



# Just Talk About It

Discussion Group Guide – Large Print Version

Produced with support from the Pennsylvania Department of Aging

**Topics:**

Advance Care Planning

Caregiving

Hospice and Palliative Care

Pain Management

A Project of



**The Take Charge of Your Life Partnership**

[www.takechargeofyourlife.org](http://www.takechargeofyourlife.org)

Produced with support from  
the Pennsylvania Department of Aging

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For additional information, see [Improving End-of-Life Experiences for Pennsylvanians: Report and Recommendations by the Task Force for Quality at the End of Life](#)

All web links in this guide were live as of June 2010.

## ■ About the Take Charge of Your Life Partnership

**A** 501 (c) (3) non-profit corporation since 2001, the Take Charge Partnership is dedicated to educating, supporting and empowering all people to deal with end-of-life issues through an innovative network of consumers, professionals, community organizations and corporations.

We began in Western Pennsylvania as a group of supporters of the PBS series, *On Our Own Terms: Moyers on Dying*, then joined with the National Issues Forum to convene a series of community meetings on end-of-life issues in our region. Over 400 area residents participated in 26 forums and we issued a report on the results, *Western Pennsylvanians Talk About Death and Dying on Their Own Terms*.

Our organization was recognized early on as one with promise by the journal of the American Medical Association. At our plenary meetings, we began featuring speakers on end-of-life topics and invited the public to attend these educational sessions. We then designed and implemented our “Take Charge of Your Life” campaign, training volunteers to hold workshops on advance care planning for community groups. Soon after, we received a grant to start “Take Charge Online,” using technology developed at Carnegie Mellon University to provide information

on end-of-life subjects via streaming video on the Internet. For this we won an Award of Excellence from Rallying Points, funded by the Robert Wood Johnson Foundation.

We then joined the newly formed Coalition for Quality at the End of Life (CQEL), which took a leadership role in organizing participants throughout Pennsylvania to contribute to a Report to the Governor, *Improving End-of-Life Experiences for Pennsylvanians: Report and Recommendations by the Task Force for Quality at the End of Life*. Members of Take Charge made substantial contributions to the chapter on “Addressing the Community,” and after its publication, we took up the challenge of raising public awareness about topics deemed important for citizens to know more and talk about. We now provide both video and text Frequently Asked Questions (FAQ) on our website, [takechargeofyourlife.org](http://takechargeofyourlife.org), as well as our *Just Talk About It* videos.

### **The *Just Talk About It* Project**

*Just Talk About It* began as a daylong conference hosted by the Take Charge Partnership at Chatham University in 2006. We chose this theme because of research showing that when individuals have discussed their values and wishes about end-of-life issues ahead of time, making decisions later on is less challenging for them and their loved ones. But we also knew that many of us want to avoid even thinking about these issues, let

alone having discussions about them. The suggestion to “just talk about it” seemed like the best way to point people toward the real benefits in trying.

Later, after the Governor’s Report was issued, *Just Talk About It* was selected as the theme for the video project we began planning. With the support of the Pennsylvania Department of Aging, we produced a series of one-minute videos about the topics that contributors from across the state identified as those the public could most benefit from learning and talking more about: advance care planning, especially choosing a health care agent; providing care for loved ones; considering hospice and palliative care; and, managing pain.

### Goals of the *Just Talk About It* Project

One minute videos depicting scenarios related to the topics will be utilized within a group setting to:

1. Raise awareness,
2. Provoke thought,
3. Stimulate discussion, and
4. Motivate participants toward action.

## ■ How to Use the Videos and Discussion Guide

**G**ATHER A GROUP interested in improving end-of-life experiences, such as: church groups, health care workers, caregivers, coworkers, college students, senior citizens, social clubs, etc. (See “Materials for Holding a Discussion” for promotional support.)

**REVIEW THE TOPICS** available for discussion: advance care planning (especially choosing a health care agent); caregiving; hospice and palliative care; and, pain management. The videos depict one-minute scenarios for each of the four topics. You can access these live on the web at the [Pennsylvania Department of Aging](#) or at [takechargeofyourlife.org](#); or, load them ahead of time onto a flash drive or DVD.

**SELECT ONE OR MORE SCENARIOS** for your group to view and discuss. In preparation, you may want to consult the FAQ on each topic on our website, [takechargeofyourlife.org](#).

