

WITH AN INTERVIEW Expert



ABOUT DIANE SIMEONE, M.D.

Diane M. Simeone, M.D. serves as the Associate Director for Translational Research at NYU Langone Medical Center and leads its pancreatic cancer center. Prior to her role at NYU Langone, Dr. Simeone was the Lazar J. Greenfield Professor of Surgery and Professor of Molecular and Integrative Physiology at the University of Michigan Medical Center. Dr. Simeone received her bachelor's degree from Brown University in 1984 and her medical degree from Duke University in 1988. She completed her surgical training in 1995 at the University of Michigan at which time she joined the faculty. She was the Director of the Multidisciplinary Pancreatic Tumor Program and the Director of Gastrointestinal Oncology for the University of Michigan Comprehensive Cancer Center. She also served as the Division Chief for HPB and Advanced GI Surgery. Dr. Simeone was the President of the Society of University Surgeons and President of the American Pancreatic Association. Dr. Simeone is a nationally recognized leader in the surgical treatment of tumors of the pancreas. In addition, Dr. Simeone has led an NIH-funded laboratory with a focus on defining the molecular mechanisms of pancreatic tumorigenesis and the development of novel pancreatic cancer therapeutics. Additionally, Dr. Simeone has published more than 165 studies in leading peer-reviewed journals including *The New England Journal of Medicine*, *Cancer Cell*, *Proceedings of the National Academy of Sciences* and *Journal of Clinical Oncology*.

Identifying a Treatment Doctor & Facility

Q&A with Diane Simeone, M.D.

A particular concern for individuals diagnosed with pancreatic cancer is whether they have time to research treatment centers and receive second opinions before settling on a course of action.

It is important that a patient who decides to be evaluated and/or treated at a high-volume center understand how long it will take to be seen. Typically, being seen within a few weeks is reasonable; longer than that is not. There are times when medical issues need to be dealt with urgently, such as when a patient is experiencing biliary obstruction, significant pain, or difficulty eating with nausea and vomiting. Generally, however, once acute medical issues are addressed, there is a window of time to seek out the best course of action. Make sure to gather all of your medical records and lab results, and get them to the center so they can work quickly to determine whether any additional testing is needed.

Once someone is diagnosed, what is the best way to select an oncologist and/or treatment center?

It is important to seek care from doctors or from a center that provides very high quality care and is experienced with the care of pancreatic cancer. This is definitely a cancer requiring a multi-disciplinary treatment approach. "Multi-disciplinary" refers to relying on the input of gastroenterologists, surgeons, medical oncologists, and radiation oncologists, as well as allied health care professionals including oncology nurses and social workers.

Generally, patients ask their primary care doctor for a referral to someone who they know is an expert in the care of pancreatic cancer. Alternatively, your doctor may refer you to a center that has expertise in treating pancreatic cancer. There are sources of information available to help patients sort this out if your doctor isn't familiar with the best oncologist or center with expertise in pancreatic cancer. One way to begin is to find out if there is a National Cancer Institute (NCI)-Designated Cancer Center in your area. NCI-Designated Cancer Centers are considered centers of excellence, which have received recognition for their expertise. Additionally, there are resources to help you find physicians experienced in the care of pancreatic cancer.

It's important to know that the doctor is board certified in his/her specialty; the volume of pancreatic cancer patients he or she has treated; how many pancreatic cancer patients are seen at the doctor's center; and whether there is a team that works together to make optimal decisions about what treatment is going to be best and the timing of treatment. You may need to meet with more than one doctor. In fact, the NCI recommends getting a second opinion to compare and contrast recommendations and get a sense of whether your doctor's recommendations are supported by others.

Tell us more about NCI-Designated Cancer Centers and the advantages of being treated at a high-volume cancer center. How might a patient check the quality-of-care offered at various cancer treatment centers?

Patients are best served by being seen in high-volume centers, which offer a multi-disciplinary team of physicians and allied support services. Additionally, these centers offer multi-disciplinary tumor board meetings, where you will be evaluated by doctors

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representing all of the different specialties who all “weigh-in” and determine your optimal treatment plan. There are numerous components to think about when it comes to the best quality-of-care at treatment centers, which are highlighted in this issue.

