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Medical Update on Pancreatic Cancer

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Learn about:

- New treatment options
- Managing side effects
- Proper nutrition
- Resources and support



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CancerCare is a national nonprofit organization that provides free support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved. CancerCare programs—including counseling and support groups, education, financial assistance, and practical help—are provided by professional oncology social workers and are completely free of charge. Founded in 1944, CancerCare provided individual help to more than 100,000 people last year and had more than 1 million unique visitors to our websites. For more information, call 1-800-813-HOPE (4673) or visit www.cancercare.org.

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New treatment combinations are improving the outlook for people with pancreatic cancer.

Each year in the United States, more than 37,000 people are diagnosed with pancreatic cancer. A small organ behind the stomach, the pancreas helps the digestive system break down and absorb fats and proteins in foods. The pancreas also produces hormones such as insulin.

Treatment for pancreatic cancer is usually based on where the cancer is located in the pancreas and whether the tumor can be removed by a surgeon. Treatment varies depending on whether the tumor:

- is confined to the pancreas and can be removed by surgery;
- is confined to the pancreas and cannot be removed by surgery;
- has spread (or metastasized) beyond the pancreas into other areas of the body.

In this booklet we discuss the most common type of pancreatic cancer, called ductal adenocarcinoma, which begins in the duct cells.

Treatments for Pancreatic Cancer

Pancreatic cancer is best treated by doctors who specialize in this disease. If you and your doctor decide that surgery is your best treatment option, be sure to find a surgeon who performs pancreatic surgery often. This may require traveling to a different city or state. Ideally, the surgeon should work at a large cancer center that treats many patients with pancreatic cancer.

SURGERY FOR CANCER CONFINED TO THE PANCREAS

Surgery is the standard treatment for pancreatic cancer located in an area of the pancreas that can be completely removed without harming nearby nerves and blood vessels. The follow-up treatment for people who have had surgery is not as clear-cut. But findings from two clinical trials strongly suggest that chemotherapy benefits people who have had surgery.

In one clinical trial, people with pancreatic cancer were divided into two groups. One group of patients received gemcitabine (Gemzar), a type of chemotherapy, for six months after surgical removal of their tumor. The other group did not receive any chemotherapy after surgery. Cancer was controlled better in the people who received gemcitabine than in those who did not receive it. Patients who received gemcitabine went longer before their cancer returned and lived longer.

Gemcitabine did cause side effects, such as lower levels of infection-fighting blood cells, swelling in the legs and arms, rash, flu-like symptoms, nausea, and—rarely—vomiting. However, these side effects were somewhat uncommon. It's important to know that doctors can control and reduce such side effects so that people can stick to their treatment. In this clinical trial, the average patient finished all six months of treatment and reported feeling good about his or her quality of life during treatment.

Another large clinical trial that is now under way is combining chemotherapy with radiation for people who have surgical treatment for pancreatic cancer. Early results from this clinical



trial suggest that receiving gemcitabine and radiation may benefit people who have had cancer removed from the right side of the pancreas, which is called the pancreatic “head.” Radiation tends to cause side effects such as upper abdominal discomfort, fatigue, nausea, vomiting, and diarrhea. More study needs to be done on this combination of treatments.

Talk with your doctor about the possible benefits and side effects of chemotherapy, or the combination of chemotherapy and radiation, after pancreatic cancer surgery.

NONSURGICAL TREATMENT FOR CANCER CONFINED TO THE PANCREAS

Sometimes pancreatic cancer stays inside the pancreas, but because the tumor is so close to blood vessels or nerves, it’s impossible for a surgeon to remove it all. In this case, surgery does not appear to benefit people. However, there are two other options: chemotherapy alone or chemotherapy combined with radiation. Most doctors believe that chemotherapy is important to help control cancer that may spread to other parts of the body. Often, if chemotherapy works, patients also are treated with radiation directed at the tumor in the pancreas.

PANCREATIC CANCER THAT HAS SPREAD BEYOND THE PANCREAS

Once cancer has moved beyond the pancreas, surgery and radiation to the pancreas are not beneficial. Pancreatic cancer that has metastasized is treated with chemotherapy, usually gemcitabine.

