiotics treat infections caused by bacteria (not by viruses). Antibiotics may be given by mouth, injected into the muscle, or injected into the blood stream through an intravenous (IV) line. The main **advantage** of antibiotics is that they directly treat bacterial infections, so the patient's infection may get better. A **disadvantage** of antibiotics is that giving them may cause discomfort, especially if it involves hospitalization. Antibiotics can also cause side effects, including a bad infection of the bowels. Finally, some of the tests doctors need in order to decide on the right antibiotics may be uncomfortable (for example blood tests, urine samples, and x-rays).



What is important to know about pneumonia?

Pneumonia occurs in about 40% of patients with advanced dementia who are near the end of life. Even if an episode of pneumonia improves, patients with advanced dementia are at risk for repeated

episodes. The best research suggests that patients with advanced dementia who are treated with antibiotics may live a few months longer than those who are untreated, but they may also suffer more discomfort. Patients who are not treated with antibiotics can receive treatments that relieve any discomfort from the pneumonia, such as oxygen for shortness of breath. It is important to know that research also suggests that patients treated with antibiotics for pneumonia in the nursing home do just as well as those sent to the hospital. Also, antibiotics given for pneumonia by mouth are usually just as effective as antibiotics given through a vein. So, if the decision is to treat pneumonia with antibiotics, it is usually possible to avoid burdensome hospitalizations or uncomfortable procedures.

What is important to know about urinary tract infections?

Antibiotics are often prescribed to patients with advanced dementia for suspected urinary tract infections (UTIs) if the patient has increased confusion, foul-smelling urine or dark urine. However, these signs alone often do not mean an infection is present. A definite diagnosis of urinary tract infection requires that the patient has signs of being sick (such as a fever) **and** has a urine sample that shows bacteria in a lab. Getting a good urine specimen for a patient with advanced dementia can be uncomfortable, as it requires a catheter (small tube) to be temporarily placed in the bladder.

*comfort as the
main goal of care*

How do I make sure the plan for managing infection is in line with the goals of care?

If comfort is the main goal of care, then symptom management without antibiotics makes sense. If living longer remains the primary goal of care, then antibiotic treatment makes sense. However, hospitalizations may still be avoided because infections can often be effectively treated outside the hospital.

Who makes the decision about the approach to infections?

Decisions about how to treat infections should be shared between the designated health care proxy and the patient's medical providers. Because infections are expected in advanced dementia, it can be helpful to discuss the preferred approach to treatment before the infections actually happen.



Section 7

How Advanced Dementia Affects the Family

*As a family member helping to care for someone with advanced dementia, your whole life is affected. Sometimes, changes in your life happen slowly over time so that you don't even think about them. But it's important to step back and look at how this experience is affecting **you** and other members of the family. This section talks about some of these effects and directs you to information about resources that may be helpful. The information may help you remember that you are not alone and that your feelings are okay. Take some time to think about how these aspects of family coping apply to you.*

The family is usually affected when a loved one is ill. What is unique about advanced dementia?

Dementia progresses over many years, so the family is affected by the disease for a long time. Patients with advanced dementia have profound memory loss, personality changes, and no longer play the role in the family they once did. Behavior problems that can go along with advanced dementia can be very distressing for family members. Finally, patients with advanced dementia are not able to make decisions on their own. The family may find the responsibility for medical decision-making stressful.

What does the term "caregiver stress" mean?

This term refers to the stress from caregiving that can affect a person's mental, physical, social, spiritual, and financial well-being.

How does a loved one with advanced dementia affect a family member's mental health?

Being responsible for a loved one with advanced dementia can feel overwhelming. Family members may experience anxiety, depression,

and grief, even while the patient is still living. Other common emotions include denial, anger, fear, guilt, and sadness.

How does a loved one with advanced dementia affect a family member's physical health?

Family members may neglect their health by not getting enough exercise, not eating properly, or neglecting their own medical problems. Caregivers may suffer injuries from providing direct physical care to a patient with dementia (for example, lifting). Emotional stress can also lead to physical problems.

How does a close loved one with advanced dementia affect a family member's social life?

As dementia progresses and caregiving demands grow, it can become more difficult for family members to enjoy an active social life. As a result, they are at risk for loneliness and social isolation.

How does a loved one with advanced dementia affect a family member's finances?

Family members can feel the financial impact in many ways. They may need to miss or reduce personal work hours or pay out-of-pocket for medical and care-giving expenses that are not covered by insurance. They may also have to take responsibility for the patient's personal finances, and for finding the resources to pay for additional care in the home or nursing home care.



What about relationships within the family?