With regard to surgery, it's particularly important to identify a surgeon with expertise in pancreatic surgery. There are data to show that the number of pancreatic resections your surgeon performs annually is an excellent predictor of surgical outcomes. At a minimum, you want him/her to perform 15 to 20 pancreatic resections per year. You also should ask your surgeon about complication rates and his/her 30-day operative mortality rate.

Patients may feel uncomfortable “challenging” an authority figure by asking about his or her “30-day survival rates” or similar statistics. Also, patients may be concerned that asking for a referral to receive a second opinion may anger their doctor. What advice would you offer patients with these concerns?

It's my firm opinion that all experts in this field should fully expect to receive questions from the patient, and not be offended by being asked these critically important questions. Patients should come prepared with a written set of questions. One way to address this is to say, “My reading has led me to understand it is wise to ask certain questions.” It is also beneficial to have a family member or friend accompany the patient to oncology appointments for support and clarification of the proposed plan of care.

SOME QUALITY-OF-CARE COMPONENTS OF A CANCER TREATMENT CENTER



- Experience in diagnosing and treating pancreatic cancer (e.g., a specialized center within a cancer facility that is dedicated to the evaluation and treatment of patients with pancreatic cancer)
- Experience in managing the symptoms and side effects of pancreatic cancer
- On-site, advanced techniques and technology, such as a state-of-the-art dual-phase helical computed tomography (CT) scanner
- An on-site laboratory to withdraw and analyze the patients' blood
- Access to investigational treatments for pancreatic cancer, such as in clinical trials
- Services for pain management and palliative care
- Access to other specialists including psychiatrists, nutritionists, and social workers

Sources:

Finding health care services. National Cancer Institute website. <https://www.cancer.gov/about-cancer/managing-care/services>. Updated August 25, 2017. Accessed December 5, 2018.

Teeley P, Bashe P. The Complete Cancer Survival Guide. New York, NY: Broadway Books; 2005.

“ DISTANCE FROM THE CENTER OF CARE IS A COMMON CONCERN, AND IN MY EXPERIENCE, MOST PANCREATIC EXPERTS IN HIGH-VOLUME CENTERS ARE WILLING TO WORK WITH A LOCAL ONCOLOGIST TO OPTIMIZE THE PATIENT’S TREATMENT PLAN. ”

Many times, pancreatic cancer patients live a considerable distance from a major cancer center, yet understand the importance of receiving treatment at a high-volume, multi-disciplinary center. Is it possible to receive a diagnosis, second opinion and/or treatment plan at a major cancer center, then implement the plan with a cancer treatment team closer to home?

Yes. Distance from the center of care is a common concern, and in my experience, most pancreatic experts in high-volume centers are willing to work with a local oncologist to optimize the patient’s treatment plan. So, it’s not unusual for part of the plan to be executed in a high-volume center, in particular, surgery, and for a post-operative treatment plan to be executed locally. Frequently, I see physicians at high-volume centers and local physicians working as a team to facilitate patient care. This is an ideal situation. It’s important to get a treatment plan outlined by experts in the disease, but if the treatment ultimately is going to be quite similar to what would be given locally, then it makes perfect sense to have that treatment plan executed locally by a qualified oncologist.

What about patients who turn to the Internet and/or other sources of information to learn more about specific treatments, perhaps even identifying a protocol that they would like to receive?

Some patients investigate the disease and come to their initial consultation with specific ideas regarding their treatment. I encourage patients to be well informed and proactive about learning their treatment options. I also think this approach needs to be taken in context with all of the different options for treatment. For example, some treatments may sound great, but aren’t well proven, or the pre-clinical data might be weak, even though the treatments are now available in clinical trials. Patients need to do their homework as best as they can, but also allow the well-informed physician to put the entire spectrum of treatment options into an overall perspective for the patient. This includes not only potential risks and benefits of a particular treatment, but also logistical considerations such as the physical, emotional and financial burden of traveling to a specific center for a clinical trial, based on what’s known about the efficacy of that trial.

When a patient comes to a medical ‘crossroads’, and may consider changing a course of treatment, is it necessary or recommended to then change treatment teams? Also, when is it time to consider experimental therapies or clinical trials?

There are times, during the course of treatment, when there needs to be a review of how things are going, especially for a disease like pancreatic cancer, where a majority of patients are not cured with surgery up front. It is important to talk with your oncologist about whether it’s time to change course and try a new treatment. Both the patient and doctor should be open to considering options locally, and at other cancer centers, especially if the treatment team has exhausted all approaches that it has to offer.