**INTRODUCE A TOPIC** to the group and view the selected videos. A brief introduction is included in this guide for each topic.

**BREAK INTO GROUPS** of 4-6 for the purpose of discussion after viewing.

**DISCUSS THE CHALLENGES AND OPPORTUNITIES** raised in the discussion points. (Suggestions are provided in purple.) Allow sufficient time to discuss each one.

**REGROUP AND SUMMARIZE** the main topic as a group – review the challenges and the opportunities that were expressed during the small group discussion time.

**EMPOWER PARTICIPANTS TO “TAKE CHARGE.”** Review and discuss the list of potential options/goals from which individuals, families, organizations, and communities can choose. Encourage each participant to choose at least one realistic goal (or to write one of their own) before leaving the session. Expect participants to have more questions than answers at the completion of the session.



## Advance Care Planning (ACP)

### Introduction

**A**dvance care directives are specific instructions prepared in advance by a competent person. They document preferences about medical care and, in the event that the planner becomes incapacitated, name someone to make decisions for him or her. Advance care directives are also known as Living Wills and Health Care Directives.

Another form of an advance care directive is called a Health Care Power of Attorney, Health Care Agent, Medical Power of Attorney, or Health Care Surrogate. These different terms all mean the same thing – the designation of a decision-maker to serve in the place of the individual who can no longer voice or make decisions about his or her treatment.

Since 1990, when the Patient Self-Determination Act (PSDA) was passed, most health care facilities are required to have a means of disseminating information about advance care directives with patients. Upon admission, you can expect to:

1. Receive a written summary of:
  - your health care decision-making rights (which each state has developed), and
  - the facility's policies with respect to recognizing advance directives.
2. Be asked if you have an advance directive, and if you do, have that fact documented in your medical record. (It is up to you to provide a copy to the facility.)

The PSDA forbids discrimination against patients based on whether or not they have an advance directive. For more information about the PSDA, consult the website of the [American Bar Association](#).

**Advance care planning** is the important process that precedes the signing of an advance care directive. Planning involves *becoming informed about health care options and advance care forms* and, ultimately, *discussion with loved ones and especially with the person named as health care agent*. Research shows that establishing communication that builds trust over time, with emphasis on the patient's most important relationships, is likely to be a more successful strategy than discussing specific treatment options (Prendergast, 2001). A [full planning guide](#) for Pennsylvanians is available online from the Pennsylvania Medical

Society and the Hospital and Health System Association of Pennsylvania.

In spite of the fact that Advance Care Directives have been available in the United States for a generation, only 29% of people say they have a living will. Even among those who have taken part in determining medical treatment for a gravely ill loved one, only 46% have written down their own end-of-life wishes (Pew Research Center, 2006).

### **References**

- Pew Research Center for the People and the Press. (2006). More Americans discussing – and planning – end-of-life treatment: Strong public support for right to die. Washington, DC: Author. Retrieved June 6, 2010 from <http://people-press.org/reports/pdf/266.pdf>.
- Prendergast, T.J. (2001). Advance care planning: Pitfalls, progress, promise. *Critical Care Medicine*, 29(2) Supplement, N34-N39.

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## Advance Care Planning Scenarios

The following scenarios, ACP #1, #2, and #3, are dramatizations of situations related to the topic of Advance Care Planning. The discussion points that follow each scenario provide a framework for participants to “just talk about it.”



### ACP #1. “A Family Way”

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A middle-aged couple and their adult daughter discuss the father’s completion of an advance care directive (living will) as requested by the hospital prior to his knee surgery.

#### Discussion Points

Why would someone who is just having knee surgery need an advance care directive (living will)?

Group members might say:

- + To be protected in the unlikely event that a medical emergency occurs during routine surgery
- + To use this relatively non-threatening hospitalization (e.g., routine surgery as opposed to crisis intervention) as an opportunity to address end-of-life wishes, perhaps for the first time

What are the barriers to completing an advance directive (living will)?

- + Denial and fear of death

- + Lack of information about end-of-life options
- + Not knowing what one's end-of-life wishes are

What are the advantages of discussing an advanced directive (living will) with your family and healthcare practitioner?

- + Your loved ones and healthcare practitioners can't be sure that your wishes are carried out if they don't know what your wishes are.
- + You can use these discussions to formulate your end-of-life wishes by considering the opinions of your loved ones and health care providers.



## ACP #2. "A Friend in Need"

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At the physician's office a new patient is advised about the need for her to name a healthcare agent.