When a family member has advanced dementia, it is extremely common for relationships between other family members to experience some strain. Disagreements and turmoil can arise over caregiving responsibilities, financial plans, goals of care, and more. Old issues may surface as everyone in the family struggles to cope with this new challenge. Each person in the family may cope in a very different way. No two of us are alike. Open communication is the best way to help ensure that these normal struggles are resolved so that long-term relationships in the family are preserved. Family meetings where the goals of care are discussed can help. Some families may benefit from temporary family counseling to resolve issues about how best to proceed as the disease progresses.

What are the positive aspects of being a family member of a person with advanced dementia?

It may feel like a struggle to find the positive side of this experience. However, many families discover meaningful new ways to interact with their loved ones and strengthen their bonds with each other. Advocating for the patient during difficult times can be personally satisfying. Many caregivers find it rewarding to help other families in similar situations by sharing their experiences.

Where can families find additional help?

You are not alone.

Support for caregivers is available. Other family members and friends

are important sources of informal support, but sometimes professional help is needed. Professionals who may be helpful with patient-related issues include health care providers, financial planners, chaplains, and social workers. Family members may seek professional counseling, medical care, and support groups for their own personal needs (*see Section 10: Resources*).



Section 8

What is Hospice and Palliative Care?

What is hospice?

Hospice provides care to patients who have a terminal illness (such as advanced dementia) and who are no longer seeking or receiving curative treatments. Hospice patients have a limited life expectancy and want treatment that is in line with the hospice philosophy. The hospice philosophy says that all care is focused on achieving the best possible patient comfort, providing strong family support, and helping the patient live as well as possible for the remainder of his or her life.

What is palliative care and how does it differ from hospice?

Hospice and palliative care are similar. They both involve a team-oriented approach to care for patients with serious illnesses, and they both focus on symptom control, communication, and family support. Palliative care may be provided at any time during a person's illness, not just in the final stages, and it may be provided along with treatments aimed at curing a particular condition. Hospice provides care for patients at the end-of-life who no longer seek curative or aggressive life-extending treatments.

Can patients with advanced dementia receive hospice care?

Yes. There are certain guidelines a patient must meet to be eligible for hospice. When a referral is made to hospice, the hospice provider will evaluate the patient to see if he or she qualifies for hospice care.

*communication
and family support*

Why would a family decide to choose hospice care?

It makes sense to start hospice care when patients are at the end-stages of an illness (such as advanced dementia), and the goal of care is to maximize comfort and quality of life rather than quantity of life. At this stage, families may choose hospice services to help meet this goal. For example, when a decision is made to no longer hospitalize a patient when an infection or other illness arises, hospice can provide the medical care needed to keep the patient comfortable at home or in the nursing home.

Where does a person receive hospice care?

Hospice programs serve patients where they live. For patients with advanced dementia, that usually means at home or in a nursing home.

Who provides hospice care?

Certified hospice agencies provide hospice care. Hospice is delivered by a team of professional caregivers. The core group includes a doctor, nurse, social worker, and chaplain. A home health aide, who can assist with some of the patient's personal care, and a hospice volunteer are also often involved.



Section 9

Glossary

Terms and Definitions

Who pays for hospice care and for how long?

Hospice is paid for by Medicare and most other insurance companies. Hospice care is provided as long as the patient remains eligible as determined by the hospice program.

How does a person get referred to hospice?

Patients or their families can ask the patient's doctor or nurse to make the referral. Or they can make the request by contacting a hospice program directly.

What if comfort is the goal of care but hospice care is not available or the patient does not qualify?

When comfort is the goal of care, patients with advanced dementia should be able to receive care consistent with that goal even if they do not qualify for hospice or it is not available. Communication with the patient's doctors and nurses is critical to achieving this goal. The family should clearly state that all care decisions should be directed at making the patients as comfortable as possible, not at curing a temporary or chronic condition.

What if the family wants the patient to be kept comfortable but at the same time still receive potentially curative treatments?

In this case, palliative care would be a good option. Palliative care focuses on symptom control, communication, and family support, but may be provided along with treatments aimed at curing a particular condition.

ARTIFICIAL VENTILATION

Artificial ventilation is used when patients cannot breathe on their own. It involves the insertion of a tube through the patient's trachea (windpipe) into the lungs. The tube is attached to a machine called a respirator or ventilator that moves air into and out of the lungs.

ASPIRATE/ASPIRATION

When food or oral secretions (saliva) go into the lungs instead of the digestive tract due to swallowing problems.

ADVANCE CARE DIRECTIVES

Information patients may have written down or discussed regarding the type of medical care they wish to receive in the future if they are unable to make medical decisions for themselves. Advance care directives include living wills; designation of a power of attorney or health care proxy; and preferences for specific treatments, such as the use of breathing machines.