SOME QUESTIONS TO ASK WHEN LOOKING FOR A TREATMENT CENTER

- How many pancreatic cancer patients does the facility typically treat each year?
- How many pancreatic cancer surgeries does the facility typically perform each year?
- Does the treatment facility offer multidisciplinary care?
- Has the facility been rated by the state, consumer, or other groups for its quality-of-care?
- Has the facility been approved by a nationally recognized accrediting body such as the Joint Commission on Accreditation of Healthcare Organizations?
- Does the facility explain patients’ rights and responsibilities? Are copies of this information available to patients?
- Does the treatment facility offer support services to help with day-to-day obstacles such as providing assistance to obtain medical equipment and supplies, arranging transportation for treatment, or handling the emotional, psychological, or financial issues that go along with having cancer?

Sources:

Finding health care services. National Cancer Institute website. <https://www.cancer.gov/about-cancer/managing-care/services>. Updated August 25, 2017. Accessed December 5, 2018.
Teeley P, Bashe P. *The Complete Cancer Survival Guide*. New York, NY: Broadway Books; 2005.

The decision about whether to change treatment teams and/or centers is the patient's call. Part of it will depend on how comfortable the patient feels with the physician, including how knowledgeable he or she is about the range of available treatment options. And certainly, it never hurts to get a second opinion from a "fresh eye." Frankly, there remains a fair amount of variability in treatment options presented to patients based on the level and areas of expertise of the physician making the recommendations.

I encourage patients to seek second opinions, especially when they're facing a crossroads in the management of their disease. Today, there are many promising clinical trials that may offer improved treatment for individuals with pancreatic cancer. From day one, when the treatment plan is outlined, the patient should ask about different treatment options, including clinical trials. Most oncologists are familiar with clinical trials that are available, not only at their institution but around the country. The patient and his or her physician can decide together whether a clinical trial might be appropriate. Trials need not be reserved for people who have failed standard treatment. These research efforts are critical to help us identify better treatments that will improve patient outcomes in the future.

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RESOURCES FOR IDENTIFYING A TREATMENT DOCTOR & FACILITY

American Cancer Society: www.cancer.org

The American Cancer Society is a nationwide, community-based voluntary health organization dedicated to eliminating cancer as a major health problem. The organization's mission is to save lives, celebrate lives, and lead the fight for a world without cancer.

Cancer.Net

Cancer.Net provides timely, oncologist-approved information to help patients and families make informed healthcare decisions on topics including finding a treatment facility.

HealthFinder.gov

Healthfinder.gov has resources on a wide range of health topics selected from over 1,600 government and non-profit organizations to bring you reliable health information.

National Cancer Institute (NCI)-Designated Cancer Centers: <http://www.cancer.gov/research/nci-role/cancer-centers/find>

NCI-designated cancer centers are characterized by scientific excellence and the capability to integrate diverse research approaches to focus on the problem of cancer.

- NCI Fact Sheet: *How To Find a Doctor or Treatment Facility If You Have Cancer*
www.cancer.gov/cancertopics/factsheet/Therapy/doctor-facility

The Joint Commission: www.jointcommission.org

An independent, not-for-profit organization, The Joint Commission accredits and certifies more than 19,000 health care organizations and programs in the U.S. Joint Commission accreditation and certification is recognized nationwide as a symbol of quality that reflects an organization's commitment to meeting certain performance standards.

- The Joint Commission's Quality Check:
www.qualitycheck.org
Quality Check® is The Joint Commission's search engine to locate Joint Commission accredited healthcare organizations in the United States. Visitors can search by city and state, by name or by zip code.

ABOUT THE LUSTGARTEN FOUNDATION

The Lustgarten Foundation is America's largest private foundation dedicated to funding pancreatic cancer research. Based in Woodbury, N.Y., the Foundation supports research to find a cure for pancreatic cancer, facilitates dialogue within the medical and scientific community, and educates the public about the disease through awareness campaigns and fundraising events. Thanks to separate funding to support administrative expenses, 100% of your donation goes directly to pancreatic cancer research. For more information, please visit lustgarten.org.

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415 Crossways Park Dr., Suite D, Woodbury, NY 11797
866-789-1000 lustgarten.org

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