Gemcitabine can also be combined with the drug erlotinib (Tarceva). Erlotinib is a type of targeted treatment that blocks the function of receptors on the surface of cells. Receptors take in messages ordering the cells to grow and divide. When they are blocked, cancer-cell growth slows or stops. Erlotinib is a pill taken once daily, every day, throughout treatment.

In a large clinical trial, the combination of erlotinib and gemcitabine worked better than gemcitabine alone in people with metastatic pancreatic cancer. Side effects of erlotinib include fatigue, nausea, and diarrhea, all of which can be managed with medication. In addition, erlotinib often causes a skin rash. The skin can feel dry or itchy. Research suggests that the rash may be a good sign that erlotinib is working properly. Doctors prescribe moisturizing creams, antibiotics (if the skin becomes infected), and anti-inflammatory medications to treat skin changes.

The findings from another large clinical trial suggest that combining gemcitabine with the chemotherapy capecitabine (Xeloda) is also more beneficial to people with metastatic pancreatic cancer than gemcitabine alone. Like erlotinib, capecitabine can be taken as a pill, making it much more convenient than other types of chemotherapy, which must be given intravenously (through a vein). The most common side effects of capecitabine are diarrhea, nausea, and vomiting; mouth and throat sores; stomach pain and upset; dry, itchy skin; pain, swelling, or redness of the hands and feet; and rash.

Managing Pain and Other Side Effects of Pancreatic Cancer

Pancreatic cancer usually causes a number of side effects, but there are many ways that your health care team can manage them. If side effects happen, tell your doctor or nurse about them. Together, you can make the best decisions for your care.

PAIN

Many people with pancreatic cancer experience pain. How strong the pain is, and how often it happens, depends on several factors: the position of the tumor, how much the cancer has grown, and the location of any tumors that have spread outside of the pancreas.

Pain affects everyone differently. Depression, poor sleep, fatigue, and anxiety can all make pain more difficult to tolerate.

Talking to Your Doctor About Pancreatic Cancer

Pancreatic cancer is a challenging disease, so good communication between you and your health care team is important. Here are some tips that can help:

Bring someone with you to your appointment. It's always helpful to have support, and the person can serve as a second set of ears. He or she may think of questions to ask your doctor or remember details that you may have forgotten.

Prepare a list of questions beforehand. Make your questions specific and brief because your doctor has limited time. Once you're at your appointment, ask your most important questions first.

Write down your doctor's answers.

Taking notes will help you remember your doctor's responses and instructions. It also allows you to go over the information later when you have more time to concentrate or do research. If possible, tape record your visits.



Be assertive. If you're having trouble understanding something, ask your doctor if there is another time that the two of you can discuss it in more detail. Using an "I" statement ("I don't understand.") is much more effective than a "You" statement ("You're being unclear.").

If something is unclear, try repeating it back to your doctor. You might start by saying, "So you mean I should..." If you understand better with visual aids, ask to see the X-rays or slides, or ask your doctor to draw a diagram.

Pain is treatable, and getting help for it can greatly improve your quality of life. People who are pain-free eat better, sleep better, and cope with chemotherapy better than those in severe pain.

Depending on the level of pain, doctors prescribe various medications. Even the most severe pain can be managed effectively with opioids, such as morphine. Although opioids can cause constipation, there are drugs that can ease this side effect. Pain medications may also cause mild nausea, sleepiness, difficulty urinating, and itching. These side effects can be managed as well.

Some people with cancer worry about becoming addicted to pain medicines. Don't let this fear keep you from getting help. Addiction among drug abusers is a psychological dependence on a drug. That's different from needing drugs to relieve physical pain when you have cancer. With long-term use of an opioid pain reliever, a person can sometimes build up a tolerance to it. Tolerance means that you may need more of a medicine to get the same pain relief. If this happens, doctors can prescribe other medicines or drug-delivery methods to relieve pain.

Another effective pain relief method for people with pancreatic cancer is the celiac plexus block. This is a procedure in which the celiac plexus (a group of nerves near the pancreas) is numbed with medication, often alcohol injected with a needle. For many patients, this greatly reduces pain and the need for other pain medications.

