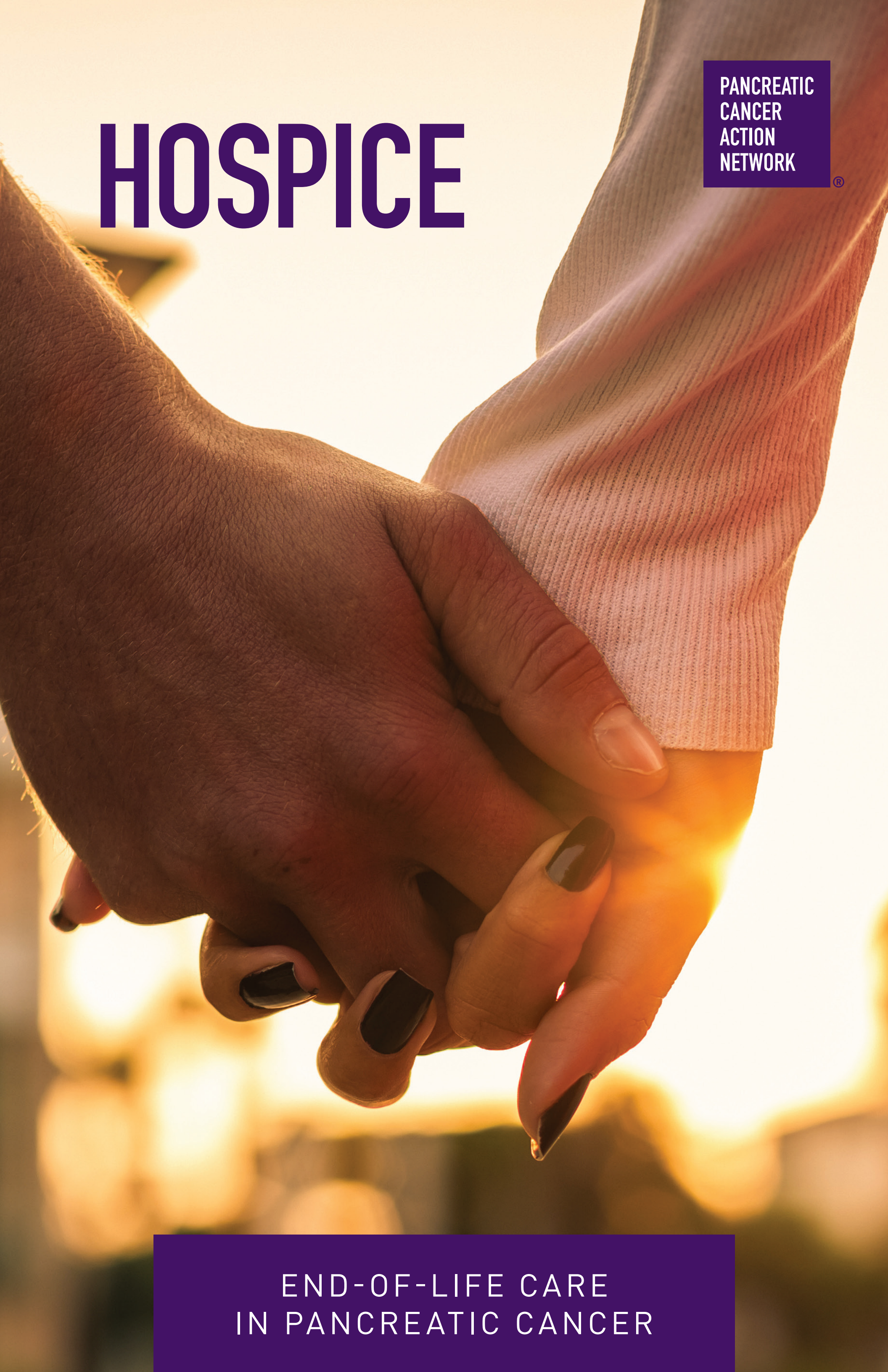

HOSPICE

PANCREATIC
CANCER
ACTION
NETWORK®

END-OF-LIFE CARE
IN PANCREATIC CANCER

PanCAN was the first organization dedicated to fighting pancreatic cancer in a comprehensive way, and for more than two decades, we've grown a nationwide movement tackling the disease from all angles.

RESEARCH

We fund transformative research - everything from early detection to innovative new treatment approaches.

PATIENT SERVICES

We provide information about treatment options, diet and nutrition, support resources and more, and we can answer all your questions along the way.

ADVOCACY

We work with thousands of grassroots advocates to urge Congress to increase federal research funding for pancreatic cancer, and we get results.

COMMUNITY

Be part of our movement! You can volunteer locally, participate in a PurpleStride community event or host your own fundraiser.

ABOUT THIS BOOKLET

This booklet provides an overview of what hospice is, how it works and what types of services are offered. It also includes topics for patients and their loved ones to discuss so that they can plan and make informed decisions about end-of-life care. This booklet is written for both pancreatic cancer patients who are facing end of life and their loved ones.

This booklet discusses many different aspects of hospice and end-of-life care. While learning about these issues may be difficult, having this information will help you and your loved ones make the best decisions for your situation. The profound emotions that come with thinking about end of life are not discussed at length. If you feel overwhelmed by the information presented or if you would like help with emotional aspects, talk to someone you trust, such as a family member, friend, healthcare team member, social worker, faith-based advisor or mental health professional. Help is available, and you do not have to face these decisions alone.

To find a professional in your area who can help, contact the Pancreatic Cancer Action Network's Patient Services toll-free at 877-2-PANCAN or email **patientservices@pancan.org**. Patient Services is available Monday – Friday, 7 a.m. – 5 p.m. Pacific Time.

Since most hospice care is provided at home, this booklet discusses the role of caregivers who are providing care in a home setting. The terms "family" and "loved ones" represent all of the people that care about the patient, including relatives, spouses, partners, children and friends. The term "caregiver" refers to whoever is providing most of a patient's day-to-day care, whether that person is a spouse, partner, child, sibling, relative, friend or privately hired person.

A glossary is provided at the end of this booklet for **bold** words in the booklet's text.

