



I Have Pancreatic Cancer. What Do I Do Now?

A Checklist for Patients & Families

A pancreatic cancer diagnosis can be overwhelming for patients, but there is a way forward.

These tips and steps to follow are suggested, tested, and proven by Project Purple's Super Human group of survivors.



****Easy-To-Follow Checklist Attached On Last Page****

Learn The Basics Of Pancreatic Cancer (PC)

When facing pancreatic cancer, it helps to understand what you are facing. For more information from medical professionals, please visit <https://www.cancer.gov/types/pancreatic>.

Don't Rush The Process

Pancreatic cancer can be intimidating, and it may be tempting to rush into treatment. But, when possible, taking a few weeks to do some additional research/interviews may be valuable. Depending on your situation, your doctor may feel it best to act sooner so please follow the directions of your trusted medical professional.

Know Your Treatment Options

When you are diagnosed with PC, you have several options for treatment, and your treatment may change throughout your care. Ask your doctor about what treatments are available to you.

For more information, visit
www.projectpurple.org
(203) 714-6052
info@projectpurple.org

Do More Tests

Additional tests may help determine your best treatment plan. Tumor testing and genetic testing can help you identify tumors caused by genetic mutations, which might respond better to certain treatments. This may help protect your family from the disease and keep them informed as well. For more information about testing options, please speak with your doctor.

Get A Second Opinion

A second opinion can provide clarity and also make you feel more confident about taking on your pancreatic cancer journey. At times, it can be life-saving. For more information on how best to ask and prepare for a second opinion, please visit bit.ly/secondopinionpc. Be sure to ask your insurance company if a second opinion will be covered.

Develop A Personal Plan

The most important thing you can do for your health is to create a personal plan to help you manage your day-to-day life, expectations, and emotions. Enlisting the help of loved ones, friends, and family is the first step in the process of creating a personal plan for your cancer journey. Our survivors suggest taking the time to process your emotions before speaking with others about your diagnosis and your expectations throughout your journey. They recommend being as upfront and honest as possible, especially with what you need from others. For a guide on how best to create your plan, please visit <https://www.cancer.org/self-management>.

When Possible, Bring A Friend Or Loved One To Appointments

While the camaraderie of bringing a loved one along is a major benefit, they can also help by asking questions and acting as a second listener. At times, listening to the information your doctor provides may become overwhelming. Having someone who is listening along with you will help you see the path forward.

Take Notes At Your Appointments

When so much information is coming at you at once, it can be difficult to remember for anyone - but especially if you are also going through chemotherapy. Taking notes can be extremely helpful.

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Seek Out Experts & High-Volume Centers

Facing pancreatic cancer is a team effort. One survivor suggests looking for an oncologist who specializes in pancreatic cancer and has a lot of experience with the disease. Getting experts on your team will help you create a more personalized treatment plan and can also ease your mind. Go to a high-volume center whenever possible, especially if you will have a Whipple Procedure. Consult with your oncologist for recommendations on what type of care you should be seeking to build the best team for you.

Talk To Your Doctor About Genetic Testing

Regardless of your family history, every new patient should undergo genetic testing.

Genetic testing can help family members know their risk for the disease, while potentially unlocking new curative treatments and early detection methods. For more information on genetic testing, please visit

<https://www.medicalnewstoday.com/articles/genetic-testing-pancreatic-cancer>.

See If Tumor Testing Is An Option

Tumor testing allows patients to seek more personalized treatment. Tumor testing seeks to find specific biomarkers that can help provide more information and insight into how cancer is affecting your body. There are two types of tumor tests patients can seek out: germline testing, which looks for inherited gene mutations in all body cells, and somatic testing, which assesses genetic material from the tumor itself to see if there are any variants present within the cells. Both tests have their pros and cons, so please consult your doctor before moving forward with either testing option. For more information on these types of tests, please visit <https://ocrahope.org/news/germline-vs-somatic-testing>.

Clinical Trials

Clinical trials are medical research studies testing possible new medications or treatments. They can be a good option if you are looking for new treatment options, especially if traditional treatments aren't working. For more information please visit <https://www.cancer.gov/clinical-trials>.

Seek Out A Caseworker

Caseworkers also referred to as nurse navigators or social workers, help you and your family cope with illness and injury, work through issues surrounding health and treatment, and connect you with the appropriate resources. They can provide referrals to county, state, and federal agencies along with other social and financial agencies. They can help with information and resources concerning your long-term or chronic healthcare needs. Also, they can assist you or your family in identifying therapy options or illness support groups that can assist you in coping with your illness or injury.

Managing Finances & Your Diagnosis

There are several options for supporting yourself and your family throughout your journey. Know that you have the option to request medical leave, or apply for disability and receive government assistance (SSI/SSDI). Check with your insurance providers to see what is covered. If you need assistance, please reach out to Project Purple through our Patient Financial Aid program at <https://www.projectpurple.org/patients-families/>.

Other Important Tips For Managing Your Diagnosis

Consider Homeopathic Options - With Your Oncologist's Supervision

There are non-traditional treatment options that may help you on your journey. We recommend using homeopathic methods in tandem with your treatment rather than as an alternative if they interest you. Discuss any non-traditional treatments you're considering with your oncologist to prevent adverse drug interactions. For more information on homeopathic treatments, please visit <https://www.mskcc.org/integrative-medicine/homeopathy>. This may not be the right fit for everyone. If you feel it is not for you, that's okay.