If pain comes from the pancreatic tumor itself or from tumors that have spread to the bone, radiation may be an option. For some people, relaxation exercises and mind/body techniques, such as deep breathing and meditation, may also help manage pain. Some cancer treatment centers have programs to teach people with cancer and their caregivers the basics of these techniques. There are also a number of easy-to-follow educational books on this subject.

JAUNDICE

In this condition, bile—a substance involved in digestion that is produced by the liver—builds up to unsafe levels. Jaundice is common in people with pancreatic cancer that begins in the head of the pancreas. It is caused by blockage of the bile duct, a small tube that carries bile out of the liver. Jaundice can cause loss of appetite, weight loss, nausea, and itching, as well as yellowing of the skin and eyes. The standard treatment for jaundice in people with pancreatic cancer is the insertion of a tube, called a stent, into the bile duct. The tube helps bile drain into the intestine.

If you have fever, chills, abdominal pain, or any recurrence of jaundice after receiving a stent, let your health care team know. These symptoms can be signs of an infection or a problem with the stent.

INTESTINAL BLOCKAGES

Some people with advanced pancreatic cancer may develop blockages in the intestines. This can happen if the tumor itself blocks the intestines or if nerve damage prevents the intestines from working properly. Intestinal blockages can cause eating difficulties and repeated vomiting. For people using opioids for pain relief, changing the dosage often helps relieve blockages. Sometimes, surgery or medicines are used to treat intestinal blockages. Another option is a gastrostomy tube inserted into the stomach to allow fluids to drain. This can help relieve vomiting.

Doctors can also drain fluids from the abdomen with a hollow needle inserted through the skin. If the fluid quickly builds up again, a permanent tube called a catheter may be needed to drain fluid continually.

Clinical Trials: An Important Treatment Option

There's no question that clinical trials have led to advances in cancer treatment, creating a brighter future for people with

What You Should Know About Clinical Trials

Your doctor can guide you in making a decision about whether a clinical trial is right for you. Here are a few things to keep in mind:

- Often, patients who take part in clinical trials gain access to and benefit from new treatments.
- Before you participate in a trial, you will be fully informed as to the risks and benefits of the trial.
- No patient receives a placebo (a look-alike pill or liquid with no active ingredient) if there is a standard treatment available for the disease. Most clinical trials are designed to test a new treatment against a standard treatment to find out whether the new treatment has any added benefit.
- You can stop taking part in a clinical trial at any time for any reason.

cancer. Clinical trials are the standard by which we measure the worth of new treatments and quality of life as patients go through those treatments. For this reason, doctors and researchers urge people with cancer to take part.

This is especially important for people with pancreatic cancer as doctors search for newer and more effective ways to treat the disease. Currently, most clinical trials for people with pancreatic cancer are phase I and phase II trials. People take part in these studies for a number of reasons, including the hope that the treatment will work for them and the desire to help future patients.

THE PHASES OF CLINICAL TRIALS

There are four phases of clinical trials:

In **phase I trials**, researchers test for the first time the safety of a new drug or dosage in people. Only a small group of 20 to 80 people, usually with advanced cancer, is included in phase I

trials. Although these clinical trials focus on the safest dose of a new drug, doctors and patients also hope to see benefits from the treatment as well. Phase I trials usually take place in special research institutions, where patients can be closely monitored.

In **phase II trials**, the new drug or treatment is given to a larger group of people (100 to 300) to see if it is effective, to further evaluate its safety, to learn more about the side effects that might occur and how to manage them, and to find the best dose. Some phase II trials in pancreatic cancer are being randomized—that is, the patients taking part are randomly chosen to be in one of two groups. One group gets the new treatment, and the other gets standard treatment. Like phase I studies, phase II clinical trials usually take place at special research institutions.

In **phase III trials**, the study drug or treatment is given to even larger groups of people, usually many hundreds to thousands. In the case of pancreatic cancer, generally hundreds of patients take part. During this phase, researchers are able to confirm the treatment's effectiveness; observe side effects that might not have occurred during earlier phases in smaller groups; compare the new treatment with currently used standard treatments; and collect information that will allow the new drug or treatment to be used safely.