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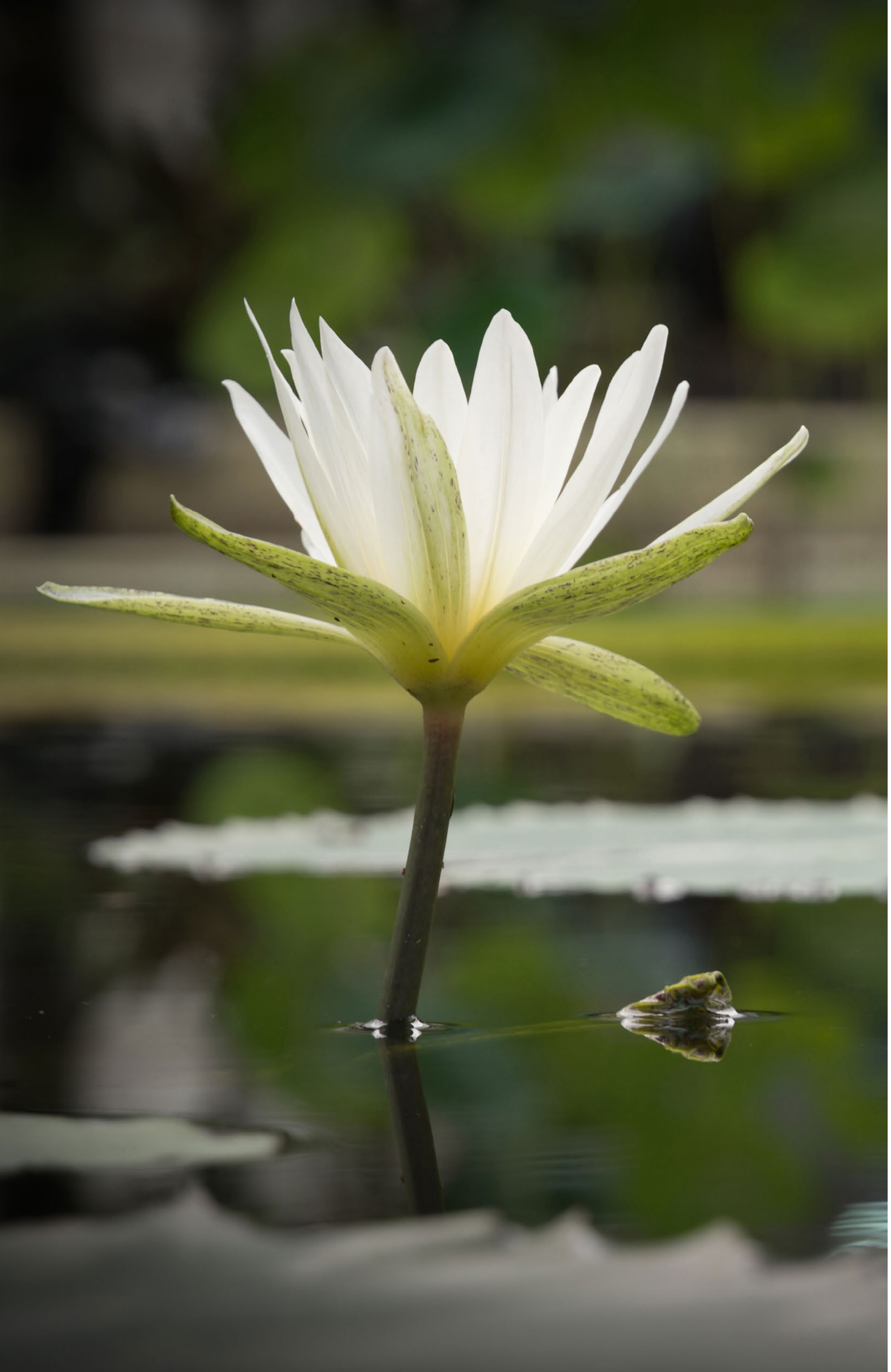


UNDERSTANDING HOSPICE

Hospice is a healthcare model that focuses on providing high-quality care during a person's last months, days and hours of life. Hospice care may be used when life expectancy is no longer than six months and there is no further benefit from curative treatments. It focuses on relieving symptoms and increasing comfort.

Hospice provides high-quality, compassionate care for people with life-limiting illnesses until death occurs naturally. This allows people with advanced pancreatic cancer to spend the remainder of their lives peacefully, surrounded by those they love. Hospice can provide:

- Medical and physical care, including the most effective pain-control treatments available
- Emotional and spiritual care for the pancreatic cancer patient and their loved ones
- **Practical care** assistance for the patient and their loved ones

A hospice organization provides care through a team of professionals and volunteers who work closely with the pancreatic cancer patient, the **caregiver** and all of the loved ones who want to be a part of the experience. Hospice care workers are trained to support the physical, emotional, spiritual and practical needs of patients and their loved ones at the end of life.

Most hospice care is given at home, with a family member, friend and/or hired caregiver providing and managing day-to-day care. However, members of the **hospice team** will regularly visit patients to provide hands-on care. While "home" for some patients means their own home, for others it may be a nursing home, assisted living community or other type of long-term care facility. Hospice care is usually given wherever the patient is living.

The goals of hospice care are to:

- Respect dying and death as a normal process.
- Acknowledge that everyone has a right to die with comfort and dignity and surrounded by loved ones, if desired.
- Allow patients to live as actively as possible for as long as possible.
- Enhance the quality of life of patients, families and caregivers.
- Support caregivers, family and friends as they care for their loved one.
- Respect the unique needs and wishes of patients and their loved ones.
- Provide compassionate care that relieves pain and other symptoms.
- Allow the dying process to occur naturally.
- Provide grief and bereavement support before and after death.
- Be available to patients wherever they live, regardless of race, ethnicity, sexual orientation or ability to pay.
- Allow death to occur in the setting that the patient wants.

Hospice staff can help pancreatic cancer patients understand their options when they do not have a loved one or friend to provide this kind of care. More effective side effect and pain management, assistance with getting personal and legal affairs in order and many options for emotional support are some of the reasons that patients and their families choose hospice care.

DOES CHOOSING HOSPICE MEAN GIVING UP HOPE?

Many patients and caregivers are afraid to ask about hospice because they believe that using hospice means giving up. Hospice is not about giving up. Choosing hospice allows families to focus their energy on quality of life. Hospice care provides an opportunity to make meaningful choices and to have those choices respected. If the patient's condition improves, the patient may be discharged from hospice and return to active cancer treatment, if desired.

Hospice is not about losing hope. However, what patients and their loved ones hope for may change. Using hospice services can help a patient find hope for new things, like getting the care he or she deserves, feeling relief from pain, spending valuable time with family and friends or finding peace and acceptance in their lives.

WHEN DOES A CANCER PATIENT BECOME ELIGIBLE FOR HOSPICE CARE?

Hospice may begin as soon as a referral is made by the patient's doctor. A doctor issues a "referring order" to hospice which certifies that life expectancy is six months or less if the pancreatic cancer follows the expected course. The patient may still be quite active, able to carry on in daily life and even travel at the time he or she is referred to hospice.

Hospice benefits are unlimited. This means that if a patient in hospice care lives longer than six months and the referring doctor states that their life expectancy is still less than six months, then hospice care can continue.

If the patient's condition improves while on hospice care, the patient may choose to stop hospice care and resume **cancer-fighting treatment**. Patients also have the right to stop hospice care for any other reason. Patients are able to go back to hospice at any time, if they are eligible.

WHEN SHOULD HOSPICE BE DISCUSSED AND WHO BRINGS UP THE SUBJECT?

Hospice may be discussed at any time. Some people are unable or unwilling to talk about death, while others are willing to openly explore the subject. The patient may ask about hospice first. However, a caregiver, family member, doctor, nurse or **social worker** may also bring up hospice as an option. Patients should do what feels best for them and their loved ones.

Usually the discussion about hospice takes place when one of the following situations occurs:

- The patient learns that their cancer is not treatable and that additional therapies will not likely provide benefit.
- The patient is told by a doctor that they have six months or less to live.
- The patient is declining physically.
- The patient decides to discontinue treatment.

