

SUPPORTIVE CARE

PANCREATIC
CANCER
ACTION
NETWORK[®]



QUALITY OF LIFE AND PRACTICAL
CARE IN PANCREATIC CANCER

Seeing healthcare professionals who focus on symptom management and supportive care improves outcomes and is critical for your quality of life.

The Pancreatic Cancer Action Network strongly recommends that symptom management and supportive care be provided early in your diagnosis as well as during and after treatment.

ABOUT THIS BOOKLET

Supportive care is meant to relieve the symptoms and side effects of a disease and its treatment. It should be provided from the time of diagnosis and throughout the pancreatic cancer journey. Studies have shown that there are measurable benefits to supportive care like better treatment results, less pain and improved emotional health. Quality supportive care should address side effects, symptoms, emotional and mental health, as well as social concerns, like finances and caregiving support.

In this booklet, the Pancreatic Cancer Action Network (PanCAN) will provide basic information about supportive care options available to pancreatic cancer patients, survivors and caregivers, answer frequently asked questions, and help address any misunderstandings about the purpose behind this type of care. This booklet help guide discussion with healthcare professionals and loved ones who are in need of updated information on the principles of supportive care.

People with pancreatic cancer who are facing end of life will have special needs that are not covered in this booklet. PanCAN Patient Services can assist with a wide variety of topics relating to pancreatic cancer. They have access to resources that may help address these concerns.

Hablamos español. Contact PanCAN Patient Services toll-free at 877-2-PANCAN or by email at patientservices@pancan.org. Patient Services Help Line is available Monday – Friday, 7 a.m. – 5 p.m. Pacific Time. All services are free of charge.

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

CONTENTS

1 UNDERSTANDING SUPPORTIVE CARE

- 2 The Purpose of Supportive Care in Cancer
- 3 When Do Patients Need Supportive Care?
- 4 Individual and Cultural Differences

5 SUPPORTIVE CARE SERVICES

- 6 Where Are Supportive Care Services Delivered?
- 6 Working with Healthcare Professionals to Obtain Supportive Care Services

10 SUPPORTIVE CARE FOR PHYSICAL CONCERNS

- 10 Pain
- 15 Jaundice
- 15 Bowel Changes
- 17 Digestive Difficulties
- 19 Weight Loss
- 19 Dysphagia (Trouble Swallowing)
- 20 Diabetes
- 21 Fatigue
- 21 Ascites
- 22 Skin and Nail Changes
- 23 Neuropathy
- 24 Low Blood Cell Counts
- 24 Blood Clots
- 25 Hair Loss
- 25 Mouth Sores
- 26 Sleep Hygiene
- 27 Exercise

30 SUPPORTIVE CARE FOR EMOTIONAL CONCERNS

- 30 Emotional Concerns
- 33 Managing Emotional Concerns and Mental Health

36 SUPPORTIVE CARE FOR PRACTICAL CONCERNS

- 37 Advance Directives

39 SUPPORTIVE CARE PROVIDERS

- 40 Physical Well-being
- 41 Emotional, Social, Spiritual Well-being
- 41 Assistance with Practical Concerns

42 CHALLENGES TO RECEIVING SUPPORTIVE CARE

- 42 Financial Limitations
- 43 Lack of Energy
- 43 Lack of Understanding
- 44 Difficulty Finding Services

45 GETTING AND STAYING ORGANIZED

- 45 Keep a Written Record of Symptoms and Concerns
- 46 Organizing for Physical and Emotional Needs
- 47 Organizing for Practical Concerns
- 47 Organizing for All Concerns

48 QUESTIONS TO ASK SUPPORTIVE CARE PROVIDERS

- 48 Physical Concerns
- 49 Emotional Concerns
- 50 Practical Concerns

51 ADDITIONAL SUPPORTIVE CARE RESOURCES

52 GLOSSARY



UNDERSTANDING SUPPORTIVE CARE

Cancer patients may require ongoing care and attention during and after **cancer-fighting treatment** to help them feel as healthy as possible.

In the healthcare community, care focused on comfort, quality of life and the patient's total well-being is known as **supportive care**. The goal of supportive care is to relieve the symptoms and side effects of a disease and its treatment. Supportive care can be used at any time after a cancer diagnosis and should be provided throughout the pancreatic cancer journey. It can accompany cancer-fighting treatments or be the focus of care.

Supportive care supports both the patient's and family's goals for the future. These goals may include the hope for a cure, to prolong life or to encourage peace and dignity throughout the illness and at the end of life. High-quality supportive care guides families through decision-making to allow them to work toward their healthcare goals. It offers assistance with all symptoms related to cancer, from the time of diagnosis throughout the patient's life.

A doctor may provide treatments intended to increase comfort and improve quality of life without calling it "supportive care." Other words that are often used to describe this type of care include "palliative care," "whole person care" or "comfort-oriented care." Supportive care can be delivered anywhere — at home, in a hospital or in a nursing home.

The patient's healthcare team should collaborate to provide supportive care that coordinates with other treatments. During cancer-fighting treatment, patients often need help managing

side effects of treatment. After treatment, they may need help managing late effects and long-term effects of cancer and cancer treatments known as **aftereffects**. These aftereffects include any type of physical, emotional or practical concern that lingers after treatment has been completed. Practical concerns can include legal and financial matters, transportation and employment problems, etc.

For some, talking about supportive care as it relates to emotional, practical or physical concerns may be a new experience. Patients often rely on family and friends to help them through the many challenges they face throughout their pancreatic cancer journey. The information presented here can help patients talk about their needs with their family, friends, **caregiver and supportive care providers**.

THE PURPOSE OF SUPPORTIVE CARE IN CANCER

Supportive care is a philosophy of care as well as a system for delivering care. It focuses on preventing, treating or eliminating discomfort whenever and however it appears. It addresses, respects and treats all physical, emotional, social, spiritual and financial needs from the time of diagnosis through the end of life. Quality of life is defined by personal satisfaction, caring for oneself and receiving help to deal with any concerns. With supportive care, quality of life is given the same importance as length of life. Improving quality of life helps both pancreatic cancer patients and their loved ones. This approach also helps with decision-making.

WHEN DO PATIENTS NEED SUPPORTIVE CARE?

Supportive care is appropriate at any time during the pancreatic cancer journey, regardless of age or prognosis. Patients have different experiences and needs, and those needs are likely to change over time. Pancreatic cancer patients may experience pain, fatigue and other side effects that reduce their quality of life. Healthcare professionals may provide supportive care inconsistently, so it is important to be active in asking for help. Patients should receive the supportive care they need and deserve throughout their journey.

At any time after a cancer diagnosis, supportive care provides:

- Relief of pain and other physical symptoms.
- Emotional support and help discussing the diagnosis with family and loved ones.
- Assistance with practical concerns, including **advance directives** (see page 37).

During cancer-fighting treatment, supportive care provides:

- Aggressive treatment of side effects related to cancer treatment.
- Relief of pain and other physical symptoms.
- Assistance with practical concerns, including help with transportation, finding caregivers, insurance issues or legal matters relating to advance directives.
- Planning for rehabilitation services, including physical or occupational therapy.
- Emotional support.

During survivorship, supportive care provides:

- Ongoing support for the survivor and their family to enhance quality of life after cancer-fighting treatment has ended.
- Services that address the survivor's physical, emotional and practical needs.

At the end of life, supportive care provided by hospice may include:

- Care to enhance quality of life, including physical, emotional and spiritual comfort.
- Pain relief and management of other symptoms to increase the patient's comfort.
- Emotional and practical support for patients and their families.
- Services provided by trained **hospice** professionals and volunteers wherever the patient is living.
- Spiritual or faith-based counseling as requested.
- Assistance with advance directives.
- Planning of funeral or memorial services.
- Grief and bereavement counseling for family members.

INDIVIDUAL AND CULTURAL DIFFERENCES

Just as people around the world eat different types of food and have unique traditions, how symptoms are perceived and approaches to supportive care may vary depending on cultural values. Because of this diversity, it is important for every person seeking supportive care to be open and honest with the healthcare team about their goals and values, what relief and comfort means to them and any important religious or cultural practices that should be remembered.

SUPPORTIVE CARE SERVICES

Different types of supportive care are available to address individual needs. Working alone to decide the patient's specific needs and where to go for help can be overwhelming. It is advised that the patient and their family work closely with the healthcare team to learn which options are most appropriate.

