



Caregiver's Guide to Pancreatic Cancer – What Should I Do Next?

Getting organized after a diagnosis of pancreatic cancer can be an important step in getting control of the situation. As a caregiver, you are going to play a big role in helping your loved one get the best possible care.

Here are ten tips to help you after learning a loved one has been diagnosed with pancreatic cancer:

1) You are not alone

Having a loved one diagnosed with pancreatic cancer can be a shock. It can be frightening, but remember - you are not alone.

Every year ~ more than 4700 Canadian families face a new diagnosis of pancreatic cancer. Pancreatic Cancer Canada is here to help. We are the only national foundation that is dedicated to supporting pancreatic cancer patients and their loved ones.

We have a website (www.pancreaticcancercanada.ca) that can connect you with other families who have faced pancreatic cancer. We also have a national toll-free telephone number (1-888-pancan9 1-888-726-2269) that you can call to speak with other people who have been affected by pancreatic cancer. Please, use our website, call us, or e-mail (info@pancancanada.ca) - **we are here to help.**

2) Understand the basic facts

Obtain the basic facts from your doctor about the specific type of pancreatic cancer that your loved one has. This will help you make future treatment decisions. Some basic questions to ask are:

- What type of pancreatic cancer does my loved one have?
- Where is the cancer located?
- What is the stage?
- Has it spread?

Try to write this information down. You may be anxious and frightened right after diagnosis. This is common. Writing notes will help you to remember important information later. Plus, you can always read your notes later, when you have had more time to think. Keeping a binder of all appointments, test results, clinical trial information, and consent forms that you receive can be helpful too.

Clarify your notes with the doctor before you leave the appointment. Get the information that you need!

3) Seek a Second Opinion

Try to get a referral to a Canadian Center that specializes in the treatment of pancreatic cancer.

Your current doctor may be an excellent resource, but it is also 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 large number of pancreatic cancer patients each year.

Below we have listed the Canadian Centers that specialize in the treatment of pancreatic cancer. There, you will find specialty teams who are dedicated to pancreatic cancer patients and their families.

<p>Alberta</p> <p>The Cross Institute/University of Alberta Hospital Edmonton, AB</p> <p>The Tom Baker Cancer Centre Calgary, AB</p> <p>Atlantic Provinces</p> <p>Victoria General Hospital Halifax, N.S.</p> <p>Saint John Regional Hospital Saing John, NB</p> <p>British Columbia</p> <p>Vancouver General Hospital Vancouver, BC</p> <p>Kelowna General Hospital Kelowna, BC</p> <p>Victoria General Hospital Victoria, BC</p> <p>Royal Columbian Hospital, New Westminster, BC</p> <p>Manitoba</p> <p>Cancer Care Manitoba (this is a hospital and an agency) Winnipeg, MN</p> <p>Ontario</p> <p>Sunnybrook Health Sciences Centre Toronto, ON</p> <p>Grand River Regional Cancer Centre Kitchener-Waterloo, ON</p> <p>Juravinski Cancer Centre - Hamilton Health Sciences Corporation, Hamilton, ON</p>	<p>University Health Network - Princess Margaret Cancer Centre/Toronto General Hospital, Toronto, ON</p> <p>Sunnybrook Health Sciences Centre Toronto, ON</p> <p>London Health Sciences Centre London, ON</p> <p>The Ottawa Hospital Regional Cancer Centre Ottawa, ON</p> <p>St. Joseph's Health Centre Toronto, ON</p> <p>Trillium Health Centre Mississauga, ON</p> <p>Kingston General Hospital Kingston, ON</p> <p>Thunder Bay Regional Health Sciences Centre, Thunder Bay ON,</p> <p>Québec</p> <p>CHOM Centre Hospitalier de L'Université de Montréal Montréal, QC</p> <p>McGill University Hospital Centre (MUHC) (Affiliated - Montreal General Hospital & Royal Victoria Hospital) Montréal, QC</p> <p>Jewish General Hospital (sometimes affiliates with McGill) Montréal, QC</p> <p>CHEQ Centre Hospitalier de Québec Québec City, QC</p> <p>Saskatchewan</p> <p>Regina General Hospital - Allan Blair Cancer Centre Regina, SK</p> <p>Royal University Hospital Saskatoon, SK</p>
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4) Discuss the Options

Discuss treatment options with your oncologist. Treatment options may include surgery, radiation and/or various types of chemotherapy. These treatments could be standard protocols or clinical trials. Use our resource, [‘You’ve just been diagnosed with pancreatic cancer – What’s next?’](#) to explore and understand the basics of pancreatic cancer treatment and the different forms of treatment available.