If you are a pancreatic cancer patient, only you know how you are truly feeling; this is your life and your decision, so openly share what you think is best for you. Usually patients and their families can make this decision together. However, the patient ultimately makes the final decision unless he or she is unable to communicate.

If you think that hospice care should be considered but are not sure how to start this conversation with your loved ones, ask a doctor, hospice social worker, hospice care provider or another trusted healthcare professional to help you and your loved ones talk about these difficult issues and understand what options are available.

CULTURAL CONSIDERATIONS

Hospice is a unique model of care that focuses on comfort and quality of life, instead of curative treatment. Hospice also focuses on dignity and respect at the end of life, which is why providers should take special care to consider each patient's culture, family, age, race, ethnicity, and more when formulating a care plan. Each of these factors has an impact on how a patient views everything from pain and symptom management to spiritual needs in the months, days, and hours leading up to the end of life. Patients will have different values at the end of life, some people value comfort, while others value being awake and present, even if it means being in a little bit of pain. There is no right or wrong way to approach hospice, and it is important for patients to remain connected to their cultural identity at the end of life. Patients should be open with their healthcare team about any end-of-life issues, rituals, religious celebrations, customs, along with goals of care so that caregivers can provide respectful, dignified hospice care that meets any physical, emotional, spiritual needs.

HOSPICE CARE SERVICES

Hospice care is flexible and can be molded to fit different needs and lifestyles. The different levels of hospice care include the following options.

HOME CARE is given in a private home. The hospice staff visits to offer hands-on care, assessment of the patient's condition and symptom management. During this type of **home care**, they also help caregivers learn how to provide day-to-day care.

IN-HOME CRISIS CARE (also called continuous care) is short-term, in-home care that is available when symptoms cannot be managed by the regular caregivers. Under some health insurance plans, crisis care nursing support can be provided in the home 24 hours a day for a limited number of days. The hospice organization determines when such care is needed and for how long.

INPATIENT HOSPICE CARE is delivered in healthcare facilities, such as a hospice facility, hospital or nursing home. This type of care is used to manage pain or other symptoms that cannot be addressed at home. The length of stay will be different at each type of facility.

Some patients may be able to indefinitely remain at the inpatient hospice facility. However, this is usually not covered by insurance and may require patients or family members to pay for some services out-of-pocket.

RESPITE CARE provides time for home caregivers and others in the household to rest while the cancer patient is cared for in an inpatient setting or nursing facility for up to five days (see page 34).

Some families may provide the majority of hospice care at home but prefer that death occur somewhere else. This choice, though potentially very difficult, should be discussed early on. Having a plan can help ensure that everyone is comfortable with what occurs during the final days and hours.

WHO PROVIDES HOSPICE SERVICES?

Hospice care is a team effort. A team of trained professionals works with caregivers to care for the patient and guide families throughout the hospice journey. The table to the right lists the different people involved in providing hospice care. Each person performs a unique set of duties aimed at improving quality of life for the pancreatic cancer patient.

If home hospice care is provided, the key person on the hospice team is the primary caregiver. The primary caregiver may be a spouse, partner, parent, child, sibling, relative, friend or privately hired person. Caregivers do many things, including: giving medication, continually monitoring changes in the patient's condition, preparing meals and helping with all aspects of **personal care**. The primary caregiver works closely with the hospice staff to keep the patient as comfortable as possible.

If a pancreatic cancer patient does not have a primary caregiver, the hospice team will assist the individual in finding available community resources and support.

Hospice doctor	• Oversees the plan of care. • Orders medications. • Works with the patient's oncologist or primary care doctor and provides consultation or primary care when necessary.
Hospice nurse	• Trains caregivers in caring for the patient's physical and medical needs. • Monitors the patient's condition. • Provides support to the patient and caregivers.
Home health aide or certified nursing assistant (CNA)	• Helps the patient with personal care needs such as bathing and grooming.
Social worker	• Links caregivers and families to community resources. • Offers help with planning and practical matters such as insurance, finances and legal matters. • Offers emotional support for all individuals involved.
Chaplain* *(pastoral counselor or other spiritual advisor)*	• Offers support to the patient and loved ones to explore spiritual and/or faith-based issues upon request. • Works with the patient's clergy, if appropriate, to make sure spiritual needs are being met.
Volunteer	• Assists the patient and caregivers in a variety of ways, including companionship and relief for the caregiver.
Grief and bereavement counselor	• Provides counseling for caregivers and other family members after death occurs. • Assists caregivers and other family members in dealing with death or any type of loss, including the patient's loss of physical abilities.
End-of-life Doula	• Assists with advance directives and logistics • Offers hands-on help and emotional support for patient and caregivers • Helps plan and prepare environment for the dying process, including spiritual, personal, and religious rituals

** Note: "Chaplain" is the term used to describe a professional who is trained to discuss spiritual questions that often become important at the end of life. Hospice chaplains do not promote any particular religion or belief system.*

ROLE OF THE PRIMARY DOCTOR

The doctor who has been providing most of the patient's care (oncologist or family doctor) will discuss with the hospice staff the patient's current condition and symptoms, as well as the history and course of the pancreatic cancer. After the patient enters hospice, the hospice team will keep the primary doctor informed about the patient's condition on a regular basis. The primary doctor will work with the hospice doctor or medical director to help oversee the hospice team and the patient's overall end-of-life care. If the patient is receiving care for a condition unrelated to their pancreatic cancer, that care can continue while the patient is on hospice.

HOW TO FIND A HOSPICE PROVIDER

Preparing for and making choices about end-of-life care, while extremely difficult, can offer patients and families a sense of relief and control. Such planning can be reassuring for everyone involved. Knowing what lies ahead can help reduce fears of the unknown. A list of questions to initiate planning is provided on pages 35–36.

Most communities have more than one hospice organization. Ask the patient's healthcare team or a social worker to help you find out what hospice care is available in your community and how to arrange for it. Keep in mind that you can switch hospice providers at any time if the patient or caregiver is unsatisfied.

The National Hospice and Palliative Care Organization (NHPCO) has a state-by-state directory of hospice providers on its website, nhpco.org. You may also receive assistance by calling the NHPCO CaringInfo HelpLine toll-free at 800-658-8898. In addition, the Pancreatic Cancer Action Network's Patient Services can provide resources to find hospice care in your area. Patient Services is available toll-free at 877-2-PANCAN or by email at **patientservices@pancan.org** Monday – Friday, 7 a.m. – 5 p.m. Pacific Time.

Good hospice organizations help you make decisions that work best for you and your family. Call the providers you want to interview and ask to meet with their admissions representatives. A list of questions to help guide your search in finding the appropriate hospice provider is available on pages 37–39.

AFFORDING HOSPICE CARE

Most health insurance companies offer hospice benefits that pay for all or most of the costs associated with hospice care. This means that families usually pay very little for end-of-life care. Contact the patient's health insurance provider for specifics on coverage. Hospice benefits generally pay for:

- Doctor services
- Nursing care
- Medical equipment (such as wheelchairs and walkers)
- Medical supplies (such as bandages and syringes)
- Medications for symptom control and pain relief
- Short-term care in the hospital, including respite and inpatient care for pain and symptom management
- In-home crisis care (as determined by hospice staff) for short-term, 24-hour nursing care at home to manage difficult symptoms
- Home health aide and housekeeping services
- Physical and occupational therapy
- Speech therapy
- Social work services
- Dietary counseling
- Grief support

Some insurers that provide hospice benefits include:

- Medicare – The Medicare Hospice Benefit
- Medicaid (in most states) – The Medicaid Hospice Benefit
- TRICARE (military health system)
- Most private insurance companies

If the patient does not have, or qualify for, any form of health insurance, some hospices can still provide care at little or no cost. Contact several hospice organizations to learn what is available.