The following is a list of some supportive care options that can be explored with the healthcare team to help patients feel better throughout all areas of their life. Other options not listed here may also be available.

Options to address physical concerns:

- Prescription and over-the-counter medications
- Nutrition counseling
- Physical or occupational therapy
- Massage
- Exercise
- Yoga
- Herbal supplements and vitamins
- Acupuncture

Options to address emotional concerns:

- Behavior therapy
- Counseling (emotional, spiritual or faith-based)
- Support groups
- Journaling
- Meditation
- Music or art therapy
- Medication (for symptoms such as depression)

Options to address practical concerns:

- Budget preparation
- Tax advice
- Wills and estate planning
- Advance directives and care planning
- Job counseling or training
- Assistance with insurance matters
- Legal advice

WHERE ARE SUPPORTIVE CARE SERVICES DELIVERED?

Supportive care may be delivered in various settings at different times, including:

- Inpatient hospitals
- Outpatient clinics
- Patient's home
- Doctor's office
- Skilled nursing or assisted living facilities
- Hospice facilities

Supportive care may also begin in one place and continue elsewhere as time progresses. When the patient and doctor work together, they can ensure that the patient receives consistent, high-quality care in a cost-effective manner. This is known as **continuity of care**.

WORKING WITH HEALTHCARE PROFESSIONALS TO OBTAIN SUPPORTIVE CARE SERVICES

Patients may receive supportive care from primary care doctors, oncologists, supportive care specialists, **pain specialists**, nurses, physician assistants or other medical specialists. Many hospitals or cancer centers have specific

supportive care programs designed to address the concerns of people living with cancer or other serious illnesses.

Supportive care programs have supportive care specialists who specialize in treating pain and other symptoms, side effects of treatment and emotional concerns experienced by patients. They supplement the regular care provided by the patient's primary doctor. Speak with the patient's primary doctor, nurse or social worker if they would benefit from a supportive care consultation.

Remember, not all hospitals have specific supportive care programs. However, the patient's primary doctor may provide treatments intended to increase comfort and improve quality of life without calling it "supportive care." The terms used are not important as long as patients receive the care they need.

In general, when meeting with the supportive care team or primary doctor to discuss supportive care, it is a good idea for patients to bring family members or caregivers to the appointments. It can be helpful to create a list of questions and concerns before meeting with the doctor to make sure everything is addressed. Consider bringing this booklet as a starting point to addressing supportive care issues with the healthcare team.

If cancer-fighting treatment has not yet started, talk to the doctors about the potential treatment options and their side effects. Find out what can be done to help avoid or alleviate any unpleasant side effects. Ask what to do if any unexpected side effects occur.

If cancer-fighting treatment is ongoing, let the doctor know about any side effects that the patient is already experiencing. Doctors can only treat symptoms and side effects if they are aware of them. The doctor can provide suggestions, prescribe medications to control side effects or refer the patient to the appropriate specialist.

Problems may still arise after cancer-fighting treatment is complete. Patients may not attribute these issues to the cancer and its treatment because they may not know what to expect after treatments are finished. Many patients may feel embarrassed, frightened or confused about their symptoms and are shy or afraid to talk about them. Or, the patient may simply not know how to describe what they are feeling. These issues are common and are part of survivorship.

In order to be most helpful, members of the healthcare team need to clearly understand the concerns of the patient and their family members. It is often difficult for patients or family members to remember what they were feeling physically and emotionally before, during and after each doctor visit. It may be useful to write about these experiences on a piece of paper or in a journal, especially if the physical symptoms and emotions often change. When meeting with the healthcare team, the family can refer to their notes to ensure all concerns are known and addressed.

During all visits, ask what changes or symptoms might be expected. Be open about discussing thoughts, feelings and experiences during the visit. Some concerns are easy to treat. Therefore, seeking help for symptoms as they occur may help prevent future problems or complications.

Good communication with the healthcare team will help patients receive the individualized care they need. Here are some tips to ensure success:

- Write down questions to discuss at the next appointment with the healthcare team.
- Tell the healthcare team about all concerns so they can provide the best care.
- Ask if other patients have had similar symptoms and find out what has helped them.



- If the healthcare team is not providing the appropriate help to treat symptoms, ask for a referral to someone who specializes in supportive care.
- Remember that getting a second opinion for major healthcare decisions is expected and common. Ask the doctor to help with this.
- Ask if there are any clinical trials that focus on supportive care.
- Contact PanCAN Patient Services and ask for help finding names of pancreatic cancer specialists, supportive care trials and additional resources.

Patients, families and healthcare providers must all work together and communicate effectively so that the patient and their loved ones receive the supportive care they need and deserve. Maintaining ongoing discussions with the healthcare team helps patients feel more confident about caring for themselves and asking for help.

SUPPORTIVE CARE FOR PHYSICAL CONCERNS

Proper supportive care can help manage symptoms or prevent side effects to improve quality of life. And, being in good physical and emotional health may help the patient better tolerate treatment.

Pancreatic cancer and its treatments can cause different symptoms and side effects in addition to pain. These will vary depending on the type of pancreatic cancer and the type, dosage and length of treatments. Every patient is different and not everyone will experience the same symptoms and side effects.

Common symptoms and side effects are discussed in this section, along with the supportive care methods used to control them. The doctor and the patient must work together to balance the potential benefits of treatment with possible side effects.

Consult with the doctor before taking any medications or herbal supplements or before starting an exercise, massage or physical therapy program.

PAIN

Pain in pancreatic cancer can be associated with the cancer itself and/or with the treatments for the cancer. Patients may experience pain in the upper abdomen or mid-back if their tumor blocks the digestive tract or pushes against or invades nerves or organs near the pancreas. Treatments, such as chemotherapy, radiation therapy and/or surgery, can also cause pain. Patients may experience different types of pain at the same time.

It is important for pancreatic cancer patients to recognize that they do not need to live with constant pain. There are a variety of options for managing pain; some may work better than others for a particular patient. The healthcare team, including pain specialists, can help control cancer pain.

General Types of Cancer-Related Pain

Acute pain	<ul style="list-style-type: none"> • It begins suddenly and usually lasts for a short period of time and then disappears. • It can range from mild to severe in intensity.
Chronic pain	<ul style="list-style-type: none"> • It is either constant or recurs frequently and lasts long periods of time. • It can range from mild to severe in intensity.
Breakthrough pain	<ul style="list-style-type: none"> • It commonly occurs in patients with persistent pain. It occurs suddenly and is usually short-lived. • It can range from moderate to severe in intensity.

The first critical step to pain management is to speak to the healthcare team. The only way the doctor can start treating the pain is to be fully informed of the patient's symptoms. Furthermore, controlling pain is much easier and more effective when the pain is addressed before it becomes too severe.

Patients should keep track of any pain they experience. It is important to give the doctor as much information as possible, including:

- Type of pain — throbbing, sharp, dull.
- Severity — on a 0 to 10 scale (0 is no pain; 10 is the worst pain imaginable).
- Its specific location.
- What time of day it occurs (specify if it is associated with eating).
- What makes it feel better or worse.

It is important to keep track of the pain as it occurs using a **pain journal**, as it will be easier for the doctor to develop an effective pain management plan if they understand the cause of the pain.

Pain Management

Pain can be managed in different ways. Some of the common ways used to treat cancer pain are discussed below. A pain management plan may include a combination of several or all of these methods.

Prescription Drugs

There are several prescription drugs that may be used depending on the patient's needs and type of pain they are experiencing. Commonly prescribed medications include:

Type of Drug	Use/Information	Drug Name
Non-opioids	For mild to moderate pain.	Tylenol® (acetaminophen)
		Advil®, Motrin® (ibuprofen)
		Aspirin
Opioids	For moderate to severe pain.	Duragesic® (fentanyl)
		MS Contin®, Oramorph® (morphine)
		OxyContin®, Roxicodone® (oxycodone)
Antidepressants and antiseizure medications	For tingling and burning pain.	Elavil® (amitriptyline)
		Aventyl®, Pamelor® (nortriptyline)
		Neurontin® (gabapentin)
		Dilantin® (phenytoin)
Steroid-based drugs	For pain caused by swelling or pressure. These can be taken alongside non-opioids or opioids.	Deltasone®, Orasone® (prednisone)
		Decadron® (dexamethasone)

Medical cannabis is legal in some states to manage cancer-related pain. It may be available in edible, inhalable and topical forms.