### Discussion Points

What important factors should you consider about yourself and about the person you will choose as health care agent?

- + Dependability
- + Good decision-making skills
- + Good communication skills
- + Trust in your agent to carry out your wishes even if they might not agree with them
- + Trust in your agent's ability to assert your wishes in an emergency situation

How might religious beliefs, age, marital status and ethnic background impact your decision about naming a health care agent?

- + If you and your agent share the same beliefs and experiences, there may be less conflict for him or her in carrying out your wishes.
- + Will a beloved spouse, son or daughter, be able, emotionally, to carry out your wishes?
- + Would a younger person be more or less able to carry out your wishes than someone closer to your own age?

**What are the benefits of naming a health care agent?**

- + A health care agent who knows your wishes can clarify any confusion or misunderstanding about them that may arise.
- + If you are unsure about exact measures to specify in an advance directive, your agent will still know about your general beliefs and preferences.
- + If medical technology has changed since an advance directive was written so that new options are available, your agent can inquire and make decisions on your behalf.



### **ACP #3. “Where There’s A Will”**

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Two men in wheelchairs discuss the importance of advance care planning.

#### **Discussion Points**

When thinking about end-of-life issues, how might biases or stereotypes affect those who are physically or mentally challenged?

- + Some may believe that the life of a physically or mentally challenged person is not worth as much as that of an able-bodied person, or, that they should not be afforded heroic measures because they are already compromised.

- + Some may feel that physically or mentally challenged people are unable to express their own wishes so others should make decisions for them.
- + Some may doubt that a physically or mentally challenged person can be reliable in reporting symptoms.

What other groups of people might face the similar fears of not having their wishes respected?

- + Members of any minority group
- + Women
- + Youth
- + The elderly
- + Any underserved population

How can advance care planning restore a sense of “control” to those who are mistakenly seen as “unable to think for themselves”?

- + The advance directive is an objective statement of your wishes and can help to counteract a bias that may arise.
- + A person whose end-of-life wishes are known can concentrate more fully on other concerns such as connecting with loved ones or enjoying themselves.

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## Advance Care Planning

*Review the options, Just Talk About it and TAKE CHARGE!  
Choose an action goal of your own.*

### **For Individuals and Families:**

If you DO NOT have an advance care directive (ACD) or health care agent...

- \_\_\_ 1. Discuss the idea of an ACD and/or your wishes with your family.
- \_\_\_ 2. Obtain various ACD forms, review them, and learn more about them.
- \_\_\_ 3. Seek more information on the subject.
- \_\_\_ 4. Decide on a health care agent.
- \_\_\_ 5. Discuss your wishes with your health care agent.
- \_\_\_ 6. Complete and sign an ACD or agent designation. Keep it in a place where it can be found easily, and make sure your agent and doctor have copies.
- \_\_\_ 7. Other:

If you DO have an advance care directive or health care agent...

- \_\_\_ 1. Discuss it (again) with family and especially your designated health care agent.
- \_\_\_ 2. Review it to see if your wishes may have changed since it was signed.

- \_\_\_ 3. Update it, if only to make the date more current. Keep it in a place where it can be found easily, and make sure your agent and doctor have copies.
- \_\_\_ 4. Other:

**For Organizations and Communities:**

- \_\_\_ 1. Review our organizational forms and policies on Advance Care Planning.
- \_\_\_ 2. Provide educational resources to group members about ACP.
- \_\_\_ 3. Partner with others in your community to provide awareness/ education about ACP.
- \_\_\_ 4. Other:



## Caregiving (CG)

### Introduction

Caregivers are individuals who help full-time or part-time to care for family members or friends. In comparison to non-caregivers, family caregivers are more likely to report physical and mental health complications, experience depression and anxiety, suffer injuries, experience decreased immune response and inhibited wound healing and are hospitalized more often with stress-related diagnoses (Schulz & Beach, 1999). The **Family Caregiver Alliance** reports that “caregiver health is quickly becoming a public health issue that requires more focused attention from health professionals, policy makers and caregivers themselves to ensure the health and safety of those individuals dedicating their lives to the care of others.”