Some costs are not covered by health insurance when hospice care is given in a retirement home or nursing facility. In this situation, the patient is usually responsible for paying for rent, meals and some routine care services that are provided by nurses and health aide workers who are employed by the retirement or nursing facility. Benefits vary among insurance plans. Be sure to check with the patient's insurance and hospice provider to ensure that the needs of the patient will be met.

MEDICAL AND PHYSICAL CARE

The hospice staff will work with the patient, the primary doctor and the caregiver to develop a **care plan** that addresses the patient's needs. This plan will be adjusted as the patient's condition changes, with the entire hospice team monitoring and responding to these modifications at all times.

Medical equipment, such as an adjustable hospital bed, may be arranged by hospice for use at home to keep the patient more comfortable and make caregiving easier. Hospice also provides necessary medical supplies such as bandages, gloves, syringes and catheters as needed.

Patients experience many different symptoms as the pancreatic cancer progresses. Time and energy will be spent trying to manage symptoms as they change. Different medications, often given around the clock, are used to relieve symptoms. Sometimes treating one symptom can cause others to appear. The caregiver will need to observe and discuss changes with the hospice staff while working to relieve any physical discomfort the patient may experience.

All difficult symptoms can be either alleviated or relieved completely. Ask your hospice team for help.

The nurse will tell the patient and caregiver what details they need to track and discuss with the hospice staff. Use a notebook to write down and describe symptom changes, including different levels of pain, new symptoms, responses to treatments and other changes, as instructed by hospice staff.

In most cases, cure-focused treatment does not continue once hospice care begins because hospice care focuses on providing comfort during the final weeks or months of advanced illness. Most insurance providers do not pay for cancer-fighting treatment once hospice care begins. However, some will pay for cancer-fighting treatment if the goal of the treatment is to decrease symptoms and increase quality of life rather than to cure the cancer.

For more information about pain and symptom management, contact Patient Services toll-free at 877-2-PANCAN or email **patientservices@pancan.org** and request a copy of the Pancreatic Cancer Action Network's educational booklet, *Supportive Care: Quality of Life and Practical Care in Pancreatic Cancer.*

MANAGING COMMON END-OF-LIFE PHYSICAL AND EMOTIONAL SYMPTOMS

Patients may experience different emotional and physical symptoms at the end of life. Many emotional challenges are accompanied by changes that caregivers need to watch for and discuss with the hospice staff. The hospice staff will guide caregivers on how to deal with these challenges.

Some of the common emotional symptoms experienced by patients are depression, anxiety, confusion and/or delirium.

- Symptoms associated with depression are feeling sad most of the time and not feeling happy at appropriate times (e.g., not feeling happy or interested when a friend comes to visit).
- Symptoms associated with anxiety include rapid heart rate, heart palpitations (feeling or hearing one's own heartbeat), breathing difficulties, dizziness, restlessness and nervousness.
- Symptoms associated with confusion or delirium include confusion about time, place, identity of loved ones; unusual changes in thinking or talking; loss of awareness about surroundings; memory loss; visions of people and places that are not present; inability to concentrate.

Poor pain management can lead to or worsen emotional issues. Medications can also cause or contribute to these issues. Some symptoms, such as sadness, are common and can be part of the dying process for the individual.

When a person is near end of life, some physical symptoms include:

- Irregular breathing, rattling sounds when breathing
- Skin becoming cool to the touch
- Decreased need for food and/or fluids, dry mouth
- Drowsiness, increased sleep and/or unresponsiveness
- Involuntary movements
- Darkened urine and a decreased amount of urine, loss of bladder or bowel control

PERSONAL CARE

The primary caregiver will provide most of the personal care with the support of home health aides, who may visit the home one to three times per week, depending on need.

Personal care involves assisting the patient with all activities of daily living including eating, dressing, bathing, grooming, using the toilet and other needs. It is likely that the patient will eventually be unable to move without assistance. Caregivers will need to help the patient change positions in bed or move around the room. It is important for caregivers to protect their own health at all times. If any of these tasks are too physically demanding, caregivers should ask for help.

If possible, the patient should choose the people they are comfortable with to perform different tasks. Also, family members and friends need to determine who feels comfortable performing these tasks.

Providing personal care is often the most physically and emotionally challenging aspect of caregiving. However, for some families it is satisfying and rewarding. For those who are not comfortable providing this care or need assistance, hiring private home health aides can help. Insurance companies that provide a hospice benefit may cover home health aide visits a few days a week as needed. Additional hours, if needed, may not be paid for by insurance.

END-OF-LIFE COMFORT CARE

The hospice staff will provide information about ways to keep the patient comfortable at the end of life. The patient's needs will change over time and the hospice team will help families understand and anticipate these changes. If questions arise, contact a member of the hospice staff.

Here are some ideas that may help keep the patient comfortable:

- Let the patient make decisions about food, activities and visitors.
- Ask what kind of lighting they prefer.
- Ask what music they like.
- Ask the patient if they would like to hear books read aloud.
- Sit in silence together.
- Make sure your hands are warm before giving a bath or touching the patient.
- Gently massage the patient's hands and feet.
- Let them know that it is okay to talk about anything, even if those topics are difficult to hear.
- Ask what they prefer to eat. Ask about having family meals together. Even if the patient has no appetite, they may still appreciate the company. Or, they may find that the sight and smell of others' food is unpleasant.
- If providing care becomes frustrating, leave the room for a moment to calm down.

If a time comes when the patient is no longer able to communicate, these suggestions may still help to provide comfort:

- Keep the light low.
- Play soothing music.
- Keep the patient's mouth and lips moist.
- Remember that the patient will probably be able to hear until the end of life, so talk to, and not about, them.

PRACTICAL CARE

Hospice can help with practical care. Practical care covers everything from insurance and other financial matters to light housekeeping and routine chores. Social workers, volunteers and housekeepers provide these practical services.

The hospice social worker can also help with many practical concerns including:

- Explaining and helping to complete advance directives (see below), if requested.
- Identifying and explaining insurance benefits.
- Explaining what services are paid for as hospice benefits.
- Setting up a system for staying organized.
- Linking the patient, caregivers and family to community resources.
- Arranging for respite care that gives caregivers time off.
- Contacting friends and relatives.
- Assisting with funeral arrangements but not funeral costs.
- Destroying remaining medication.

Most hospice organizations have trained volunteers to help patients and their families. Volunteers may be available to:

- Help with household chores and responsibilities.
- Run errands.
- Help with child care.
- Stay with the patient while the caregiver takes time to rest.