This is not a complete list of the medications available to treat cancer pain. Talk with the patient's doctor about what kind of pain medication is right for them, including those available over-the-counter.

Pain medications can be administered by mouth, by injection, through skin patches, intravenously or by rectal suppository. Make sure to tell the doctor whether the pain medication is providing relief and/or whether it is causing severe side effects. A common side effect of opioids is constipation (see next section). Most side effects can be successfully treated, but sometimes it is necessary to change the dose or type of pain medication.

Common concerns regarding opioid-based pain medication

Some patients avoid taking opioid-based pain drugs because of fear that it may lead to addiction and/or cause unwanted changes in their mental state.

It is important for patients to discuss these concerns with their healthcare team. While most patients with cancer adhere to their prescribed pain medications, some may be at risk of addiction or misuse. Additionally, patients may feel "foggy," tired or lethargic after taking these medications; however, these feelings usually improve within a few days. If these symptoms persist, the patient should talk to their doctor. A doctor can adjust the dose or prescribe a different medication.

Interventional Procedures

Depending on the location of the tumor, pain might be controlled with a procedure called a **celiac plexus block**. This procedure is used to damage a bundle of nerves located in the back of the abdomen, against the spine. It is common for a pancreatic tumor to cause pain by pressing on the nerves in this area. During a

celiac plexus block, a substance (typically alcohol) is injected into the nerves to destroy them. This prevents pain signals from traveling to the brain so the patient no longer feels pain. This procedure can be performed in several ways: during surgery, during an endoscopic ultrasound (EUS) or sometimes by going through the skin under X-ray guidance.

A celiac plexus block can be performed by a gastroenterologist, radiologist, anesthesiologist or pain management professional.

For more information about the celiac plexus block, contact PanCAN Patient Services and ask for the fact sheet *Celiac Plexus Block*.

Other Pain Management Techniques

Pain may also be managed by treating the source of the pain (the tumor) through radiation therapy, surgery or chemotherapy.

If pain is associated with eating, sometimes adding or adjusting the dosage of prescription **pancreatic enzymes** will help reduce the pain. For more information about pancreatic enzymes, contact PanCAN Patient Services.

Some people find relief from non-drug approaches, including acupuncture, relaxation, massage, hot or cold compresses, meditation, guided imagery or physical and occupational therapy. Consult with the healthcare team to discuss and determine the potential benefits from any of these options.

Individual and Cultural Differences in Pain Management

Pain is a very individual sensation. Physical differences, cultural beliefs, spirituality and past experience with pain and trauma can all impact the way a person experiences pain. Often, these factors together can make people feel like they should approach pain management in a certain way. Because pain is so personal, every person should have open and honest conversations with the healthcare team about their own

values and how they view pain, even if it differs from family or societal expectations. The healthcare team can then create a personalized pain management plan, with everything from goals of care to personal values in mind.

JAUNDICE

A tumor in the head of the pancreas can push on the bile duct and prevent bile from flowing properly into the small intestine. This causes a buildup of bile products in the blood and results in a yellowing of the skin and eyes called jaundice. Itchy skin, very dark urine and light or clay-colored stools are also symptoms of jaundice.

Jaundice is usually treated by inserting a **stent** into the bile duct. A stent is a small plastic or metal tube that helps keep a blocked duct open. Plastic stents are usually used for temporary or short-term relief of jaundice. In general, plastic stents will remain open and unclogged from a few weeks to a few months. Metal stents are typically used for long-term relief. They generally remain open from several months to over a year.

Both plastic and metal biliary stent placement is performed by a gastroenterologist. In most cases, the gastroenterologist will place the stent during a procedure called **endoscopic retrograde cholangiopancreatography (ERCP)**.

Alternatively, surgery to remove the tumor or to bypass the blockage can provide relief.

For more information about jaundice and stents, contact PanCAN Patient Services and request the fact sheet *Jaundice and Biliary Stents*.

BOWEL CHANGES

Many patients with pancreatic cancer experience constipation, diarrhea or both. Proper bowel function is critical to a patient's health and well-being. Be sure to speak to the healthcare team about any gastrointestinal changes that the patient experiences.

Constipation

Constipation is a condition characterized by hard, dry and/or less frequent bowel movements. It is associated with discomfort in passing stools. Constipation is a common problem for patients taking pain medications, especially opioids. As a result, the doctor may prescribe medications to prevent or alleviate constipation or adjust the dosage or type of pain medication. In addition, the patient should drink plenty (6-12 cups) of non-caffeinated, non-alcoholic fluids every day. As long as the patient is maintaining good hydration, they can slowly add foods that are high in fiber to their diet. If the doctor approves, the patient can participate in moderate exercise to improve bowel function.

Diarrhea

Diarrhea is a condition marked by abnormally frequent bowel movements that are more fluid than usual. Patients describe it based on their past and present experiences. Therefore, what one person considers normal may be considered diarrhea to another. In general, healthcare professionals characterize diarrhea as three or more loose stools per day.

Diarrhea is a common side effect experienced by many patients with cancer. It may be caused by lactose intolerance, bacterial infection, damage to the intestinal wall, inflammation of the bowel, malabsorption, pancreatic enzyme insufficiency, chemotherapy or radiation therapy, or the use of other medications.

In order to determine the best treatment for the diarrhea, it is important for the doctor to first understand its cause. Generally, a patient who experiences diarrhea should avoid foods that are high in fat, grease, sugar or insoluble fiber and avoid gas-forming foods such as cabbage, onion, dried beans, corn and popcorn. Over-the-counter or prescription medications can help control both diarrhea and abdominal cramping. Dairy products that contain Lactaid® (lactase) should be used if lactose intolerance is a problem. Pancreatic enzyme replacement products should be considered for patients suffering from pancreatic enzyme insufficiency.

Talk to the doctor before starting any new medications, including those purchased over-the-counter.

DIGESTIVE DIFFICULTIES

Common digestive difficulties associated with pancreatic cancer include poor appetite, indigestion, nausea and vomiting. These can happen because of the cancer itself or treatments like chemotherapy and surgery.

Nausea and Vomiting

To help reduce nausea and vomiting:

- Eat small, frequent meals of easily digestible food, such as rice, broth and soda crackers.
- Drink peppermint or ginger tea.
- Limit fluids with meals.
- Slowly sip cold, clear liquids, ginger ale or other carbonated beverages between meals to stay hydrated and avoid feeling overly full.
- Avoid spicy, greasy, hot or very sweet foods.
- Wear loose clothing.
- Talk to the doctor about prescription anti-nausea medications.

Nausea and vomiting that lasts or worsens may indicate an obstruction in the area where the stomach connects with the small intestine. It may also indicate **gastroparesis**, a condition in which the stomach cannot empty food properly. In order to determine if there is an obstruction, the doctor will usually perform an **upper gastrointestinal endoscopy**.

Appetite Changes

To stimulate appetite:

- Get plenty of rest.
- Engage in light exercise before meals.
- Stay well hydrated.
- Select enjoyable foods at meals and snacks.
- Talk to the doctor about prescription medications. Common medications to stimulate appetite include:
 - Megace® (megestrol acetate) or Megace® ES
 - Marinol® (dronabinol)
 - Prednisone
 - Dexamethasone
 - Remeron® (mirtazapine)

It can take several weeks of use before appetite enhancement occurs. Some of these medications may cause severe side effects, so it is important to discuss them with the doctor before starting them.

Taste Changes

Cancer treatments can change the way food tastes. Taste changes can be managed by:

- Trying foods that the patient normally does not find appealing.
- Using plastic cutlery to minimize metallic tastes.
- Sweetening foods that taste overly salty. Or, add salt, vinegar and/or lemon juice to overly sweet foods.
- Seasoning foods with herbs such as basil, oregano, rosemary, mint or curry.

Every person is different, so not all suggestions will work for everyone. The patient, doctor and dietitian should work together to manage these symptoms and side effects.

WEIGHT LOSS

Weight loss is a common problem for patients with pancreatic cancer. While some people may not return to their original weight, gaining and maintaining a healthy weight is an important goal. Eating enough calories is the best way to stay healthy and strong. Since it may be difficult to handle a large amount of food, it is important to avoid filling up on items that provide little caloric and nutritional benefit, like diet soda or foods that are highly processed and high in sugar and salt. Many people use meal replacement shakes like Ensure®, protein powders or other supplements to get the nutrients they need.