DO NOT RESUSCITATE (DNR)

DNR is an advance directive. In the event that the patient's heart or lungs should stop (cardiac or respiratory arrest), a DNR order reflects the patient's or proxy wish not to attempt to restart the heart with compressions or shocks and not to start artificial ventilation (see above). In health care settings, such as a nursing home or hospital, the patient's primary care provider can write a DNR order in the medical record. Also, many states have official forms any person can complete stating that they do not wish to be resuscitated.

DO NOT HOSPITALIZE (DNH)

DNH is an advance directive that reflects the patient's or proxy wishes to avoid future hospitalization because it is not compatible with the patient's goals of care. In health care settings, such as a nursing home, the patient's primary care provider can write a DNH order in the medical record.

GERIATRICIAN

An internal or family medicine physician with advanced training in the care of patients age 65 years or older.

HEALTH CARE PROXY

An individual designated by a patient to make medical decisions on his/her behalf when the patient is unable to make decisions on their own. A health care proxy is designated by a patient when they still have the mental capability and judgment to make this decision independently. The proxy acts as the "spokesperson" for the patient, making choices based on the patient's individual wishes and beliefs. Health care proxies may also be referred to as surrogate or substitute decision-makers. Health care proxies are often formally appointed in a written document.

INTRAVENOUS (IV)

A method of delivering fluids, medications, or antibiotics directly into a vein through a small plastic catheter.

LIVING WILL

A written document that states a patient's preferences regarding the medical scenarios one might encounter in the future. This can include directives regarding specific treatments (e.g. feeding tubes), life support choices in the event of terminal illness, or specific directives (e.g. DNR). It is important to note that the legal status of this document varies by state, and it is impossible to include every possible future scenario.

HOSPICE

Specialized care provided to patients with a terminal illness that focuses on patient comfort instead of "curative" treatment. Hospice often focuses on optimizing quality of life and provides support to the patient and the patient's family and loved ones.

MEDICARE

A federal program that pays for certain health expenses for eligible patients age 65 years or older.

NURSE PRACTITIONER

An advanced practice nurse who has completed graduate-level education and holds national certification in a specialty area (for example, geriatrics, palliative care).

Section 10 Resources

PALLIATIVE CARE

Care focused on patient comfort and symptom management. Unlike hospice, palliative care can be provided at any time during an illness, including at the same time as curative treatments.

PERCUTANEOUS ENDOSCOPIC GASTROSTOMY (PEG) TUBE

A tube placed directly into the stomach of a patient with eating problems. Commercially available liquid food, water, and medications can be delivered into the stomach.

References appear at the end of the booklet.

End-of-Life Decision-Making

www.agingwithdignity.org



Aging with Dignity is a national non-profit organization with a mission to “affirm and safeguard the human dignity of individuals as they age and to promote better care for those near the end of life.” The organization helped create “Five Wishes”, a document used by millions of people as a means of drafting their living will.

www.MyCareCommunity.org



This website is aimed at addressing concerns and questions that caregivers encounter on a daily basis, from basic direct-care concerns to end-of-life issues.

Advanced Dementia

www.alz.org/living_with_alzheimers_late_stage_care.asp



This website is created by the national Alzheimer's Association and has a wealth of information about what to expect in late-stage Alzheimer's disease, medical concerns related to this stage of dementia, and end-of-life considerations for patients in late-stage.

www.helpguide.org/elder/alzheimers_disease_dementia_caring_final_stage.htm



Helpguide is a website created by a family with the goal of providing information and resources to help people in need. The section focused on late-stage Alzheimer's disease is largely directed to caregiver issues and end-of-life decision-making, as well as links to other resources about grief and coping.

www.pdcronline.org



Palliative Dementia Care Resources (PDCR) was established in 2006 to provide resources and information to help people make decisions about end-of-life care and services for individuals with dementia. This website addresses issues of quality end-of-life care for individuals with advancing dementia.

Tube-feeding

www.decisionaid.ohri.ca/dec aids.html#feedingtube



This website is from the Patient Decision Aids Research Group affiliated with the University of Ottawa, designed to help patients and their health practitioners make "tough" healthcare decisions. You can access a decision-aid about feeding tubes via this website.

www.healthinaging.org/public_education/pef/tube_feeding.php



This website is from the American Geriatrics Society and provides a detailed description of feeding tubes and the concerns related to their placement.

Hospice and palliative care

www.nhpco.org/i4a/pages/Index.cfm?pageID=3254



The National Hospice and Palliative Care Organization (NHPCO) is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The Caring Connections website is designed to provide information about hospice care, palliative care, and end-of-life concerns and needs.

www.hospicefed.org



This website is from the Hospice & Palliative Care Federation of Massachusetts. This website has general information about hospice services and palliative care and also is a guide to help locate hospice agencies and hospice facilities within Massachusetts.

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