CHECKLIST FOR NEWLY DIAGNOSED PATIENTS

As overwhelming as a pancreatic cancer diagnosis can be, it is important to act quickly and put a treatment plan into place, as there are therapies available that you can benefit from. While it is important to identify an appropriate treatment team, treatment should ideally begin within one month after you receive your diagnosis. At the Lustgarten Foundation, we are committed to helping you fight this disease and have developed the checklist below for immediate steps that you and your loved ones should take upon receiving this diagnosis.

Understand the Disease

Thoroughly understand what stage of pancreatic cancer you have. Staging cancer is a standardized way to classify a tumor based on its size, whether it has spread, and where it has spread. Staging measures the extent of the disease and will impact treatment.

Get genetic testing.

Inquire about having your blood or saliva tested to identify possible genetic predispositions to cancer. This testing can have implications for family members and can guide your pancreatic cancer treatment program. According to new guidelines from the National Comprehensive Cancer Network, all pancreatic cancer patients should undergo genetic or germline testing for inherited genetic mutations, regardless of family history. Under these new recommendations, this testing should be done by your physician and should be covered by insurance. There are also companies like Color Genomics (color.com) and Myriad Genetics (myriad.com) that can do the testing.

Get Tumor testing.

Tumor testing, also known as somatic testing, is still in the early stages of being studied. If you are being treated at a major cancer center, you may want to inquire about having your tumor tested for genetic mutations, which in some instances can help identify additional therapy programs.

Seek opinions from experts.

Get two opinions and make sure that one is from a large academic institution that specializes in treating pancreatic cancer.

Know your healthcare team.

Treating pancreatic cancer requires an interdisciplinary approach that includes your oncologist and other specialists who will be involved in your care. Continue to see other doctors who are involved in your overall care, such as your internist.

Contact your insurance company.

Thoroughly understand your health insurance policy. Know what services are covered and what your out-of-pocket obligation will be per calendar year. Request a case manager to help you optimize your benefits and to navigate the intricacies of your policy.
Get Organized.

Record your questions in a notebook and bring it with you to all doctors' appointments. Use it to keep track of test results and appointment dates. Write down the contact numbers of all your doctors in one place or save them in your cell phone. Additionally, know the number to call if you have a problem or concern after hours or on a weekend.

Develop a support system.

Have someone accompany you to oncology appointments for support and clarification of the proposed plan of care.

Delegate responsibilities.

Enlist the help of family members, friends, and neighbors who want to help with errands or chores, meal preparation, and driving.

Control what you can.

Closely monitor your nutrition, physical activity, and pain level and provide feedback to your healthcare team. Utilize complementary therapy such as Reiki therapy, yoga, meditation, acupuncture, and pet therapy.

Initiate goals of care

Incorporate the palliative care team to help you control your symptoms so that you can have a better quality of life. Proper symptom management will help you stay on your treatment plan. Palliative care doesn’t mean you are giving up.

Take care of your emotional health.

Maintain daily routines and continue to partake in activities you enjoy as much as possible. If needed, seek out supportive services such as counselors, social workers, and support groups.

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