DYSPHAGIA (TROUBLE SWALLOWING)

Dysphagia, or trouble swallowing, occurs in some people living with pancreatic cancer. This can happen because of the disease itself or because of treatments like chemotherapy or radiation. Dysphagia can impact quality of life by causing anxiety or preventing people from consuming food and drink they enjoy. It is important to talk to the healthcare team about any concerns about swallowing because dysphagia can make people more likely to choke on their food or drink. This can lead to more serious problems, like pneumonia (a bacterial infection in the lungs).

In the clinic, the doctor or a speech-language pathologist can perform tests to see if there are any swallowing problems. Based on specific needs, they can provide recommendations, dietary changes or even exercises to help relieve anxiety and improve comfort.

DIABETES

Patients may develop diabetes before or after a pancreatic cancer diagnosis. Insulin, a hormone secreted by the pancreas, helps the body use glucose (sugar) efficiently. Normally, insulin allows glucose to enter cells and be used for energy. In the case of diabetes, the body either does not produce enough insulin or the amount that is produced is not fully effective. Instead of entering cells, the glucose remains in the blood, resulting in high blood glucose levels.

Diabetes can cause major health problems. However, pancreatic cancer patients can have a positive influence on their blood glucose levels and overall health by choosing foods wisely. It is important to talk to a registered dietitian who is familiar with both diabetes and cancer. This person can provide specific nutritional guidance and should be consulted before making any diet modifications.

Generally, patients should eat well-balanced meals and choose foods from each food group at every meal. Eating meals and snacks at regular times helps control sugar levels. It is generally a good idea to limit added sugar in the diet as long as weight can be maintained. Changes in diet and sometimes insulin therapy are necessary to control blood sugar levels in people with diabetes.

For more information about dietary issues related to pancreatic cancer, contact PanCAN Patient Services to request a free copy of the Pancreatic Cancer Action Network's educational booklet, *Diet and Nutrition: Nutritional Concerns with Pancreatic Cancer*.

FATIGUE

Both pancreatic cancer and its treatments can cause an extreme lack of energy called fatigue. If fatigue is related to anemia (low red blood cell counts), it can be treated with medications to boost red blood cell production. Good nutrition can also help increase the patient's energy levels.

Drinking non-caffeinated fluids and taking short walks and short rests throughout the day can help boost energy. For some patients with severe fatigue, a prescription medication such as Ritalin® (methylphenidate) or Provigil® (modafinil), may be appropriate.

ASCITES

Ascites is the abnormal buildup of fluid in the abdominal lining which causes a swollen and distended belly. People whose pancreatic cancer has spread to the tissues in the abdominal lining commonly experience this condition. Discomfort, bloating, pain, difficulty breathing, nausea and decreased appetite may occur as the amount of fluid increases. The patient should rest in a reclined position with their feet

elevated to alleviate pressure on the internal organs. It is also important to prevent or manage constipation as the fluid can impair bowel movement.

Ascites may be managed by effectively treating the tumor, by draining the fluid through a procedure called **paracentesis**, and in some cases by taking prescription diuretics (water pills) such as Aldactone® (spironolactone). For severe and recurrent ascites, the doctor may recommend the placement of a long-term drainage catheter (tube), such as PleurX™, in the abdomen.

SKIN AND NAIL CHANGES

The targeted therapy drug erlotinib is often associated with a skin rash on the body and/or face that generally appears within the first 10 days of treatment. Although this rash resembles acne, it is important to avoid treating it with acne medications which may dry and irritate the skin. Patients may care for affected areas using mild soap and water followed by an alcohol-free moisturizer. Avoid exposure to direct sunlight and use sunscreen with SPF 15 or higher. In addition, the doctor may also prescribe an antibiotic or mild steroid to help alleviate the rash.

Other medications can also produce skin changes. Changes in the dose of treatments and in grooming methods may help soothe the skin. Contact a doctor before using over-the-counter treatments.

Nail changes may also occur during treatment. Avoid biting nails, pushing back cuticles and using fake nails or wraps. Consult a doctor before having a manicure or pedicure. Wear gloves during household chores and moisturize hands and feet frequently. If the nail area becomes inflamed, ask the doctor about treatment with antibacterial/antifungal ointments to prevent infection.

Hand-foot syndrome

Chemotherapy and targeted therapy drugs can cause a condition called hand-foot syndrome. Symptoms include pain, swelling, numbness, tingling, peeling or redness of the hands or feet.

To manage these changes, consider the following suggestions:

- Soak hands in cool water for 10 minutes and then apply a mild moisturizer or petroleum jelly.
- Apply urea-based creams or moisturizers to hands and feet.
- Protect hands and feet by wearing cotton socks or gloves and avoid tight-fitting shoes.
- Avoid hot water and any excess friction to the hands or feet as symptoms may worsen with increased heat.
- Cool the skin with ice packs to help relieve pain and tenderness.
- Ask the doctor if an oral supplement of vitamin B6 is appropriate.

NEUROPATHY

Peripheral neuropathy is a condition that results from damage to the nerves outside of the brain and spinal cord called peripheral nerves. Peripheral nerves carry information between the central nervous system and other parts of the body. Some chemotherapy drugs such as ABRAXANE® (albumin-bound paclitaxel), Taxotere® (docetaxel), Eloxatin® (oxaliplatin), Taxol® (paclitaxel) and Platinol® (cisplatin) can cause peripheral neuropathy.

Peripheral neuropathy may cause symptoms such as pain, burning, numbness, tingling, swelling or muscle weakness that usually begin in the hands or feet and worsen over time. Patients may also suffer from poor balance and decreased hand function. The onset and severity of neuropathy vary depending on the drug and the patient's reaction; however, it may become more severe right after chemotherapy.

It is important to inform the patient's healthcare team of any symptoms that might be attributed to peripheral neuropathy. The doctor may conduct a series of physical tests and/or ask the patient questions about their symptoms in order to properly diagnose it.

The treatment for peripheral neuropathy depends on the cause and the related symptoms. It may be helpful to protect hands and feet by wearing cotton socks or gloves and avoiding tight-fitting shoes. Also, protect hands and feet from extreme heat and cold, as extreme temperature changes may aggravate symptoms.

Medications cannot reverse the neuropathy; however, they may help relieve the pain associated with it. Antidepressants such as Elavil® (amitriptyline), Aventyl® or Pamelor® (nortriptyline) and Norpramin® (desipramine), and antiseizure medications, such as Neurontin® (gabapentin) and Lyrica® (pregabalin) are commonly used to treat neuropathic pain. For mild neuropathic pain, over-the-counter pain medications may be recommended.

Patients may also benefit from physical or occupational therapy, acupuncture or relaxation therapy to improve strength and relieve the symptoms. Ask the doctor if pain medications, antidepressants, antiseizure or other treatments are appropriate.

After treatment, the symptoms caused by peripheral neuropathy may diminish or disappear completely; however, it can take several months for this to happen.

LOW BLOOD CELL COUNTS

Low blood cell counts refer to low numbers of red and white blood cells and platelets. This is a common side effect of some chemotherapy treatments and can result in fatigue, bleeding, anemia and susceptibility to infection. A doctor may prescribe medications and/or change the dose of chemotherapy to increase the patient's blood counts. A blood transfusion may also be necessary to raise red blood cell and platelet counts.

BLOOD CLOTS

Surgery for pancreatic cancer or the cancer itself can cause blood clots to form in the veins, usually in the legs. This is a potentially serious condition called **deep vein thrombosis (DVT)**. Blood clots may go unnoticed and cause no symptoms. However, they are often associated with swelling, pain and tenderness in the affected area. Swelling in only one leg is often a sign of DVT. If a patient experiences any of the symptoms mentioned above, they should contact a doctor immediately. Fragments of the clot may break loose and travel to the lungs, causing shortness of breath, chest pain and damage to the lung tissue from the sudden decrease in blood supply. This is called a **pulmonary embolism** and is a life-threatening condition.

Blood clots can be treated with drugs called **anticoagulants**. These drugs help thin the blood to prevent existing clots from getting larger and new clots from forming. Also, the risk of blood clots may be decreased by avoiding extended bed rest, unless instructed by the doctor. If the patient is bedridden, it is important for their arms and legs to be regularly moved to increase blood flow. Smoking increases the risk for developing blood clots and should be avoided.