ADVANCE DIRECTIVES

Advance directives give patients the control and legal ability to state exactly how they want to be cared for, and who they want to make decisions for them if they become unable to communicate their wishes. When patients are no longer able to discuss medical options with their healthcare teams or their families, advance directives make their wishes known.

Advance directives include documents such as a "Directive to Family and Doctors" (more commonly known as a "living will"), a "Durable Medical Power of Attorney," a "Do Not Resuscitate" (DNR) order and a "Physician Orders for Life-Sustaining Treatment" (POLST) form.

A "Directive to Family and Doctors" document outlines the patient's wishes regarding medical treatments that they do and do not wish to receive. This includes mechanical breathing aids (respirators or ventilators), tube feeding and cardiopulmonary resuscitation (CPR). Doctors and loved ones can help patients make and document these important decisions.

Pancreatic cancer patients may also wish to obtain a "Durable Medical Power of Attorney." This document allows the patient to designate a trusted person as their healthcare agent or proxy. A healthcare agent/proxy is able to make medical decisions for the patient if they are incapacitated and therefore unable to make decisions. When choosing a healthcare agent, it is important to have an open discussion with that person to make sure they understand the patient's thoughts and opinions regarding their illness. The healthcare agent should know how the patient wishes to live the remainder of their life. A medical power of attorney is different from a legal power of attorney. A legal power of attorney grants an individual the authority to make financial and other decisions on behalf of the patient.

A "Do Not Resuscitate" (DNR) order is an advance directive that states that no life-saving medical procedures, including CPR, are to be used if the heart or breathing stops. The use of CPR on patients with advanced pancreatic cancer may reduce quality of life and prolong the dying process.

The "Physician Orders for Life-Sustaining Treatment" (POLST) form is a medical order that specifies what a patient wishes to do in case of an emergency. This may be inclusive of a DNR order as well as other requested interventions in case the heart or breathing stops.

If advance directives have not been completed at the time of hospice admission and the patient would like to complete them, the staff can help to arrange for and finalize these documents. Hospice staff and the patient's doctor can discuss the benefits and risks of CPR, a DNR order and a POLST form so that an informed decision can be made. Advance directives and DNR orders can be changed by the patient at any time. In all cases, creation or modification of advance directives must be initiated by the patient, not by the hospice or healthcare teams.

These documents can be prepared at the patient's request and must be signed by the patient before they are given to the doctor. The patient decides what provisions will be included in each document. However, if the patient is incapacitated and not able to clearly communicate their wishes when hospice care is needed, then certain family members can prepare these documents on the patient's behalf.

Hospice professionals support the patient's right to make their own decisions. Patients are not required to have a DNR order to receive hospice services.

In addition to the hospice team, legal advisors can help finalize details of the patient's advance directives.

PLANNING MEMORIAL SERVICES

Discussing funeral or memorial services can be extremely difficult. Some people facing end of life want to talk about these arrangements and discuss what music, rituals or readings would be most meaningful to them. Others, however, are not comfortable discussing these things and prefer to leave all decisions to their loved ones.

Hospice staff, social workers and faith-based advisors are available to talk to patients and their loved ones to find out whether they want a discussion about funeral or memorial planning. If the patient does not want to discuss such plans, their feelings should be respected. Families and other loved ones can make appropriate arrangements when the time comes.

For those planning a service, the following questions may be helpful to ask:

- Will the event be held at home, at a religious institution or at another location important to the patient?
- Will a family member, friend or religious official speak?
- Will there be songs performed or music playing?
- Are there poems or readings that will be presented?
- Will pictures or videos be displayed at the service?
- Who will be invited to attend?
- Will there be flower arrangements?
- Will a public notice for the service be printed in a local newspaper?

EMOTIONAL AND SPIRITUAL CARE

Hospice care offers emotional and spiritual support for both patients and their loved ones. Each patient's experience at the end of life will be unique. Some individuals have many loved ones or friends around them, while others may take comfort in the support provided by caring hospice staff members or volunteers. Hospice intends to provide a peaceful environment for any patient regardless of their situation. The social worker, chaplain and other hospice team members help provide emotional and spiritual support.

Social workers, if requested, answer questions and help loved ones talk about how they are feeling and what they are experiencing. Should tensions arise among family members or loved ones, the social worker can offer assistance in discussing difficult issues.

The hospice chaplain, if requested, can work alone or with the family's spiritual advisors to answer questions and guide conversations about the meaning of life, death and other faith-based issues that the patient and loved ones may want to discuss. Both the social worker and chaplain also offer caring companionship, lead discussions about death and dying and assist with grief and bereavement.

WHAT EMOTIONS CAN BE EXPECTED?

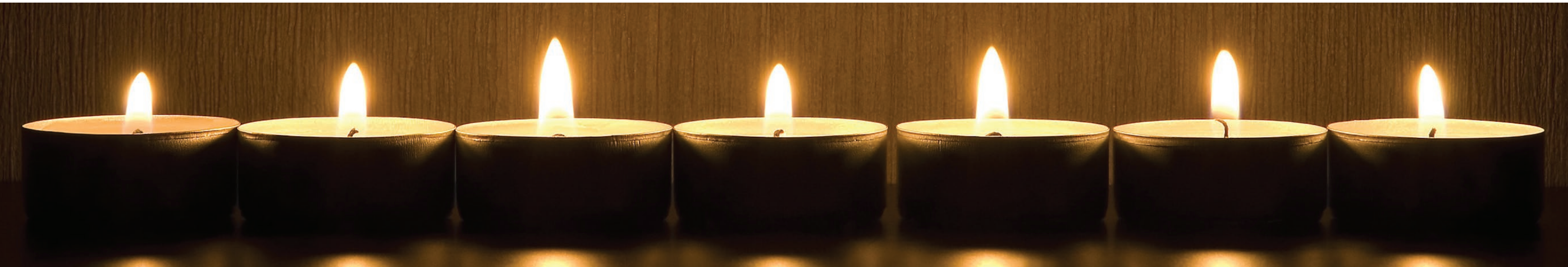
Patients and their loved ones are often in different places emotionally when hospice care begins. Having patience and respect is very helpful for all involved.

Patients and their loved ones may experience many types of emotions, both expected and unexpected, and these emotions may come and go without warning, including:

- Denial about death
- Fear of the unknown, the future and separation
- Anger that cancer is taking away life
- Depression and anxiety
- Guilt about lifestyle habits that may have affected health
- Grief and tremendous sadness
- Relief that the pain and suffering are nearly over
- Peace and acceptance

The hospice journey can be an extremely sad time for everyone and emotions are often intense. Some families are able to use their remaining time together to grow closer. They celebrate the life they have shared by talking, laughing, telling stories and being open about their feelings, perhaps as never before.

The end-of-life process may affect patients in both physical and emotional ways. Patients may have trouble sleeping, which can



lead to fatigue. The fatigue, in turn, can make negative feelings worse and even result in depression. Caregivers or loved ones who become emotionally overwhelmed may be helped by the hospice social worker or by a therapist.

It is a good idea for patients to talk with the hospice staff about emotions regarding hospice care, including whether they are willing or able to have loved ones present. These factors may affect overall quality of life. Hospice staff are both willing and able to help manage these challenges.