In 2007 the economic value of family caregiving was estimated at 375 billion dollars a year (Houser & Gibson, 2008). Neither these nor personal costs are counted as part of national health care spending. Most of us want to die at home, and most of us want to provide care if we possibly can, regardless of the array of

associated risks. But motivation alone does not ensure success. While studies show that caregivers can benefit from programs that provide education and support, few caregivers utilize them, and many are unaware of community, state and national resources available to assist with the care of their ailing family member (Alzheimer's Association and National Alliance for Caregiving, 2004; Scharlach, Sirotnik, Bockman, Neiman, Ruiz, & Dal Santo, 2003).

### **References**

- Alzheimer's Association and National Alliance for Caregiving. (2004). *Families care: Alzheimer's caregiving in the United States*. Chicago, IL: Alzheimer's Association and Bethesda: National Alliance for Caregiving.
- Houser, A., & Gibson, M.J. (2008). *Valuing the invaluable: The economic value of caregiving*, 2008. Update. AARP Public Policy Institute, Washington, DC.
- Scharlach, A., Sirotnik, B., Bockman, S., Neiman, M., Ruiz, C., & Dal Santo, T. (2003). *A profile of family caregivers: Results of the California statewide survey of caregivers*. Berkeley: Center for the Advanced Study of Aging Services, U.C. Berkeley Press.
- Schulz, R., & Beach, S.R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *Journal of the American Medical Association*, 282, 2215-2219.

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## Caregiving Scenarios

The following scenarios, CG #1, #2, and #3, are dramatizations of situations related to the topic of Caregiving. The discussion points that follow each scenario provide a framework for participants to “just talk about it.”



### CG #1. “Support Group”

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An older couple attends a family caregiver support group for the first time.

#### Discussion Points

What barriers keep family caregivers from seeking support?

- + Lack of time
- + Worry about their ill family member
- + Worry about failing in their efforts to care
- + Fatigue

What are some of the challenges and fears of older family caregivers? .....of younger family caregivers?

Older family caregivers:

- + Physical ability to care
- + Lack of experience with medical equipment
- + Watching a loved one’s condition deteriorate

Younger family caregivers:

- + Assuming the role of “parent”
- + Administering physical care
- + Juggling work and care responsibilities

Why is it important for caregivers to take care of themselves?

- + To provide the best care they can for their loved one
- + To be able to make good decisions about next steps in their loved one’s care
- + To help them bear their own feelings of grief and loss



## CG #2. “So Guilty”

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Over coffee, a woman offers support to her friend who is overwhelmed in her role as a full-time family caregiver.

### Discussion Points

In what ways could the burden of responsibility impact the wellbeing of the family caregiver: physically, emotionally, socially, and spiritually?\*

- + Increased stress
- + Suppressed immune system
- + Slower wound healing
- + Poor health
- + Increased mortality in caregivers compared to non-caregivers
- + Psychological illness (e.g., depression)

- + Lost wages, Social Security and pension benefits

How can families, friends, and healthcare professionals best support the full-time family caregiver to prevent burnout?

- + Offer to help with household chores.
- + Offer to drive to appointments or run errands.
- + Offer to provide respite care.

How can the full-time family caregiver best identify and communicate his/her needs to family, friends, and healthcare professionals?

- + Think about what might make tasks easier (for example, occasional takeout meals).
- + Ask for assistance with specific tasks.
- + Share schedules with others and let them know when their help would be welcome.
- + Let people know when there are things you can't do by yourself and enlist their help.

\* These caregiver symptoms have been studied and documented:

Houser, A., & Gibson, M.J. (2008). *Valuing the Invaluable: The economic value of caregiving*, 2008. Update. AARP Public Policy Institute, Washington, DC.

Kiecolt-Glaser, J.K., & Glaser, R. (2003). Chronic stress and age-related increases in the proinflammatory cytokine IL-6. In proceedings of the National Academy of Sciences.

Kielcolt-Glaser, J.K., Marucha, P.T., Malarkey, W.B., Mercado, A.M., & Glaser, R. (1995). Slowing of wound healing by psychological stress. *Lancet*, 346, 1194-1196.

Navaie-Waliser, M., Feldman, P.H., Gould, D.A., Levine, C.L., Kuerbis, A.N., & Donelan, K. (2002). When the caregiver needs care: The plight of vulnerable caregivers. *American Journal of Public Health, 92*, 409-413.

Schulz, R., O'Brien, A.T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates and causes. *Gerontologist, 35*, 771-791.



### **CG #3. "Conference Call"**

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A family of six siblings spread across the country discovers a way for all to be involved in their father's care when he is unable to make decisions for himself.

