GETTING ORGANIZED AFTER DIAGNOSIS

PANCREATIC CANCER ACTION NETWORK®

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? What treatments do you recommend?

2. BE INFORMED

Visit pancan.org and contact Patient Central, who can provide resources and answer 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 Patient Central to learn about pancreatic cancer specialists in your area.

5. SEEK A SECOND OPINION

You have a right to seek a second opinion. Pancreatic cancer is rare and general oncologists may not be familiar 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. The Pancreatic Cancer Action Network strongly recommends discussing your treatment goals with your healthcare team and knowing all of your options at every stage of your disease.

Options may 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 Patient Central to learn more about available treatment options.

HOW DO I CONTACT PATIENT CENTRAL?

Call **877-2-PANCAN** (toll free) or email **patientcentral@pancan.org**. Patient Central is available Monday - Friday, 7 a.m. - 5 p.m., Pacific Time.

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. The Pancreatic Cancer Action Network 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.

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.

Ask for supportive care as needed. Good nutritional care improves outcomes and is critical for quality of life. The Pancreatic Cancer Action Network strongly recommends patients have access to pancreatic enzymes and see a registered dietitian.

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

9. FIND RESOURCES

There may be many services in hospitals that are available to patients, such as 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.

11. GET SUPPORT

Support for the pancreatic cancer patient is critical to improve quality of life and overall well-being. Having a support system of caregivers, family, friends, healthcare professionals and Patient Central 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 Patient Central to learn about our Survivor & Caregiver Network and other support resources.

12. GET INVOLVED

Visit pancan.org to get involved by donating, volunteering and through advocacy. You can also join the Pancreatic Cancer Action Network's Patient Registry to help accelerate pancreatic cancer research. This registry is an online database created to look for patterns that will lead to improved treatment options and outcomes for patients. Contact Patient Central or visit pancan.org/patientregistry to set up an account.

PANCREATIC CANCER ACTION NETWORK®

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