HAIR LOSS

Chemotherapy attacks cells in the body that divide rapidly, including hair follicles. Therefore, chemotherapy can commonly cause hair thinning or hair loss.

To manage hair loss, avoid frequent hair washing and use a gentle shampoo. Gently pat hair dry. Use a wide-tooth comb instead of a brush. Avoid barrettes, rubber bands, hair products and hair dryers. Wear head coverings when outdoors.

MOUTH SORES

Chemotherapy may also cause mouth sores. These generally appear a few days after treatment and produce burn-like sores on the lips, gums, tongue and on the roof and floor of the mouth. Since mouth sores can make eating and swallowing painful, it is best to eat soft, moist, bland foods, and avoid spicy and acidic foods. Cold foods such as ice chips, ice cream or popsicles may provide pain relief. Avoid caffeine and alcohol as they may irritate the mouth and worsen symptoms. Eating high protein foods may help mouth sores recover more quickly. Keeping mouth and lips moist may also help. Rinse the mouth frequently with cool water or a solution of baking soda and water and apply lip moisturizer. Also, keep the mouth and teeth clean using a soft-bristle toothbrush. The patient's doctor or dentist can prescribe medications that help manage the pain or that stimulate the mouth to repair its cells more quickly.

For additional tips on managing symptoms of pancreatic cancer and side effects of treatments, contact PanCAN Patient Services.

SLEEP HYGIENE

Sleep hygiene is a term used to describe healthy sleep habits. These practices help people improve the quality and duration of sleep. For those experiencing sleep disturbances, proper sleep hygiene in combination with treatments like breathing support

(like CPAP machines if indicated), medication to aid sleep and mental health interventions (like counseling or talk therapy) can help improve rest and healing.

Healthy sleep hygiene habits include:

- Performing regular and safe physical activity (based on the patient's ability and health status).
- Seeking out bright light during the day and avoiding bright light at night.
- Healthy digital practices and tech hygiene, which include turning off devices during bedtime or using a night filter to limit exposure to blue light.
- Avoiding alcohol and nicotine before bed.
- Avoiding caffeine at least four hours before bedtime.
- Making the bedroom comfortable for sleep by keeping it dark and quiet.
- Practice meditation or seek out other methods to calm a racing mind.
- Avoid lengthy naps during the day, if possible.

It is important to talk to the healthcare team about any sleep disturbances. They can order a sleep study to learn more about sleep patterns and uncover any problems that may be addressed.

EXERCISE

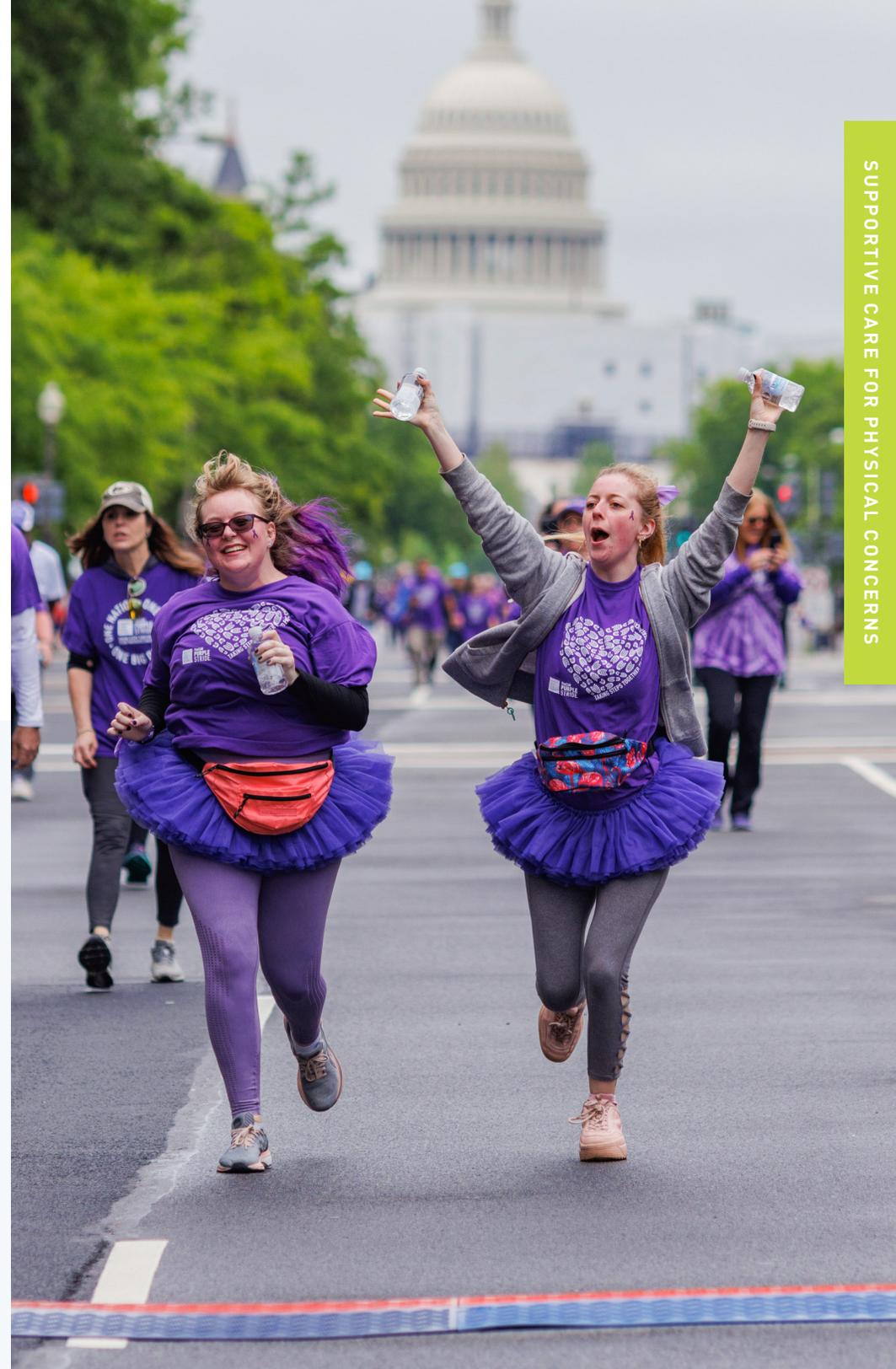
Engaging in exercise has been found to have health benefits for patients with cancer. It increases muscle strength and improves cardiovascular function and quality of life, including increased appetite and sleep. Staying physically active before, during

and after treatment is also known to help elevate one's mood and ease feelings of fatigue, anxiety and depression that may accompany a cancer diagnosis.

Every patient's exercise and/or activity plan should be based on what is safe and what works for them and it should include activities that the patient enjoys. It is important to work with the healthcare team or a physical or occupational therapist who can tailor a plan that takes into consideration the patient's diagnosis, overall physical and medical condition as well as fitness level. Treatment regimens may cause patients to experience low energy days with each cycle. It can be helpful to plan activities around days when the patient feels like they have the most energy.

It is generally advised that patients should increase their level of activity slowly and make progress based on their own fitness and comfort level. The goal should be at least 20-30 minutes of aerobic exercise four to five days a week. Some suggestions to incorporate in a weekly plan may include:

- Dress comfortably.
- Stay hydrated during the workout and throughout the day.
- Make exercise enjoyable – listen to music, work out with friends and family and find new activities to try (e.g. gardening, dancing).
- Add variety in the weekly plan by trying stretching, aerobics, breathing exercises and strength training as tolerated.
- Listen to the body – take breaks as needed, especially if experiencing any discomfort.
- Eat a nutritious and protein-rich diet to help the body recover post-workout.
- Look for programs designed for cancer patients – speak with local centers and hospital staff that can help find specialized sessions.
- Work with the healthcare team before starting any sort of exercise/activity plan.



SUPPORTIVE CARE FOR EMOTIONAL CONCERNS

Physical symptoms are not the only issues pancreatic cancer patients face. Patients and their loved ones also encounter emotional, social and spiritual challenges. Supportive care can improve how pancreatic cancer patients and their loved ones feel in all areas of their lives. Emotional concerns may arise for patients at any point during their pancreatic cancer journey.