#### **Discussion Points**

What factors have made "long-distance caregiving" a necessity for many families?

- + Our mobile society – families are often far flung
- + Obligations of employment
- + Obligations of raising a family

What are some of the caregiving challenges and concerns of large families?... of very small families?

- + Communication
- + Decision making
- + Family members who live closer often take on more care, or may feel more pressure to care; may come to resent those living at a distance for not helping more.

- + Family members at a distance often lack day-to-day contact with the loved one; may feel left out; may feel they don't know enough to offer opinions about care; may feel ignored in decision making.

In addition to conference calling, what are some creative ways in which families can participate in the care of a loved one when they live at a distance?

- + Daily email log; blog; video postings

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## Caregiving

*Review the options and TAKE CHARGE!  
Choose at least one goal or write one of your own.*

### **For individuals and families:**

If you **ARE** a family caregiver:

- \_\_\_ 1. Do one thing for yourself this week (something that makes you happy).
- \_\_\_ 2. Make a list of your needs and seek help from family, friends, or neighbors.
- \_\_\_ 3. Contact a social worker at the local hospital to learn about local resources.
- \_\_\_ 4. Call local agencies to find a support program; if available, find a way to join it.
- \_\_\_ 5. Utilize the internet to connect with other caregivers.
- \_\_\_ 6. Make a long needed appointment with your family doctor, dentist, eye doctor or other healthcare provider.
- \_\_\_ 7. Other:

If you **KNOW** a family caregiver:

- \_\_\_ 1. Ask what you can do for him/her -- make them lunch, relieve him/her to get away.
- \_\_\_ 2. Offer services using your special skill (computer work, sewing, carpentry).

- \_\_\_ 3. Complete some needed task for the caregiver (hedge trimming, painting).
- \_\_\_ 4. Help find professional support or other helpful resources.
- \_\_\_ 5. Listen to the caregiver's stories -- intently and with empathy and compassion.
- \_\_\_ 6. Other:

**For organizations and communities:**

- \_\_\_ 1. Review organizational policies to see how you can be more sensitive to the needs of employees who are also family caregivers; work with HR to add or restructure benefits.
- \_\_\_ 2. Compile and provide a list of resources that might be helpful to caregivers.
- \_\_\_ 3. Partner with other organizations to provide support and education to family caregivers.
- \_\_\_ 4. Other:



## Hospice and Palliative Care (HPC)

### Introduction

**H**ospice and palliative care provide a team-oriented approach for terminally ill individuals and their families. The care is managed by healthcare professionals who have advanced training and expertise in end-of-life issues, and its focus is on comfort rather than on cure.

At the very core of hospice and palliative care is the holistic approach to meeting not only the physical needs of the patient but also the emotional and spiritual needs of patient and family.

A 2009 study (National Hospice and Palliative Care Organization, 2009) indicates that hospice is able to provide high-quality care with high levels of satisfaction. Evidence shows improved pain assessment and management, improved bereavement outcomes, better overall satisfaction, and lower mortality rates among family members of patients who received hospice care.

There are many barriers, including lack of experience, that prevent patients and their families from receiving hospice and palliative care. Only one third of all eligible patients in the U.S.

utilize hospice services and many patients enroll so late in their illness that they miss many of the important benefits that hospice care can provide.

### **Reference**

National Hospice and Palliative Care Organization. (2009). *Facts and figures: Hospice care in America*. Washington, DC.

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## Hospice and Palliative Care Scenarios

The following scenarios, HPC #1, #2, and #3, are dramatizations of situations related to the topic of Hospice and Palliative Care. The discussion points that follow each scenario provide a framework for participants to “just talk about it.”



### HPC #1. “Hospice in the Home”

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A young woman encourages her friend to consider hospice care for her mother at home.

#### Discussion Points

What cultural, ethnic, religious and gender beliefs might interfere with accepting “outside help”?

- + Cultural roles may dictate that “family takes care of family.”
- + Women may feel it is their role to care, or that they are in the best position to care, rather than get outside assistance.

What misunderstandings about hospice prevent eligible patients from receiving this care?

- + Some people may think that hospice means “nothing more can be done.”
- + Some people think that hospice is not needed until the last few days of a life-threatening illness.

- + Some people may not realize that hospice provides a team approach to support the family in their care of their loved one.

In what ways can hospice care at home benefit the patient?... the family?... the patient's primary care provider?