In **phase IV trials**, researchers study drugs after they have been approved by the U. S. Food and Drug Administration and marketed to the public. These trials gather additional information on safety and effectiveness.

Eating Well

Because the pancreas plays a key role in digestion, pancreatic cancer can cause a number of nutrition-related side effects. These side effects may be a result of the cancer itself or treatment. The right nutrition can help you maintain your weight, strength, and quality of life as you go through treatment for pancreatic cancer.

The most common nutrition-related side effects people with

pancreatic cancer experience are malabsorption (difficulty digesting or absorbing nutrients from food), nausea and vomiting, loss of appetite, taste changes, feeling full early, pain with eating, fatigue, and changes in bowel movements. If eating poses a challenge, let your health care team know and ask to see a registered dietitian.

The following tips can help you cope with nutrition-related side effects of pancreatic cancer:

Eat small, frequent meals. Try to eat about six to eight times a day.

Plan meals and snacks. Each day, take time to plan what and when you will be eating the next day. This will help you cope with times when you don't feel hungry or don't know what to eat.

Drink plenty of fluids.

Most people need to drink at least six to eight cups of water or other fluid every day. Don't include beer, wine, or other alcoholic drinks in the daily tally.

Limit the amount of fat in your diet. High-fat foods can contribute to changes in bowel habits or to feeling full quickly.

Eat high-protein foods. Pancreatic cancer and its treatment increase a person's protein needs. To meet these needs, include a protein-rich food with each meal or snack. Good sources of protein include:

- Lean cuts of meat, poultry, or fish
- Beans, peas, or lentils
- Low-fat or fat-free dairy products
- Eggs



Signs That You Might Need Pancreatic Enzymes

A healthy pancreas secretes a number of substances called enzymes that help with digestion. When a person has pancreatic cancer, the cancer or the treatments for it may affect the ability of the pancreas to secrete needed enzymes. Prescription pancreatic enzymes are available. Talk with your doctor if you experience any of the following symptoms:

- Feelings of indigestion
- Cramping after meals
- Large amounts of gas
- Foul-smelling gas or stools
- Unexplained weight loss
- Floating stools
- Greasy or fatty stools
- Frequent stools
- Loose stools or diarrhea

Everyone needs a different amount of pancreatic enzymes to help with digestion, and pancreatic enzymes vary from brand to brand. If you have been prescribed pancreatic enzymes, it may take some time to find the brand and dose that works best for you.

- Milk alternatives such as soy milk, rice milk, and hemp milk
- Meat alternatives such as tofu or veggie burgers
- Protein powders, including dry milk powder
- Nuts and seeds
- Meal-replacement drinks such as homemade smoothies or commercial liquid nutritional supplements

Choose foods that are dense in nutrients. Milk and dairy products, high-protein foods (such as lean meat), fortified cereals, and fruits and vegetables all pack in healthy amounts of vitamins and minerals.

Stay as active as possible. Physical activity helps stimulate the appetite and preserve muscle mass. Talk with your doctor about what level of exercise is right for you.

Use anti-nausea medications if you need them. Nausea can interfere with eating and quality of life.

Your Support Team

When you are diagnosed with pancreatic cancer, you're faced with a series of choices that will have a major effect on your life. Help is available. Your health care team, family members, and friends will likely be an invaluable source of support at this time. You can also turn to these resources:

Oncology social workers provide emotional support for people with cancer and their loved ones. These professionals can help you cope with the challenges of a pancreatic cancer diagnosis and guide you to resources. CancerCare® offers free counseling from oncology social workers on staff who understand the challenges faced by people with pancreatic cancer.

Support groups provide a caring environment in which you can share your concerns with others in similar circumstances. Support group members come together to help one another, providing insights and suggestions on ways to cope. At CancerCare, people with pancreatic cancer and their families can take part in support groups in person, online, or on the telephone.



Financial help is offered by a number of organizations, including CancerCare, to help cover cancer-related expenses such as transportation to treatment or child care. There are also organizations such as the CancerCare Co-Payment Assistance Foundation, which help people cover the cost of co-payments for pancreatic cancer drugs.