Knowing what patients and their loved ones need and where to go for help for emotional concerns can be difficult and confusing. Patients may feel detached from their medical team once treatment is complete. They may not recognize that the emotional and physical toll of pancreatic cancer and its treatment remain during the post-treatment phase. However, living a full and productive life is worth the effort of asking for help.

EMOTIONAL CONCERNS

Although cognitive and emotional changes may be harder to identify, they are just as significant as physical concerns. Common emotional concerns for both pancreatic cancer patients and their loved ones include, but are not limited to:

- Anger
- Anxiety
- Loss of Control
- Guilt
- Depression

Anger is a common feeling that patients with pancreatic cancer may experience. It can arise from questions such as, “Why me?” and cause patients to take out their frustration on family, friends and their healthcare team. It can sometimes be associated with feelings of panic, fear and helplessness.

Patients and caregivers may also experience feelings of anxiety. This may stem from the uncertainty and “what ifs” related to a diagnosis – unexpected finances, lifestyle changes, shifts in family and friend dynamics and/or fear of the future. Some may experience anxiety-associated stress in the form of lack of sleep, fatigue and loss of appetite.

Patients may also feel like they have lost all control related to their diagnosis, treatments or even how their body responds. These feelings of not being in charge and having to create a “new normal” can lower one’s self-esteem. The feelings of disruption can also be related to losing hope, grief and depression (see next section).

Some patients with a cancer diagnosis may also experience what is known as **survivor’s guilt**, which is defined as feeling guilty for surviving an event which others may not. Patients with this emotional concern may feel that they are a burden to others, question pre-diagnosis lifestyle choices and blame oneself for exhibiting a range of emotions. Patients may feel no one understands what they are going through, which can put a strain on relationships and lead to feelings of isolation and loneliness.

Caregivers and loved ones can also experience guilt and may feel as though they are doing too much or not enough. They may also have guilt over their own emotional responses such as anger, fear, sadness and feelings of loss around the changes that cancer has brought to their lives. Couples, in particular, may benefit from shared and/or separate support or counseling to address changes in their relationship needs and dynamics.

Depression

Depression is common in cancer patients. However, it may be more common in pancreatic cancer patients than in patients with other cancers. It is important for patients to know that depression is a treatable condition.

Some of the signs of depression include loss of interest or pleasure in daily life activities, loss of appetite, difficulty making decisions and concentrating, insomnia, decreased energy, excessive sleeping, feelings of worthlessness, hopelessness or guilt, and negative thoughts and behaviors. It is important to note that having some, or all, of these symptoms does not mean that a person is depressed – not all cancer patients experience depression. It is common for a person who has been diagnosed with pancreatic cancer to feel sad, anxious and angry. However, if these symptoms happen regularly, continue for a long period of time or keep coming back, they may be a sign of depression. Ask a healthcare professional to evaluate the patient for depression.

Depression in pancreatic cancer patients may worsen physical symptoms such as fatigue, loss of appetite, weight loss and pain. Additionally, depression may have a negative effect on quality of life, recovery and survival. Therefore, it is important for patients to successfully manage this symptom.

Depression may be treated with prescription medications and/or professional counseling. Studies have shown that the best approach for treating depression is a combination of both of these methods.

There are several types of medications doctors can prescribe to treat depression. While some antidepressants work faster, many take time to work. It can take a few weeks to a month before patients start noticing a change. The patient's doctor will recommend the most appropriate medication based on the patient's specific needs.

Professional counseling and/or therapy can provide the patient with an outlet to vent frustrations and concerns about their diagnosis and

process emotions that may arise. It may also provide patients with coping strategies to help them navigate cognitive and emotional changes.

It can be beneficial for both patients and caregivers to have someone besides each other to talk to separately for support. This allows them to process their own emotions and speak more freely about their fears, guilt, anger, etc., without fear of adversely impacting the relationship with their loved one.

If you or your loved one is in crisis or considering suicide, please call the National Suicide Prevention Lifeline at 1.800.273.8255 to speak with a caring crisis hotline volunteer. The Lifeline provides 24/7, free and confidential support.

MANAGING EMOTIONAL CONCERNS AND MENTAL HEALTH

For Patients

Having a support system of **caregivers**, family, friends and healthcare professionals is important in managing the emotional and mental health of a patient. Every patient will have a different way of navigating the emotions that arise and communicating their needs. Having the option to speak with someone with whom they feel comfortable is key. Quality of life and overall well-being can be improved by creating a supportive network for the patient.

For Caregivers

Being a caregiver can sometimes be an overwhelming responsibility, resulting in its own emotional concerns. Besides trying to cope with the normal emotions associated with knowing a loved one has been diagnosed with pancreatic cancer, a caregiver may also be managing additional feelings of stress, fatigue and frustration. Due to their critical role, the caregiver must find time to take care of themselves and reach out for support. Finding support for both patients and caregivers can come in many different forms.

General Types of Emotional Support

In-person	<ul style="list-style-type: none"> Connecting with others face-to-face provides an opportunity for patients and caregivers to discuss issues that are unique and specific to this disease and learn how others have managed specific symptoms or life problems
Online	<ul style="list-style-type: none"> For those who cannot travel to an in-person group and/or may prefer a more anonymous setting Ability to connect with others in online forums and discussion boards in various public sites and secured groups
Telephone	<ul style="list-style-type: none"> Provides the opportunity to connect with others who may be in different areas Communicating with other patients and caregivers, keeping the healthcare team informed of any side effects or symptoms and connecting with professional counselors can all be done over the phone
Professional	<ul style="list-style-type: none"> Some patients and caregivers find it helpful to connect with a professional counselor or therapist to help them sort through some of the emotions that may arise with a cancer diagnosis There are organizations that can connect patients and families to one-on-one counseling sessions with professionals who are experts in assisting with cancer-related issues

The patient's healthcare team should be informed and made aware of any emotional concerns. This may be an oncologist, family doctor, supportive care specialist, nurse, physician assistant, social worker or any other medical professional the patient visits. The patient should share their concerns with the healthcare professional and consider asking the following questions:

- How can I address these emotional concerns?
- Are there medications that can help treat my emotional concerns? If so, how will they interact with other medications I am currently taking?
- Are there other healthcare professionals who specialize in treating people with these symptoms or concerns? Specifically ask about specialists who have experience in working with cancer patients.

- Are there resources in the community that can help?
- Do any local institutions or hospitals offer counseling or supportive care programs?

If the healthcare team cannot answer these questions, ask them to assist in finding other professionals who can help. The patient can also talk to their spiritual or faith-based leader about their emotional concerns.

PanCAN Patient Services can connect patients and caregivers with various support resources including in-person and online support groups, resources to help locate professional counselors and therapists and peer-to-peer support through our Survivor and Caregiver Network. This network is made up of volunteers throughout the country who are available to communicate one-on-one with those diagnosed with pancreatic cancer and their loved ones to provide support and inspiration.

SUPPORTIVE CARE FOR PRACTICAL CONCERNS

In addition to physical and emotional concerns, patients are faced with practical concerns involving financial matters and the well-being of the family. Common practical concerns include:

- Work
- Financial changes
- Insurance matters
- Advance directives
- Power of attorney
- Wills
- Care for children
- Transportation

Oncology or hospital social workers are a good place to start when looking for help with practical concerns. Social workers often have lists of community resources that can help guide families through plans for the future. It may also be helpful to ask friends if they can recommend tax and legal professionals whom they trust.

For help with insurance matters, ask if someone in the doctor's office can help explore the different options associated with the patient's specific insurance plan. Often, large institutions and hospitals have staff members who can talk to insurance companies on behalf of the patient.

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 Physicians" (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 Physicians" document outlines the patient's wishes regarding medical treatments 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.

It is also advisable for pancreatic cancer patients 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. Oftentimes, a patient with advanced pancreatic cancer chooses not to receive CPR as its use can be seen not as extending life, but as reducing quality of life and prolonging 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.

Hospice staff and the patient’s doctor can arrange a discussion of the benefits and risks of CPR, a DNR order and a POLST form so that an informed decision can be made.

These documents can be prepared at the patient’s request and must be signed by the patient before they are given to doctors. The patient decides what provisions will be included in each document. However, if the patient is incapacitated and not able to clearly communicate his or her wishes, then certain family members can prepare these documents on the patient’s behalf. 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.