EMOTIONAL AND SPIRITUAL SUPPORT FOR FAMILIES AND CAREGIVERS

The primary caregiver and the patient's family are invited and welcome to talk about their feelings with the hospice nurse, social worker and chaplain.

Because caregiving is such a great responsibility, caregivers need to take care of themselves. Otherwise, they may become physically, emotionally and spiritually exhausted. Caregivers may choose to share experiences and talk openly and honestly with someone other than the loved one for whom they are caring. Keeping feelings or emotions inside can be harmful. Expressing and sharing them can be freeing. Find someone to talk with and cry with, someone who will just listen and not judge.

Hospice provides families and loved ones with bereavement support free of charge for one year after a death. There is no obligation to choose this. Caregivers will receive letters and phone calls on a regular basis during this time. Caregivers will have opportunities to participate in grief support groups or individual counseling (if offered) and the option to hold memorial services. Special counseling services are sometimes available for children and friends who have lost loved ones.

CAREGIVER ROLES AND RESPONSIBILITIES

Hospice is patient- and family-centered, meaning that it is designed to look after the needs of the patient as well as the needs of the caregiver and other loved ones.

The final phase of the individual's pancreatic cancer journey may be a very intense experience. Caregivers provide a very loving gift by ensuring that the people they love die with peace and dignity.

Many caregivers say that caring for a loved one nearing death was an important time of personal growth. Providing care for loved ones in this way may also help with the grieving process after death. The experience often brings a great sense of joy and satisfaction in having helped to make a loved one's last days happier and more peaceful.

A person living with advanced pancreatic cancer usually has a variety of symptoms that caregivers work to manage. The needs of a cancer patient in hospice will probably increase over time. Each patient's experience will be different. Caregivers may provide:

Physical care

- Organizing and giving medication.
- Monitoring symptoms and discussing treatments with loved ones and hospice staff.
- Providing assistance with personal care such as bathing, dressing, eating and using the toilet.

Emotional care

- Listening, talking, reading or playing music.
- Providing caring companionship and love.

Practical care

- Handling insurance and other financial matters.
- Paying bills.
- Coordinating visits from family, loved ones, friends and hospice staff.
- Discussing last wishes to ensure that they are carried out (if the caregiver is the healthcare power of attorney).

CAREGIVER PLANNING

During the hospice journey, many memories are created – the last memories that caregivers and family members will share with their loved one. Keep this in mind when planning for end-of-life care. Becoming a home caregiver for someone who is dying may come suddenly or after many years of pancreatic cancer treatment. Take time to look within and think about personal strengths and limitations.

Serving as a caregiver can be extremely rewarding. Many partners, family members or friends who have helped with caregiving found it very satisfying and would not have chosen any other option. However, caregiving is also a considerable responsibility that is both physically and emotionally demanding. It is important for caregivers to maintain their own self-care or they will not be able to care for their loved one at the most crucial times.

QUESTIONS FOR CAREGIVERS TO ASK THEMSELVES

1. *Am I physically strong enough to lift and move my loved one?*
2. *Do I have any health issues that may limit me in providing care?*
3. *Can I take care of personal and family needs at the same time?*
4. *Can I afford to take time off from work if necessary?*
5. *Do I want to provide end-of-life care at home?*
6. *Could I handle being a caregiver for several months?*
7. *Do my loved one and I want death to occur at home or somewhere else? Does everyone involved in caregiving understand how this decision will be carried out?*
8. *Do I have family members and loved ones who are willing and able to help?*

CAREGIVERS AND THE HOME HOSPICE TEAM

Caregivers and the hospice staff will work together to keep the patient as comfortable as possible. The staff will help set up a space in the home where care is easiest to give. Hospice arranges for and provides all equipment and supplies that are needed to care for the patient.

The hospice staff is available by phone 24 hours a day to answer questions. Together with caregivers and patients, the hospice team will create a care plan that is based on specific needs. The care plan includes visits from the hospice team members and can be modified on an ongoing basis to meet the patient's needs. Below is a typical example of scheduled visits from hospice staff.

- Hospice nurse: once or twice a week
- Social worker: once a month
- Chaplain: once a month
- Home health aide: one to three times a week
- Volunteers: several hours a week as needed by caregivers

The hospice staff may visit the patient's home more often, if needed. They will also prepare, train, guide and support caregivers throughout the hospice experience. The hospice nurse can teach caregivers to monitor the patient's symptoms, safely lift and move the patient if appropriate, safely operate the necessary medical equipment, organize and give medications, provide personal care, and understand changes that occur and plan ahead. The social worker can help caregivers get organized in order to provide care, find community support resources, talk about feelings and emotions and plan for the future.

WORKING EFFECTIVELY WITH THE HOSPICE TEAM

Remember, the caregiver is a vital part of the team. Because home hospice care entails hospice staff visiting the home only a certain number of hours per week, caregivers are responsible for their loved one's care most of the time. The day-to-day care of the patient is essential to good hospice care. The hospice staff will be there every step of the way to help provide this care. Here are tips for working well together:

- Create a notebook (see page 30) to keep caregiving information in one place; bring this notebook along when talking to the hospice staff.
- When describing a new symptom, give as many details as possible, such as time of onset, duration, strength, recurrence and steps taken as a result. These details will help the hospice team find the best solutions.
- Always feel free to ask questions and seek help from the hospice staff.
- If something is not clear, keep asking questions until it is understood completely.

Caregivers should expect the hospice staff to listen respectfully and respond quickly at any hour of the day or night. A 24-hour hospice emergency number will be provided; be sure this number is kept in an obvious and visible place.

You can also call 911 if there is an emergency, such as if the patient falls and the caregiver cannot safely lift the patient. In this case, tell the operator that transport to the hospital is unnecessary, but you need help lifting the patient.

ORGANIZATIONAL TIPS FOR CAREGIVERS

Caregivers keep track of important information regarding the patient's care. Setting up and maintaining a system to organize this information will make life as a caregiver much easier. Some people are able to organize all of the information by themselves, but most people need help. Hospice staff can help develop an organizational system. Or, caregivers can ask a trusted family member or friend for help. Here are some ideas to get started.

- Have a notebook or 3-ring binder with sections to keep everything in one place, including:
  - Calendar for keeping track of visits from the hospice staff, volunteers, family and friends
  - List of prescriptions, date(s) prescribed and prescription numbers
  - Medication journal – dosages, times to give, purpose of medication and side effects
  - Symptom journal
  - Instructions from hospice staff
  - Phone numbers and other contact information
  - Medical records
  - Questions to ask at the next appointment
- Keep this notebook in one convenient place so that anyone who comes into the home has easy access to it.
- When talking with the hospice staff, take notes for reference at a later time.
- Keep all medicines in one place and out of reach of children.
- Keep supplies within easy reach of where they will be used.

