



Getting Organized After Diagnosis

1. Learn the Basics

Obtain detailed information about your specific diagnosis from the doctor. This will help you understand your diagnosis and 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 treatments do you recommend?

2. Be Informed

Visit the Pancreatic Cancer Action Network website at www.pancan.org and contact a Patient and Liaison Services (PALS) Associate. PALS Associates can answer your questions about pancreatic cancer, provide treatment information, search for clinical trials, and offer additional resources on pain management, dietary concerns, side effects, finances and support. PALS Associates are available at 877-272-6226 or pals@pancan.org Monday - Friday, 7 a.m. - 5 p.m., Pacific Time.

3. Obtain Copies of Your Records

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

4. Seek a Second Opinion

Schedule an appointment with a doctor who specializes in pancreatic cancer. Your current doctor may be an excellent resource, but it is important to see a pancreatic cancer specialist. Pancreatic cancer is rare and general oncologists do not see patients with this type of cancer very often. Treating cancer is a team effort so your doctor should not be offended if you decide to seek a second opinion.

5. Hire an Expert Doctor

Pancreatic cancer specialists see and treat a high number of individuals with pancreatic cancer. Select the most qualified doctor to treat you. Comprehensive cancer centers may have the most thorough care with highly qualified doctors and specialized cancer services. However, you may find that a smaller local hospital also has the expert care you are looking for. Contact a PALS Associate to learn about pancreatic cancer specialists in your area.

6. Learn About Treatment Options

Discuss treatment options with your oncologist. Your options may include surgery, radiation chemotherapy, and/or targeted therapy and may be given as a standard protocol or as part of a clinical trial. Making decisions in a timely manner is important, but getting care from the appropriate doctor/institution is even more important. Do not feel rushed – get the information you need! Contact a PALS Associate to learn more about available treatment options.



7. Consider Participating in a Clinical Trial

The Pancreatic Cancer Action Network recommends that all patients consider clinical trials when exploring treatment options. Clinical trials are research studies that investigate new treatments or new combinations of treatments. They are the only way for researchers to determine whether new treatments are beneficial for pancreatic cancer patients. In addition, clinical trials provide patients the opportunity to receive new, potentially better treatments. Our highly trained PALS Associates can help you simplify the process and perform a customized clinical trials search for you.

8. Prepare for the Doctor

As new symptoms or side effects occur, record them in a notebook. Write down all of your questions before meeting with your doctor. If possible, email, fax or mail this information to your doctor's office ahead of time so the doctor is aware and prepared at your next appointment. It may also be helpful to bring a tape recorder into your appointments. This approach lends itself to better doctor-patient communication. Be sure to ask your doctor and his or her staff for permission before recording your visits.

9. Keep Doctors Informed

Proper diet and vitamins may be extremely important to your cancer care. 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.

10. Find Resources

Contact the oncology social worker at the institution where you are receiving treatment. The oncology social worker is an expert in helping patients and their families obtain psychosocial support, arrange for home care services, utilize healthcare resources, advocate for their loved one, receive follow-up care and understand the healthcare system. Keep in mind there are a multitude of services in each hospital that are available to you as a patient.

11. Appeal When Rejected

If an insurance claim is rejected, appeal it by re-submitting the claim. Every insurance company has an appeals process. Throughout that process, make a copy of all the paperwork that is submitted. Receiving the most state-of-the-art care during treatment may be a vital step toward positive outcomes. If your claim continues to be rejected after multiple reviews, contact the state insurance commission.

12. Get Involved

The best way to stay informed and learn more about ways to get involved is to join the Pancreatic Cancer Action Network's mailing list to receive our newsletter and information about activities and events happening in your area. This is also a great way to meet other survivors and family members.