



Getting Organized After Diagnosis

1. Learn the Basics

Obtain facts from the doctor about your specific pancreatic cancer diagnosis. This will help you make informed decisions. Some basic questions to ask are: What type of pancreatic cancer do I have? Where is it located? What is the stage? Has it spread? 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!

2. Be Informed

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

3. 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. Pancreatic cancer specialists see and treat a high number of individuals with pancreatic cancer. Treating cancer is a team effort. Your doctor should not be offended if you decide to seek a second opinion. Contact a PALS Associate to learn about pancreatic cancer specialists in your area.

4. 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.

5. Find Resources

Contact the medical social worker at the institution where you plan to receive treatment. The medical 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 health care system. Keep in mind there are a multitude of services in each hospital that are available to you as a patient. Our PALS Associates can provide you with forms to help you organize your medical history, medical procedures and tests and insurance information.

6. Hire an Expert Doctor

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.



Patient and Liaison Services (PALS)

PANCREATIC CANCER ACTION NETWORK

7. 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.

8. Consider All Options

Discuss treatment options with your oncologist. Your options may include surgery, radiation and/or various types of chemotherapy regimens. Treatment regimens may be standard protocols or clinical trials. Contact a PALS Associate to learn more about available treatments or to receive a list of clinical trials for which you may be eligible.

9. Analyze It

Ongoing research on pancreatic tumors is needed to work towards a cure. If your doctor recommends a biopsy or if surgery is an option, discuss the opportunity to donate tissue samples to research prior to the procedure. Your tumor may be used for learning more about the disease, vaccine development and gene therapies.

10. 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.

11. Stay Aware

Once your treatment is completed, monitor your tumor. Tiny cells can travel to distant locations and form tumors called metastases. Schedule regular follow-up visits with your oncologist to monitor the tumor. These visits should include CT scans and blood tests (CA 19-9).

12. 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 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 reviewers have evaluated it, contact the state insurance commission.

13. Become Active

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.