- If there is a Do Not Resuscitate (DNR) order or a Physician Orders for Life Saving Treatment (POLST) form, put it in a visible place that anyone in the house can easily see.
- Make a list of important phone numbers and keep this list in a convenient location, such as on the refrigerator. Include names and contact information for the following:
  - Hospice staff including day and night numbers
  - Caregiver's cell phone number, work number and other numbers
  - Emergency contact in case the caregiver cannot be reached
  - Pharmacy address, phone number and hours
  - Family members and friends who can help
  - Other individuals who can make medical decisions

CAREGIVERS AND WORK OBLIGATIONS

Caregiving does require a time commitment. The amount of time and energy needed to provide care for someone is not easy to predict. Sometimes a rotating schedule with other family members and loved ones is helpful. However, as caregiving can be very demanding at times, it may be necessary to take time off from work at some point. Caregivers should talk with their employers about flexible hours, schedule changes, working from home, vacation time and/or sick-leave time.

Serving as a caregiver for an immediate family member (spouse, child or parent) may be covered by the Family Medical Leave Act, which protects an individual's job standing and benefits during unpaid leave of up to 12 weeks during any 12-month period. These 12 weeks can be used consecutively or broken up into months, weeks, days or hours. As not all companies qualify for this benefit, consult the employer's human resources specialist for more specific information.

SELF-CARE FOR CAREGIVERS

Taking care of one's self as a caregiver is very important. There are several ways to make the job of providing care less difficult.

The following are some ideas intended to help caregivers take care of their own needs:

- Get enough rest. Fatigue is the number one challenge for caregivers.
- Maintain a healthy, balanced diet.
- Pay attention to your own health. Continue to take medications and visit healthcare providers.
- Set aside some time every day to read, take a walk, have lunch with friends or just relax.
- Let some things go or assign tasks to other family members or friends.
- Talk to the hospice staff, friends and spiritual advisors about your feelings and what the experience is like.
- Find and take advantage of opportunities to share, laugh and remember.
- Express feelings.
- Let the patient have time alone, if requested.
- Talk to a social worker or a counselor if feelings become overwhelming or if depression is present.
- Participate in online support groups to learn how others have handled caregiving.
- Engage in spiritual activities.
- Schedule respite care (see page 34).
- Be as patient and compassionate with yourself as you are with your loved ones.
- Appoint one person to stay in touch with loved ones and friends about the patient's condition. Emailing or creating an online journal, or **blog**, can also make communicating with many people easier and faster.

Have a back-up plan in the event caregiving becomes too much for you as the primary caregiver. Even if the back-up plan is never used, it may be relieving to know there are other options.

Getting help

Caregiving is a 24-hour-a-day job. Most caregivers cannot do it alone – they need help. Asking for and accepting assistance may be hard but will give other loved ones the opportunity to serve and feel good for doing so. Talk to family members, loved ones and friends about when and how they can help, and give them specific tasks to do such as grocery shopping, housekeeping or picking up prescriptions.

Make a list of helpers to call on, people who are trustworthy and reliable. Talk with these people and tell them what is needed. Make up a weekly schedule of when helpers will be available. Write down all the information necessary to stay in touch with the helpers. Here is an example of an organizational chart:

NAME	PHONE/EMAIL	AVAILABILITY	WILL HELP WITH
Mary Smith	555-0000 smith@email.com	Weekdays, 6-8 p.m.	Sorting mail
John Ames	555-1111 ames@email.com	Tues, Thurs evenings	Picking up prescriptions
Connie Brown	555-2222 brown@email.com	Weekdays, 7-10 a.m. Saturdays until noon	Cleaning house and buying groceries

Caregivers may also wish to keep an ongoing list of specific tasks that need attention in a convenient place. When someone unexpected offers to help, refer to the list.

If outside help is hired, such as home health aides, write a list of duties so these individuals will know exactly what is expected of them. Hospice does not pay for the services of any private professionals that are hired.

Respite care

Caregivers may need extended breaks to avoid physical and emotional exhaustion. Hospice offers respite care to relieve caregivers for up to five days per month. Hospice benefits pay for the patient to be cared for outside the home (at a hospice facility or other residential care facility) while the primary caregiver rests and spends time on personal interests. Caregivers can visit their loved one at any time during this period of respite care. Talk with hospice staff about arranging for respite. Try to plan ahead as respite care may not be available immediately.

END-OF-LIFE CARE PLANNING

Patients can begin planning for end-of-life care by asking themselves some basic questions and discussing their desires with loved ones. If needed, the healthcare team can also help plan the best level of end-of-life care.

QUESTIONS FOR PATIENTS TO ASK THEMSELVES

If my condition gets worse, where do I want to live?

- Where would I feel most comfortable during my final months and weeks?
- Would this be my own home or the home of a loved one or friend?
- Could I live in an assisted living facility or nursing home?
- Would I like to go to a dedicated hospice setting, if available?
- Where do I want to die – at home or somewhere else?

Who would I want to take care of me and who would I like to be my primary caregiver?

- Who do I want to help me with my daily care needs such as bathing, dressing, eating and going to the bathroom?
- Who do I trust and feel totally comfortable around?
- Who in my life is able and willing to stay with me and care for me in my final days?
- Would my caregiver be my spouse, partner, another relative, friend or neighbor?

- Would I like to have around-the-clock nursing or home health assistance?
- Can I afford such assistance since private services are not covered by hospice benefits?

What, if any, types of medical support do I want to receive as death approaches?

- Would I want healthcare workers to attempt to revive me with CPR if my heart or breathing stops?
- Do I want life support technology to be used to attempt to keep me alive?
- Do I want death to occur without medical interventions?

What hospice organizations and other end-of-life care organizations are available in my area?

QUESTIONS TO DISCUSS WITH HOSPICE PROVIDERS

HOSPICE

- How long has the hospice organization been established in the community?
- Who owns the hospice? Is it owned by an individual, a partnership or a corporation? Is it a for-profit corporation or a nonprofit organization?
- Is this hospice organization licensed by the state and certified by Medicare?
- What other accreditation does the organization have?
- What industry quality standards does the organization meet?

STAFF

- Who is the medical director and what are their credentials? Are they certified in hospice?
- How many members of the nursing staff are certified in hospice?
- What are the credentials of the social workers and chaplains?
- What are the credentials of the other staff members?
- How are home caregivers trained?

SERVICES

- What services are provided by the hospice?
- What services are provided in nursing homes or other residential care facilities?
- At which facilities (hospitals, nursing facilities and other healthcare settings) does the hospice provide care?
- Does the organization have its own facility for inpatient care? If not, where does the hospice provide inpatient hospice care?
- Is there 24-hour access to the hospice staff?
- What services are available after hours?
- How often will the hospice staff visit the patient and caregiver at home?
- What hospice services are not paid for by insurance, Medicare or Medicaid?

MEDICAL CARE

- How is the patient's personal doctor involved in hospice care?
- What is the role of the hospice doctor?
- Which cancer-fighting treatments can be continued and which must be stopped?
- Is there a RN (registered nurse) on-call 24 hours a day? Are the on-call RNs certified in hospice?

VOLUNTEERS

- Are volunteers available to help the family?
- What type of training do volunteers receive?
- What is the volunteer's role in the organization?

FAMILY SUPPORT

- How does the hospice organization support the family?
- Are housekeeping services offered?
- How and where is respite care provided?
- How are the emotional and spiritual needs of the patient and family addressed?
- What bereavement support is provided?