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Talking To Family & Friends About Pancreatic Cancer

Before you speak to someone about your diagnosis, you should consider how you want to tell them, and who you want to speak to. One survivor suggests if you have younger children, it's best to tell them separately in a one-on-one setting. Remember to be honest, clear, and as open as you feel you can be about your emotions. Try to let others know what you will need from them while going through treatment - both literally and emotionally. If someone you love needs additional resources, please direct them to our website at <https://www.projectpurple.org/>.

Seek Help From Friends & Family

Now is the time to count on friends and family for both emotional and physical support as you take on this journey. Don't be afraid to ask them to take on certain tasks, especially if they have offered to help you. For more information on how to talk with friends and family about your needs while going through treatment, please visit <https://www.roswellpark.org/cancertalk>.

Consider Enzymes

Ask your oncologist if pancreatic enzymes are right for you. Not all doctors think of prescribing them. They aid in digestion and help with the absorption of nutrients.

Consult A Nutritionist

Regardless of treatment type, pancreatic cancer takes a toll on the body and a person's ability to maintain a healthy diet and nutrition. For more information on pancreatic cancer nutrition, please visit <https://www.hopkinsmedicine.org/health/conditions-and-diseases/pancreatic-cancer/pancreatic-cancer-nutrition>.

Understand That Your Treatment May Change Overtime

Don't be alarmed if your treatment, or dosages, change throughout your diagnosis.

According to one of our survivors, doctors will often start patients on full-strength chemotherapy and then work backward to find a dosage that works best for that patient. Give doctors a chance to tweak medications, regimens, and dosage, and don't be too scared to try something different, especially when recommended by your care team.

Mental Health Matters

One of our survivors gave us a great piece of advice for patients. They said, "Wake up in the morning and ask yourself, 'What would make me happy today?' and then make an effort to do that." When going through pancreatic cancer, it is easy to give into depression and anxiety. Notice when those emotions pop up to work through them to maintain your mental and physical health as well. We have also had many survivors recommend therapy for both themselves and their loved ones. If your insurance covers it, the use of a mental health professional can be an invaluable tool.

Consider A Medication Schedule

Managing medication during treatment can be difficult. Having a medication schedule or routine can help make sure you don't miss or overtake your medicine. For more information on medication management please visit <https://www.hopkinsmedicine.org/health/wellness-and-prevention/help-for-managing-multiple-medications>.

Other Informational Resources

We know that information, education, and inspiration are essential for anyone battling pancreatic cancer. That's why we've gathered valuable resources to help you on your journey. You can listen to [survivor stories](#) to provide hope and encouragement or podcasts on [support and advocacy](#) for practical advice and emotional support. We also connect you with podcasts on the [latest research and health updates](#), so that you can stay informed about new treatments and advancements. For more informational resources, please visit <https://www.projectpurple.org/>.

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Become Familiar With These Terms

Please consult your doctor for more information on these terms. Some of these are complicated, so do not be overwhelmed if it takes some time to learn them.

CA 19-9: The CA 19-9 Radioimmunoassay (RIA) is a simple blood test that measures the level of tumor-associated antigens found in the blood. Healthy people typically have CA 19-9 levels between 0 and 37 U/mL. Levels above this range are considered high and could be a sign of cancer. It's important to note that non-cancerous conditions can also cause elevated CA 19-9.

CEA: A CEA test measures the level of carcinoembryonic antigen (CEA) in the blood or other body fluid. The CEA test result alone cannot definitively diagnose cancer. Doctors do not use the CEA test for routine cancer screening or diagnosis. A CEA level above 2.9 ng/mL is considered high, but it does not always indicate cancer.

CT Scan: A computed tomography scan is a medical imaging technique used to obtain detailed internal images of the body.

PET Scan: A positron emission tomography (PET) scan is a type of imaging test. It uses a radioactive substance called a tracer to look for disease in the body. A PET scan shows how organs and tissues are working.

MRI: Magnetic resonance imaging (MRI) is a noninvasive medical imaging technique that uses a magnetic field and computer-generated radio waves to create detailed images of the organs and tissues in your body. It produces high-resolution images of the inside of the body that help diagnose a variety of conditions.

EUS: Endoscopic ultrasound is a procedure that combines endoscopy and ultrasound to create images of the digestive tract and nearby organs and tissues. EUS helps diagnose conditions that affect the digestive tract and nearby organs and tissues.

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| <input type="checkbox"/> | Develop A Personal Plan | <input type="checkbox"/> | Seek Out A Caseworker |
| <input type="checkbox"/> | When Possible, Bring A Friend Or Loved One To Appointments | <input type="checkbox"/> | Managing Finances & Your Diagnosis |

Become Familiar With These Terms

- CA 19-9
- PET Scan
- CEA
- MRI
- CT Scan
- EUS

Remember you are never alone. At Project Purple, we are here to help you and your loved one navigate a pancreatic cancer diagnosis.

For more information visit:
www.projectpurple.org.

Other Important Tips For Managing Your Diagnosis

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- Talking To Family & Friends About Pancreatic Cancer
- Seek Help From Friends & Family
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