- + Hospice support can provide a knowledgeable listener for a dying person who wants to talk to someone other than a family member about the dying process.
- + Hospice volunteers can provide family caregivers with important respite time from direct caring so that they can care for themselves.
- + Hospice health care professionals can help family members or the patient communicate symptoms to their primary care provider.



## HPC #2. "Sooner Rather Than Later"

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The daughter of an elderly woman introduces the idea of hospice to her mom as an option for care that could benefit both of them.

### Discussion Points

What are some reasons why families receive hospice services "too late" (or not at all)?

- + Sometimes doctors do not refer patients early enough during the course of a life threatening illness.
- + Sometimes the hope for a cure and/or new treatments postpones inquiries about and referrals to hospice.

The mother in this video does not look sick and is not actively dying – why do you think she is eligible for hospice?

- + She has elected not to have dialysis and knows that kidney failure will eventually cause her death.
- + The earlier hospice services are enlisted for a life-limiting illness, the more they will benefit the patient and her family.

How can receiving hospice services “sooner rather than later” benefit the caregiver in the short-term? ...over the long-term? ...after the death?

- + Hospice services include education about the dying process so that the family caregiver can better understand what to expect.
- + Hospice services provide important information about how to manage physical care.
- + Hospice volunteers can assist with physical care that may be too difficult, either emotionally or physically, for a family caregiver.
- + After a death, hospice provides bereavement services to help family caregivers during their grieving.



### **HPC #3. “Nursing Home Hospice”**

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Three siblings discuss the idea of hospice services for their father who lives in a nursing home.

#### **Discussion Points**

Why do nursing home patients sometimes not receive the services of hospice?

- + Many people are unaware that families can elect hospice care in a nursing home.
- + Families may assume that hospice care and nursing home care are the same.

What are the advantages to using hospice services within the nursing home setting for the patient? ...the family? ...the nursing home staff? ...the hospice staff?

- + One advantage of electing hospice care in a nursing home is that the frequency of stressful trips to the emergency room are likely to be reduced.
- + The family can feel more secure in the knowledge that the hospice team is dedicated to managing issues of pain and grief.
- + Hospice staff can supplement the care provided by nursing home staff.
- + The hospice staff can coordinate care by working with several patients in one location.

What are some of the challenges that confront family members who live at a distance compared to family members who live nearby and have the bulk of the caregiving responsibility?

- + Family members who live at a distance are usually not as familiar with their loved one's day-to-day condition as those who live nearby, and may not see the need for changes in treatment.
- + People who live at a distance may have a harder time admitting that their loved one is dying.

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## Hospice and Palliative Care

*Review the options and TAKE CHARGE!  
Choose at least one goal or write one of your own.*

### **For Individuals and Families:**

If you have been diagnosed with an illness that could be life-limiting:

- \_\_\_ 1. Begin learning now about all your options for care over the course of your illness.
- \_\_\_ 2. Talk with your family about your fears, worries, and concerns as well as your hopes.
- \_\_\_ 3. Ask your physician to be clear in describing your disease process.
- \_\_\_ 4. Other:

If you know someone who has a life-limiting illness:

- \_\_\_ 1. Be open to listening to their fears, worries, and concerns as well as their hopes.
- \_\_\_ 2. If the opportunity arises, share information that was learned today.
- \_\_\_ 3. Within your own limitations, take time to “companion” them even as the illness changes.
- \_\_\_ 4. Other:

### **For Organizations and Communities:**

- \_\_\_ 1. Review health care insurance policies to be aware of the stipulations and the amount of coverage provided for services such as hospice and palliative care.
- \_\_\_ 2. Partner with other organizations to hold an event to raise public awareness of services offered in the community concerning end-of-life care.
- \_\_\_ 3. Other:



## Pain Management (PM)

### Introduction

**B**ecause the experience of pain is subjective – that is, only the sufferer can experience it – it can be hard to define. There are many different types of pain and they can range from mild and transient to severe and lasting. For many suffering from both acute and chronic diseases, it can be debilitating. In spite of the fact that there are many treatments for pain, both medical and non-medical, there are many reasons why pain is often under-treated. These include the belief that pain is inevitable, and fear of the role of narcotics in addiction and hastening death.