To learn more about how CancerCare helps, call us at 1-800-813-HOPE (4673) or visit www.cancercare.org.

Frequently Asked Questions

Q During the past decade, what progress has been made in extending survival for people with pancreatic cancer?

A Improving pancreatic cancer survival rates has been particularly challenging. This is because the cancer tends to be detected late, the symptoms may not be very specific, the cancer tends to resist chemotherapy, and the biology and genetics of the cancer are extremely complex. However, researchers are making strides in treating pancreatic cancer. They are continually developing better ways to study pancreatic cancer, and many people are working on new treatments. Researchers are hopeful that there will be significant changes in survival for people with pancreatic cancer during the next five years.

Q I recently read that turmeric is being studied as a possible treatment for pancreatic cancer. Is there any evidence that the active ingredient in the spice is useful, and is it safe to take?

A Studies suggest that the spice may have a role in treating cancer, but this has not yet been proved. Researchers are trying to pinpoint the best dose to take. The amount of turmeric a person would have to take by mouth is quite large, and not all of it seems to get into the bloodstream. Researchers are trying to create a drug form of the active ingredient in turmeric, called curcumin, which could be given to patients intravenously (through a blood vein). As of now, there is no evidence to prove that curcumin is helpful or whether it is safe. Researchers hope to know more about it soon.

Q What is the treatment and prognosis for a neuroendocrine tumor that begins in the pancreas?

A Neuroendocrine tumors that start in the pancreas are quite different from the pancreatic cancer tumors discussed in this booklet. Neuroendocrine tumors affect cells in the pancreas that produce hormones, including insulin. The pancreatic cancer we have been discussing affects duct cells—pancreatic cells that drain substances called enzymes from the pancreas into the bowel.

Neuroendocrine tumors appear to grow more slowly and in a different way than other pancreatic tumors. They are often removed surgically and then treated with different chemotherapy than is used for standard pancreatic cancer. Also, neuroendocrine tumors are often treated with hormones and a special type of radiation.

Q For a person with pancreatic cancer who has already been treated with surgery and chemotherapy, what is the current standard of care?

A The standard procedure is to have CT scans of the abdomen and pelvis every four to six months. In addition, blood tests are used to check levels of CA19-9, a substance released by pancreatic tumors. It is used as a marker of tumor growth. If the level of CA19-9 is high before surgery and then rises after surgery, extra tests may be needed to see if a tumor has returned.

Resources

CancerCare

1-800-813-HOPE (4673)
www.cancercares.org

CancerCare Co-Payment Assistance Foundation

1-866-552-6729
www.cancercarescopay.org

American Cancer Society

1-800-227-2345
www.cancer.org

Cancer.Net

Patient information from the American Society of Clinical Oncology
www.cancer.net

National Cancer Institute

Cancer Information Service
1-800-422-6237
www.cancer.gov

Gilda's Club Worldwide

1-888-445-3248
www.gildasclub.org

Hirshberg Foundation for Pancreatic Cancer Research

310-473-5121
www.pancreatic.org

The Lustgarten Foundation

1-866-789-1000
www.lustgarten.org

National Coalition for Cancer Survivorship

1-888-650-9127
www.canceradvocacy.org

Pancreatic Cancer Action Network, Inc.

1-877-272-6226
www.pancan.org

The Wellness Community

1-888-793-9355
www.thewellnesscommunity.org

To find out about clinical trials:

Coalition of National Cancer Cooperative Groups

www.CancerTrialsHelp.org

National Cancer Institute

www.cancer.gov/clinicaltrials



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The material presented in this patient booklet is provided for your general information only. It is not intended as medical advice and should not be relied upon as a substitute for consultations with qualified health professionals who are aware of your specific situation. We encourage you to take information and questions back to your individual health care provider as a way of creating a dialogue and partnership about your cancer and your treatment.

All people depicted in the photographs in this booklet are models and are used for illustrative purposes only.

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When one word changes your world,

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makes all the difference



With CancerCare,
the difference comes from:

- Professional oncology social workers
- Free counseling for you and your loved ones
- Education and practical help
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