SUPPORTIVE CARE PROVIDERS

Supportive care is provided through a team approach that may include the services of a variety of healthcare and other professionals. In order to receive appropriate supportive care, a patient must inform the healthcare team about any symptoms or needs that are present. Then, the healthcare team can determine which professionals are best suited to provide the needed therapies or treatments. It is important to make sure the healthcare team is aware and approving of any supplemental treatment or services the patient might receive.

Professionals especially relevant to supportive care include social workers and supportive care, sometimes called palliative care, specialists. Social workers are professionally trained to assist and counsel patients and families. The role of the social worker is to provide resources regarding treatment, support groups, finances, end-of-life care, transportation assistance or home care. Most hospitals and cancer centers have specific oncology social workers. Supportive care specialists could be doctors, nurses or other medical staff who are particularly trained to attend to patients’ supportive needs.

The following tables detail the different members of the healthcare team who may be involved in providing supportive care.

PHYSICAL WELL-BEING

Primary care doctor, oncologist, supportive medicine specialist, nurse practitioner	<ul style="list-style-type: none"> Supervises the patient's medical care. Designs treatment plans. Prescribes medication. May consult with or refer the patient to specialists.
Social worker	<ul style="list-style-type: none"> Often coordinates supportive care among all the different professionals. Provides referrals to resources regarding support groups, financial and transportation assistance, home care and end-of-life care.
Pain specialist	<ul style="list-style-type: none"> Works with the primary care doctor or oncologist to prescribe and monitor pain medications and other therapies.
Other medical specialists	<ul style="list-style-type: none"> Treats specific aftereffects, such as sexual side effects of treatment, cognitive problems or skin problems.
Registered nurse, often certified in hospice and supportive care	<ul style="list-style-type: none"> Provides direct care. Explains or answers questions about treatment. Often helps coordinate care with other members of the team.
Physical and/or occupational therapist	<ul style="list-style-type: none"> Works with the patient to regain strength or movement following treatment. Provides assistance with activities of daily living, such as dressing and bathing.
Dietitian	<ul style="list-style-type: none"> Offers nutrition therapy recommendations to help patients manage side effects and choose the right foods for their situation.
Home health aid	<ul style="list-style-type: none"> Provides assistance with personal care activities, such as getting in and out of bed, walking, bathing and dressing.
Massage therapist	<ul style="list-style-type: none"> Provides therapeutic body massages.
Pharmacist	<ul style="list-style-type: none"> Answers questions and provides medications ordered by doctors.
Complementary / integrative therapy providers	<ul style="list-style-type: none"> Specializes in yoga, meditation, acupuncture or other complementary/integrative therapies.

EMOTIONAL, SOCIAL, SPIRITUAL WELL-BEING

Psychiatrist, psychiatric nurse	<ul style="list-style-type: none"> Evaluates and prescribes medication for emotional difficulties. May provide counseling services.
Counselor, social worker, psychologist, therapist	<ul style="list-style-type: none"> Offers patients and families help in talking about emotions and thoughts and help find ways to manage any concerns.
Chaplain, spiritual or faith-based leader	<ul style="list-style-type: none"> Counsels patients and families on faith-based and spiritual matters.
Grief and bereavement counselor	<ul style="list-style-type: none"> Assists in dealing with death and any type of loss or anticipated loss, including the loss of physical abilities.

ASSISTANCE WITH PRACTICAL CONCERNS

Accountant, financial planner, tax adviser	<ul style="list-style-type: none"> Helps track expenses, prepare budgets or tax returns and plan financially for the future.
Attorney	<ul style="list-style-type: none"> Creates advance directives and wills.
Social worker	<ul style="list-style-type: none"> Coordinates supportive care among all of the different professionals. Provides referrals to resources regarding support groups, financial and transportation assistance, home care and end-of-life care.

CHALLENGES TO RECEIVING SUPPORTIVE CARE

The number and quality of supportive care programs across the country is increasing in response to the increased need and better understanding of supportive care. Many pancreatic cancer patients have their pain and other symptoms and side effects of treatment properly assessed and treated. However, there is still a great deal of improvement needed for evaluation and assistance with emotional and practical care concerns. Pancreatic cancer patients and their loved ones still experience many challenges to receiving comprehensive supportive care. Some of those challenges are discussed here.

FINANCIAL LIMITATIONS

The diagnosis of pancreatic cancer and treatment for the disease can create a substantial financial strain on patients and their families, even those with health insurance. Some people think they cannot afford supportive care and may choose not to learn about these options for fear of adding to their financial burden. However, some supportive care services cost very little and some are provided free of charge. When talking with the healthcare team, explain that services need to fit within a certain budget. Some supportive care services may be covered under traditional health insurance, but the insurance plan generally will not use the term “supportive” to describe these services.

LACK OF ENERGY

Some side effects of cancer-fighting treatments can leave patients feeling too exhausted to ask for help. The sooner the patient or loved one can request proper care, the sooner some of these symptoms can be alleviated, hopefully increasing the patient’s energy and strength.

LACK OF UNDERSTANDING

Patients may not know that they can get help for many of the side effects they experience while receiving cancer-fighting treatments. Also, patients who have completed or chosen to stop treatment may not want to report aftereffects of treatment as they don’t know that they can get help to manage these symptoms. Often pancreatic cancer patients believe that nothing can be done for their symptoms and side effects since the doctor has not already offered these options. Remember that doctors can only treat problems if they are aware that problems exist. It is important for the patient and caregivers to proactively inform their healthcare team of symptoms and side effects and request advice or treatment options.

Lack of understanding may also result if a patient is not seeing a pancreatic cancer specialist for treatment. A general oncologist may not be as familiar with all of the side effects caused by common treatments for pancreatic cancer. As a result, the doctor may not offer a full range of options for treating the side effects. Even doctors who are experts in pancreatic cancer may not know what emotional and practical supportive care services are available. Ask the doctor specific questions relating to supportive care. If the doctor does not have a suitable answer, ask to speak to a supportive care specialist or social worker.

Additionally, some healthcare workers may avoid referring patients to supportive care services because they incorrectly

think that this means giving up on treating or curing the cancer. Remember, supportive care includes recognizing and treating the physical, emotional, social, spiritual and practical concerns of a patient at any stage of living with cancer or other serious illnesses. Supportive care is appropriate at any time during the pancreatic cancer journey, regardless of age or prognosis.

DIFFICULTY FINDING SERVICES

Supportive care programs exist in many hospitals across the country. However, patients may find it hard to decide what type of help they need and where to find these services.

If a patient is seeking supportive care and is facing any of these challenges, it is important to speak to the doctor and other members of the healthcare team for more information. When a professional does not have answers or does not pay attention to individual concerns, the patient can choose to visit someone else. Each patient deserves to receive the help they need and feel comfortable with their healthcare team.

Patients and their caregivers should look to supportive care as a way to feel the very best in every area of life. Patients and their loved ones will be best equipped to deal with the challenges of their pancreatic cancer journey when their physical well-being and emotional attitude are as strong and positive as possible. Total well-being matters to each patient and should be considered by all members of the healthcare team.

To locate supportive care services, ask the doctor for a referral, or visit www.getpalliativecare.org. PanCAN Patient Services can also help direct patients and caregivers to other resources that may help.

GETTING AND STAYING ORGANIZED

Pancreatic cancer patients may see and work with many types of professionals. Along with their healthcare team, they may need the services of non-medical providers such as financial planners or attorneys. Keeping track of all these professionals and the services they provide can be difficult. The following are some ways to get and stay organized.

In addition, there are many smartphone applications (apps) available to people with pancreatic cancer and their loved ones that can help keep track of symptoms, mental health and more. You can typically find these in your smartphone application store/marketplace.

KEEP A WRITTEN RECORD OF SYMPTOMS AND CONCERNS

During and after treatment, be aware of the changes in the patient's day-to-day physical and emotional health. Keep the healthcare providers informed about changes that affect the patient's overall well-being and ability to go about daily routines.

Telling the healthcare team about all of the physical and emotional symptoms the patient is experiencing is very important in getting the right care. However, describing symptoms and concerns can be difficult. Writing this information down before the next visit can help organize thoughts and make sure that important information is discussed.

Create a journal to write down all of the patient's physical and emotional symptoms and concerns and to keep track of questions.