Pain is a quality-of-life issue that will become more of a concern with an aging population. Pain is the number one reason people seek medical care in the United States and its under-treatment represents a major healthcare problem, some even say an epidemic (Kirsch, Berdine, & Zablotsky, 2000). As a result, patient rights groups and regulatory bodies are calling for proper pain management. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) standards now require that individuals seeking care in JCAHO accredited

facilities have the right to appropriate evaluation and management of pain (Phillips, 2000).

There are a multitude of factors that interfere with the proper identification of pain, accurate diagnosis of pain, and effective treatment, including non-medical treatments for pain relief.

While the issue is complex, denying the epidemic of pain threatens to compound the impact pain has on pain sufferers, their families, our society, and the health care system as a whole.

### **References**

Kirsch, B., Berdine, H., Zablotsky, D., et al. (2000). Management strategy: identifying pain as the fifth vital sign. *Veterans Health System Journal*, 49–59.

Phillips, D., for the Joint Commission on Accreditation of Healthcare Organizations. (2000). JCAHO pain management standards are unveiled. *Journal of the American Medical Association*, 284, 428-429.

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## Pain Management Scenarios

The following scenarios, PM #1, #2, and #3, are dramatizations of situations related to the topic of Pain Management. The discussion points that follow each scenario provide a framework for participants to “just talk about it.”



### PM #1. “What’s Right For You”

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A son tries to convince his elderly father that there are more options for pain management than those he has tried.

#### Discussion Points

In what ways does under-managed pain affect the quality of life of the individual in pain? ...of the family?

- + Under-managed pain increases a patient’s stress and saps energy.
- + Since pain can often be expressed as irritability, under-managed pain could lead to negative social interactions.

What are some different attitudes that people have about pain?

- + Many people who value their independence do not like to think of themselves as needing help, including medication.
- + Some people think that pain is a necessary part of the dying process and that it can’t be treated.

- + Some people believe that admitting pain is a sign of weakness.

Why do some people stop taking their pain medication?

- + Sometimes it doesn't work as expected, or people dislike the side effects.
- + People aren't aware that there are alternatives they could try.
- + Some people think that relieving a symptom like pain isn't as important as treating the disease that causes it.
- + Some people who are taking a number of medications may not want to take more.



## PM #2. "I'm Fine"

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An elderly woman fails to report that she is in pain in order to avoid medication.

### Discussion Points

What attitudes and myths prevent individuals from asking for or accepting adequate pain management?

- + Some people do not believe it is right to complain about being ill or having pain.
- + Some people think that they are showing weakness if they can't manage their pain on their own.
- + Some people do not want to burden others with their complaints about symptoms, including pain.

What obstacles do health care providers face in providing effective pain treatment?

- + Health care providers often encounter people who are worried that pain medication will make them unaware, and uncommunicative.
- + Some people also believe that they will become addicted if they take pain medication.
- + Some people believe that their death will be hastened by taking pain medication.

Consider the statement made by the nurse: “If you are having pain, then we need to do a better job.” What are some ways that health care providers can “do a better job”?

- + Health care professionals can reassure patients about any fears or worries associated with pain medication.
- + Health care professionals can make it a priority to ask patients about their pain experiences.
- + Health care professionals can educate patients about the range of pain management options, including non-medical treatments that can help to alleviate pain.



### **PM #3. “Old Buddies”**

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A man in chronic pain is approached by his friend about the use of non-medical therapies for pain management.

#### **Discussion Points**

What are some of the barriers to seeking non-medical treatments?

- + Some people believe that these treatments are fraudulent.
- + Insurance may not cover these treatments.

- + Some people resist some treatments because they are rooted in unfamiliar cultural traditions.

**How might age, gender, and ethnic background play a role in the pursuit of treatment for chronic pain?**

- + Cultural roles that emphasize independence and strength, as opposed to interdependence and getting help, may influence underreporting of pain.
- + For men, who are encouraged to project strength, admitting pain may signify weakness.
- + Women who feel their complaints have not been taken seriously by health care professionals in the past may be reluctant to report their pain.
- + Older people may see their needs as a burden for others.

**How could patients and their health care providers become better informed about non-medical treatments to relieve pain or complement a current pain management regime?**

- + Health care providers could offer information about non-medical treatments in their practices.
- + Individuals could ask health care providers for information about non-medical treatments.