5) Be an Advocate

Help to communicate the concerns of your loved one to the health care team. Contact the medical social worker at the hospital where your loved one plans to have treatment. The medical social worker is an expert in supporting patients and their families, arranging for home care, understanding the healthcare system, and advocating for patients. They can help you to make good treatment decisions and to make sure that plans are followed efficiently.

Besides the medical social worker, there are other supports at each hospital such as a Patient and Family Library or Resource Centre. These libraries and resource centers are often located near the clinic that they serve: in this case they might be near the Pancreatic Centre or the Gastrointestinal Clinic. When you get to the clinic for treatment, ask the medical social worker or the clinic staff if there is a Patient and Family Resource Centre on site and how you can access it.

6) Keep a Running Log

As new problems arise, record them in a notebook for your loved one. Keep a list of all medications that your loved one is taking. Make sure to order and re-order prescriptions early so that you always have the medications that your loved one needs.

It can help to write down any questions that come up between appointments. Then you can refer back to your notes when meeting with the doctor and make sure that you get answers to your questions.

Don’t be afraid to ask the other clinic staff questions too. Staff such as the medical social worker or treatment nurses may have treated other families dealing with pancreatic cancer. Medical social workers or nurses can often help answer any other questions that you might have, and since they spend more time with your family, they can be a great source of support.

7) Keep Your Loved One as Healthy as Possible

Helping your loved one to eat well during treatment may be very important to a good outcome. Always encourage your loved one to consult the oncologist before changing their diet, taking vitamins or beginning dietary supplements – this can help to avoid potential negative drug interactions. If your loved one is considering alternative treatments, encourage them to work with your healthcare team to investigate the scientific validity and safety of these treatments.

During the treatment of cancer it is very important that patients eat enough calories to stay healthy. Often patients will not want to eat and, as a caregiver, this can lead to unexpected challenges. Try to take advantage of times when your loved one wants to eat, no matter when this is! Try to vary the texture of foods from soft to crunchy until you find the right one for your loved one. Try to serve lots of proteins such as meat, eggs, Tofu, and fish since protein is needed by the body to fight the cancer. Serve many small meals during the day rather than three large meals - a full plate of food can be a put off to cancer patients.

Keeping hydrated can be hard when someone is sick. Aim for at least 8 glasses of total fluid a day. If your loved one can't drink a full glass of fluid at once, try serving smaller amounts of fluid throughout the day. Smaller servings of fluid can help to reduce bloating and stomach discomfort. To sneak in some more calories, try serving juice, milk, milkshakes, or broth soups instead of water.

Finally, help your loved one to take the medications and enzyme supplements that were prescribed by the oncologist. Together with a good diet, these medications and supplements can help to ensure a better outcome. If you want more suggestions about keeping a healthy diet for your loved one, talk to a dietician at the cancer clinic where you receive treatment.

8) Take Time for Yourself

Caring for a loved one with pancreatic cancer can be demanding - don't be afraid to ask for help. If you are working, try sharing information with your immediate manager. You may be able to ask for reduced responsibilities at work and/or for a more flexible schedule.

Also, try to make some time for what you love to do. A rest can make you a better caregiver.

9) Remain Vigilant

Once treatment is over, encourage your loved one to monitor their cancer.

Even after treatment, it is possible that tiny cancer cells could survive. Regular follow-up with your oncologist is required to maximize the chance that returning disease is caught early. Follow-up can include body scans and blood tests to check for the presence of cancer.

10) Help Others

Use your experience of pancreatic cancer to help other families who are dealing with a new diagnosis.

Join the Pancreatic Cancer Canada mailing list to connect with other families who are dealing with pancreatic cancer and to receive our newsletter and information about activities and events that are happening in your area.

Help us to raise awareness about pancreatic cancer!

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