The journal should include:

- A list of questions: before the next appointment with the healthcare team, organize these questions into a logical order.
- Log of each appointment date, the questions that were asked and the answers that were given.
- A list of concerns: these can be organized by importance or category of each concern.
- Journal of the physical and emotional symptoms, when each one was noticed and how long each persisted.
- List of medications, when and how they are taken, what they are taken for and their dosages. These include medicines prescribed by the doctor or purchased over-the-counter.

ORGANIZING FOR PHYSICAL AND EMOTIONAL NEEDS:

- Ask the healthcare team to explain how all of the care they provide fits together.
- In a journal or notebook, keep track of symptoms and questions to ask the healthcare team.

- Be active in talking about needs and asking for help. The team needs to know what is happening in order to provide the best care.
- Keep track of treatments and the names and phone numbers of the healthcare professionals that have been consulted. This will help in remembering what techniques work best for each physical, emotional or practical concern. It is also useful to have this information handy to update the primary care doctor and other providers about which treatments are being used or were tried in the past.
- Keep each member of the team informed about what choices are being made, who is providing care and what therapies are showing the best results.

ORGANIZING FOR PRACTICAL CONCERNS:

- Ask the healthcare team how to keep track of medical records and services received. This may involve getting copies of test results and medical records.
- For practical matters, such as insurance and financial planning, ask the doctor, nurse or social worker for a referral to professionals who are experienced in helping cancer patients with these concerns.
- For help preparing budgets, financial plans, tax returns, or to track expenses associated with supportive care, ask family or friends for help.

ORGANIZING FOR ALL CONCERNS:

- Keep a folder that contains information on all services received.
- Ask family and friends to help organize and maintain records on the different kinds of supportive care received.
- Download a web-based application (app) designed to store, manage and organize medical information.

QUESTIONS TO ASK SUPPORTIVE CARE PROVIDERS

PHYSICAL CONCERNS

At any time after diagnosis:

- Can you refer me to an oncology social worker to help find the supportive care I need?
- What symptoms should I expect to experience from the cancer?

Before cancer-fighting treatment:

- How can I prepare for possible side effects of treatment?
- What side effects are common for the treatment I will receive?

During cancer-fighting treatment:

- What side effects are common for the specific treatment I am receiving?
- How can I manage side effects while I receive treatment?
- What medications can help?
- Are there dietary changes that can help manage side effects?
- Should I see a specialist for managing any of these side effects?

After cancer-fighting treatment:

- What aftereffects are common for my type of pancreatic cancer treatment?
- What medications are available to help manage physical aftereffects?
- Are there other methods that might be helpful to relieve my physical aftereffects?
- How long should it take before my symptoms are relieved?
- Whom should I call if my symptoms are not relieved?
- If you are not able to relieve my symptoms, is there a specialist who can help me? If necessary, will you refer me to a supportive care specialist?

EMOTIONAL CONCERNS

- Are there pancreatic cancer support groups or meetings I should join?
- Who can help me talk to my family and educate them about supportive care?
- What if I am not satisfied with my supportive care treatment or providers?
- Are there common emotions I can expect and what can be done to address them?
- What are some ways I can reduce or manage my stress or anxiety?
- What types of services or professionals are available to help me with the emotional effects of cancer and its treatment?

PRACTICAL CONCERNS

- Is there anyone within your office who can help me sort out insurance and financial matters? If not, where would you suggest I look for help?
- How are services for supportive care paid? Will my insurance cover it?
- What types of services or professionals can help me manage the financial and legal aftereffects of cancer treatment?
- Who can help me prepare the necessary legal documents?



ADDITIONAL SUPPORTIVE CARE RESOURCES

American Academy of Hospice and Palliative Medicine (AAHPM)

aahpm.org
847-375-4712

American Society of Clinical Oncology

cancer.net

Center to Advance Palliative Care (CAPC)

getpalliativecare.org
212-201-2670

National Cancer Institute Palliative Care Fact Sheet

cancer.gov/about-cancer/advanced-cancer/care-choices/
palliative-care-fact-sheet
800-4-CANCER (800-422-6237)

National Coalition for Hospice and Palliative Care

nationalcoalitionhpc.org/ncp/

National Hospice and Palliative Care Organization (NHPCO)

nhpco.org
703-837-1500

988 Suicide and Crisis Lifeline

988lifeline.org
Dial or text 988

Contact Patient Services toll-free at **877-2-PANCAN** or email patientservices@pancan.org.
Hours: Monday – Friday, 7 a.m. – 5 p.m. Pacific Time

GLOSSARY

Advance directives: The legal documents that state exactly how the patient wants to be cared for and whom they want to make decisions for them if they become unable to communicate their wishes.

Aftereffects: Side effects of cancer treatment that linger after treatment has ended. New side effects from cancer treatment can also manifest months, or even years, after the treatment regimen is complete.

Anticoagulants: Sometimes called blood thinners, medication that decreases the blood's ability to clot.

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.

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.

Celiac plexus block: A procedure in which a substance such as alcohol is injected into the celiac plexus of the abdomen to destroy the nerves. These nerve-destroying substances prevent pain signals from traveling to the brain so the patient no longer feels pain.

Continuity of care: A system of care in which the patient and doctor work together to ensure that the patient receives consistent, high-quality, cost-effective medical care.

Deep vein thrombosis (DVT): The formation of a blood clot in a deep vein, generally in the lower extremities. DVT can cause serious problems if it breaks loose and travels through the bloodstream to the lungs. Symptoms of DVT include swelling, pain when walking or flexing the foot and sometimes redness in one leg.

Dysphagia: Trouble swallowing foods or liquids. Can be mild (slight difficulty swallowing) to severe (inability to swallow safely).

Endoscopic retrograde cholangiopancreatography (ERCP): A procedure used to image the digestive tract, including the pancreas. In this procedure, a thin, lighted tube called an endoscope is guided through the mouth and stomach and into the first part of the small intestine (duodenum). A narrower plastic tube, called a catheter, is inserted through the endoscope and into the bile and pancreatic ducts from the small intestine.

Gastroparesis/Delayed gastric emptying: A condition where the stomach cannot empty food into the small intestine properly. This condition is not caused by a blockage.

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.

Pain journal: A detailed record of the different aspects of pain: when it occurred, what caused the pain (if anything), how the pain feels (for example dull, achy, sharp, radiating), and other information that may be helpful.

Pain specialist: A healthcare professional who specializes in the diagnosis and treatment of pain. Anesthesiologists, neurologists and neurosurgeons frequently specialize in pain management. Some physiatrists also specialize in pain management.

Pancreatic enzymes: The proteins made by the pancreas that aid in food digestion. The three types are amylase, lipase and protease. Together, these enzymes are commonly referred to as pancreatic juice.

Paracentesis: A surgical procedure to remove fluid from the abdomen.

Pulmonary embolism: A life-threatening condition where a clot, or fragment of a clot, breaks loose and travels in the bloodstream, blocking arteries in the lungs. This causes damage, shortness of breath and chest pain. Requires immediate medical attention.

Sleep hygiene: A term utilized to describe when a person follows healthy sleep habits. These practices help people improve the quality and duration of sleep.

Stent: A small metal or plastic tube inserted into the center of a vein, artery or duct in order to open a blocked passageway.

Supportive care: A medical approach to care that serves to prevent, treat or eliminate symptoms and stress of serious illness, regardless of prognosis. Supportive care may include surgery, chemotherapy or radiation therapy if their intent is to alleviate pain and discomfort rather than to fight the cancer.

Survivor's guilt: The feeling of guilt for surviving an event that others may not.

Upper gastrointestinal endoscopy (UGI): A procedure that uses an endoscope (a thin, lighted tube) to see the inside of the upper gastrointestinal track, which includes the esophagus, stomach and first part of the small intestine (duodenum).

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.



Want to know more about any of the services we offer? Hablamos español. Contact PanCAN 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.***

©2003-2023 Pancreatic Cancer Action Network, Inc. PANCAN®, PANCREATIC CANCER ACTION NETWORK® and Know Your Tumor® are registered trademarks.

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 Patient Services staff 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.

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.

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. Hablamos español.

**PANCREATIC
CANCER
ACTION
NETWORK**

®

1500 Rosecrans Avenue, Suite 200
Manhattan Beach, CA 90266
877-2-PANCAN
pancan.org