ADDITIONAL HOSPICE RESOURCES

Cancer*Care*, Inc.
cancercare.org, 800-813-HOPE (4673)

Compassion & Choices
compassionandchoices.org, 800-247-7421

Federal Trade Commission – Funeral Planning Tips
consumer.ftc.gov/articles/0070-shopping-funeral-services

GriefNet
griefnet.org

The Hospice Association of America
hospice.nahc.org 202-547-7424

Hospice Foundation of America
hospicefoundation.org, 800-854-3402

Medicare Hospice Benefits
medicare.gov/Pubs/pdf/02154-Medicare-Hospice-Benefits.PDF

Mental Health America
nmha.org, 800-969-6642

National Hospice and Palliative Care Organization (NHPCO)
nhpco.org, 703-837-1500

National Hospice and Palliative Care Organization (NHPCO) CaringInfo
caringinfo.org, 800-658-8898

National Hospice Foundation
nationalhospicefoundation.org, 877-470-6472

GLOSSARY

Blog: A website that functions as an online diary or commentary on a particular subject. A blog may combine text, images, audio, video and links to other online resources. Many blogs allow readers to leave comments or responses regarding the author's content. The term blog is a fusion of the words web and log (web log).

Cancer-fighting treatment: Any cancer treatment whose goal is curative in nature. Cancer-fighting treatments may include surgery, chemotherapy, radiation therapy, targeted therapy and/or immunotherapy. Once treatments to fight the cancer are no longer an option, patients will only receive treatments that improve quality of life.

Caregiver: A term used to refer to whoever is providing most of the patient's day-to-day care, whether that person is a spouse, partner, parent, child, sibling, relative, close friend or privately hired person. This person is also referred to as the primary caregiver.

Care plan: A strategy that is based on fulfilling the cancer patient's individualized needs.

Home care: The most common type of hospice in which the hospice staff visits the private home to assess the patient's condition and manage symptoms. Most of the patient's day-to-day care is provided by a family member or close friend.

Hospice: A healthcare model that focuses on quality of life during the last months, days and hours of life. Hospice care begins when life expectancy is no longer than six months and there is no further benefit from curative treatments. Most hospice care is provided in the home with a family member or close friend assuming the role of primary caregiver.

Hospice team: A group of health professionals who work with the caregivers to provide end-of-life care for the cancer patient. The health professionals on the hospice team include the hospice doctor, registered nurse, home health aides/certified nursing assistants, social worker, chaplain, volunteers and bereavement counselor.

Personal care: A type of caregiving that involves assisting the cancer patient with activities of daily living including eating, dressing, bathing, grooming, using the toilet and other needs.

Practical care: A type of hospice care provided by housekeepers, social workers and volunteers. Practical care covers everything from insurance and other financial matters to routine chores.

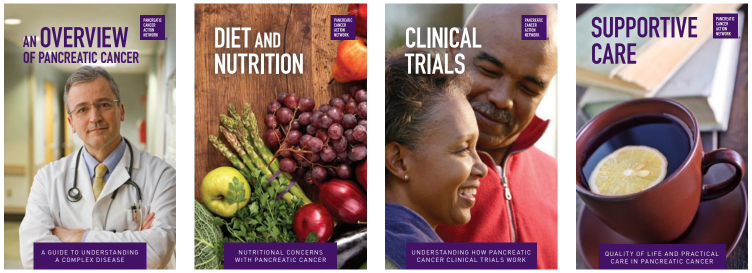
Social worker: A professional who is trained to assist and counsel patients and families. Most hospitals and cancer centers have specific oncology social workers. The role of the social worker is to provide resources regarding treatment, support groups, financial resources, end-of-life care, transportation assistance or home care.

The Pancreatic Cancer Action Network thanks the Patient Services Committee members of our

SCIENTIFIC AND MEDICAL ADVISORY BOARD

for providing their medical expertise in reviewing this booklet. These members are experts from such institutions as MD Anderson Cancer Center, Memorial Sloan-Kettering Cancer Center, Virginia Mason Medical Center, etc.

To see all of our Scientific and Medical Advisory Board members, visit pancan.org/SMAB.



Other booklets in the Pancreatic Cancer Action Network's educational library

Want to know more about any of the services we offer? Contact Patient Services, Monday through Friday, 7 a.m. to 5 p.m. Pacific Time.

Call toll-free **877-2-PANCAN**
Email **patientservices@pancan.org**

Because of the philanthropy of generous friends, we are able to provide all of our resources and services to you, ***free of charge.***

The information and services provided by the Pancreatic Cancer Action Network, Inc., are for informational purposes only. The information and services are not intended to be substitutes for professional medical advice, diagnosis or treatment. If you are ill, or suspect that you are ill, see a doctor immediately. The Pancreatic Cancer Action Network does not recommend nor endorse any specific physicians, products or treatments even though they may be mentioned in this booklet. In addition, please note that any personal information you provide to the Pancreatic Cancer Action Network's Associates during telephone and/or email consultations may be stored in a secure database to assist the Pancreatic Cancer Action Network, Inc., in providing you with the best service possible. Portions of the constituent data stored in this database may be used to inform you about future programs and services of the Pancreatic Cancer Action Network, Inc., and may be provided in aggregate form to third parties to guide future pancreatic cancer research and treatment efforts. The Pancreatic Cancer Action Network, Inc., will not provide personal identifying information (such as your name or contact information) to third parties without your advanced written consent.

CREATING A LEGACY

Patients and their family members have often shared with Patient Services their admiration for, and alliance with, the mission of Pancreatic Cancer Action Network (PanCAN) to support the fight to end pancreatic cancer.

Many individuals choose to partner with us in that fight by creating a legacy through a "planned gift."

What Is a Planned Gift?

Typically, this type of gift is arranged now and will benefit the organization at a later date (most often, after the donor has passed away). Planned gifts may even provide tax benefits for donors.

Planned gifts can be comprised of many types of assets, including:

- cash
- securities
- real estate
- insurance or retirement plans

The most popular — and simplest — example of a planned gift is a bequest.

You Can Make a Planned Gift

Anyone can make a planned gift. Through strategic and careful planning, many families are able to provide critical resources for PanCAN to continue its important work.

Each and every planned gift provides important resources for PanCAN — and every gift provides a legacy in which your family can find meaning and a lasting demonstration of your values.

How to Make a Planned Gift

If you wish to learn more about how your planned gift can create a legacy for you and your family while aligning your values and support with our vision, please call **877-2-PANCAN** and ask for our Development Department. You may also ask Patient Services to have someone call you.

** This information is not intended as legal, accounting or other professional advice.*
For assistance in charitable planning, always engage the services of a qualified professional.

ACTION FOR PATIENTS BEGINS HERE

The mission of the Pancreatic Cancer Action Network (PanCAN) is to take bold action to improve the lives of everyone impacted by pancreatic cancer by advancing scientific research, building community, sharing knowledge and advocating for patients.

Our vision is to create a world in which all patients with pancreatic cancer will thrive.

Through our Patient Services program, we provide extensive individualized support and hope. PanCAN Patient Services connects patients, their caregivers and family members to reliable information and resources. Our highly educated and expertly trained staff's passion is equaled only by their depth of knowledge about pancreatic cancer.

To learn more about our free, personalized resources and services, visit pancan.org or call 877–2–PANCAN.

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