

# GETTING ORGANIZED AFTER DIAGNOSIS

## 1. LEARN THE BASICS

Understanding your specific diagnosis will help you make informed decisions. Some basic questions to ask are: What type of pancreatic cancer do I have? Where in the pancreas is it located? What is the stage? Has it spread to other organs? What tests do I need? How can I access genetic and biomarker testing? What treatments do you recommend?

## 2. BE INFORMED

Visit [pancan.org](http://pancan.org) and contact PanCAN Patient Services for resources and answers to your questions about pancreatic cancer, treatment, tests, clinical trials, pain management, dietary concerns, side effects, finances and more.

## 3. GET COPIES OF YOUR RECORDS

Always ask for a copy of your medical records and lab results, including CT scan, MRI, EUS, ERCP, CA 19-9 and biopsy results. These are very important when meeting with other doctors, especially when seeking a second opinion. Although some institutions may require new testing, it may save time and money to have your previous tests readily available. You have the rights to all of your records and lab results.

## 4. CHOOSE YOUR HEALTHCARE TEAM

Seeing pancreatic cancer specialists (physicians who diagnose and treat a high volume of pancreatic cancer patients) improves outcomes. The Pancreatic Cancer Action Network (PanCAN) strongly recommends consulting with pancreatic cancer specialists who have experience diagnosing and treating the disease.

You should feel comfortable and supported by your healthcare team. PanCAN strongly recommends seeking a healthcare team that suits all of your physical, mental and emotional needs. Comprehensive cancer centers may have the most thorough care with highly qualified doctors and specialized cancer services. However, you may find a smaller, local hospital also has the expert care you need. Contact PanCAN Patient Services to learn about pancreatic cancer specialists in your area.

## 5. SEEK A SECOND OPINION

You have a right to get a second opinion. Pancreatic cancer is rare and general oncologists may not be experienced with treating this disease. PanCAN strongly recommends seeking a second opinion, as needed, at any point in your diagnosis.

## 6. LEARN ABOUT TREATMENT OPTIONS

You are your own best advocate. PanCAN strongly recommends discussing your treatment goals with your healthcare team and knowing all of your options at every stage of your disease.

Options include surgery, radiation therapy, chemotherapy and/or targeted therapy that may be given as a standard protocol or as part of a clinical trial. Making decisions quickly is important, but getting care from the appropriate doctor/institution is even more critical. Do not feel rushed – get the information you need! Contact PanCAN Patient Services to learn more about available treatment options.

## 7. CONSIDER A CLINICAL TRIAL

Pancreatic cancer patients who participate in clinical research have better outcomes. Every treatment available today was approved through a clinical trial. PanCAN strongly recommends clinical trials at diagnosis and during every treatment decision.

Clinical trials are research studies that examine new investigational treatments or new combinations of existing treatments. Contact PanCAN Patient Services for a personalized clinical trials search, providing you a list of relevant options to discuss with your healthcare team.

## 8. COMMUNICATE WITH YOUR HEALTHCARE TEAM

Prepare for doctor's visits. Write down all of your questions, symptoms or side effects. Give this information to your healthcare team before the appointment. Invite a trusted friend or family member to attend the visit and/ or ask the provider if you can record the appointment.

Always consult with your doctor and a dietitian before taking vitamins or dietary supplements to avoid negative drug interactions. When considering alternative treatments, work with your healthcare team to investigate the scientific validity and safety of these treatments.

Seeing healthcare professionals who focus on symptom management and supportive (palliative) care improves outcomes and is critical for quality of life. PanCAN also strongly recommends symptom management and supportive (palliative) care be provided early in your diagnosis as well as during and after treatment. Contact Patient Services for resources to find dietitians and supportive care professionals.

## 9. FIND RESOURCES

There are services in hospitals available to patients, like counseling, navigation services and complementary medicine. An oncology social worker may be particularly helpful in connecting you with resources.

## 10. APPEAL WHEN REJECTED

If an insurance claim is rejected, appeal it by resubmitting the claim. Every insurance company has an appeals process. Keep copies of all the paperwork submitted. If your claim continues to be rejected after multiple reviews, contact the state insurance commission. Contact PanCAN Patient Services if you need more support related to finances and insurance.

## 11. GET SUPPORT

Support for pancreatic cancer patients is critical to improve quality of life and overall well-being. Having a support system of caregivers, family, friends, healthcare professionals and PanCAN Patient Services is important to address and manage the needs of the patient.

It is valuable to connect with others who are also experiencing pancreatic cancer. Contact PanCAN Patient Services or visit [pancan.org/scnform](https://pancan.org/scnform) to learn about our Survivor & Caregiver Network and other support resources.

## 12. GET INVOLVED

Visit [pancan.org](https://pancan.org) to get involved by donating, volunteering and through advocacy.

**For more information, visit [pancan.org](https://pancan.org)  
For questions, contact us at 877-2-PANCAN**

Contact PanCAN Patient Services M – F, 7 a.m. – 5 p.m. PT, at **877-2-PANCAN**  
or [patientservices@pancan.org](mailto:patientservices@pancan.org). Hablamos español.