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## Pain Management

*Review the options and TAKE CHARGE!  
Choose at least one goal or write one of your own.*

### **For Individuals and Families:**

If you suffer from pain:

- \_\_\_ 1. For one week, keep a detailed record: when does the pain occur? what does it feel like? what makes it feel better? what makes it worse? Take this record to your next doctor visit.
- \_\_\_ 2. Make an appointment with your physician to address (or re-address) your pain issue.
- \_\_\_ 3. Request a pain specialist consult.
- \_\_\_ 4. Explore information about relaxation techniques, biofeedback, or other methods of enhancing the management of pain.
- \_\_\_ 5. Other:

If you know someone who suffers from pain:

- \_\_\_ 1. Believe a person who says they have pain.
- \_\_\_ 2. Watch and listen for clues if you suspect that someone is in pain even though they may deny or minimize their pain.
- \_\_\_ 3. Share something you have learned in this session.

\_\_\_\_ 4. Encourage the person to address (or re-address) the issue with her/his physician.

\_\_\_\_ 5. Other:

**For Organizations and Communities:**

\_\_\_\_ 1. Invite a local health care professional to provide an educational session about the impact of pain on employees and employers and options for pain management.

\_\_\_\_ 2. Partner with other organizations to create a community awareness event about pain issues.

\_\_\_\_ 3. Other:

## ■ Materials for Holding a Discussion

### Suggested News Release – (Your Organization Letterhead)

For Immediate Release  
[date of your release]

Contact: [Your Name]  
Ph: [Phone #]  
[Your email]

#### **You Are Invited to “Just Talk About It”: [Your Town]**

*There are important benefits to discussing  
the world’s most unpopular topic*

(Your City, ST) – No one wants to talk about death and dying but there’s a good reason for doing so. Research has shown that when individuals have discussed their values and wishes about end-of-life issues ahead of time, making decisions later on is less challenging for them and their loved ones.

*Just Talk About It*, a series of one-minute videos, was created in response to recommendations in a Report to the Governor (2007) on improving end-of-life experiences for Pennsylvanians. Experts from across the state suggested that everyday citizens needed to know more about and discuss advance care planning, caregiving, hospice and palliative care, and pain management. The *Just Talk About It* project addresses

these topics in scenarios that provide information and tips about how to get these conversations started.

“We tried to make the scenarios entertaining as well as informative, to engage people in a topic from which we normally flee,” said Dr. Peggy Stubbs, Professor of Psychology at Chatham University and project co-director along with Cynthia Pearson. Stubbs and Pearson are authors and founding members of the Take Charge of Your Life Partnership, a grassroots organization dedicated to educating, supporting and empowering all people to deal with end of life issues. The series and a helpful User’s Guide were made with support from the Pennsylvania Department of Aging, and may be accessed at [takechargeofyourlife.org](http://takechargeofyourlife.org).

[Provide information about why your organization is interested in holding this meeting/helping people engage in this topic]. Our meeting to “Just Talk About It” is scheduled for [time] at [location]. Join us for video viewing and discussion. For more information about the event, please contact [your contact info].

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## Suggested Calendar Listings – for Internet or newsletter posting

### Listing One:

*Just Talk About It.* No one wants to talk about death and dying, but when individuals have discussed their values and wishes about end-of-life issues ahead of time, making decisions later on is less challenging for them and their loved ones.

Join us to view and discuss *Just Talk About It*, a series of one-minute videos created from recommendations to the Governor (2007) on improving end-of-life experiences for Pennsylvanians and produced with support from the Pennsylvania Department of Aging.

For more information or to reserve a space at this event, please contact [local contact information.]

### Listing Two:

Join us to view and discuss *Just Talk About It*, a series of one-minute videos created from recommendations to the Governor (2007) on improving end-of-life experiences for Pennsylvanians and produced with support from the Pennsylvania Department of Aging.

WHAT: Just Talk About It

WHERE: [Location]

WHEN: [Date and time]

WHO: [Your Organization]

RSVP: [Event contact person]

## 30-Second Public Service Announcement – for Radio

Tragic accidents, life-threatening illness: these are things we never want to think about. Yet families find themselves faced with these overwhelming situations every day. “Just Talking About” end-of-life wishes with loved ones can make decisions about medical care less challenging.

For information and tips on how to start the conversation, join [your organization] to view and discuss the “Just Talk About It” video series, based on recommendations to the Governor about improving end-of-life care for Pennsylvanians, and funded by the Pennsylvania Department of Aging.

The event will be held at [location] on [date] at [time].

For more information or to reserve a space, please contact [local contact information].