PANCREATIC CANCER MANUAL

Raising Awareness on the Prevention of Pancreatic Cancer among Black/African American Individuals

FLORIDA A&M UNIVERSITY

UF UNIVERSITY of FLORIDA

USC Norris Comprehensive Cancer Center
Keck Medicine of USC

FLORIDA - CALIFORNIA CaRE² CARE: HEALTH EQUITY CENTER

This manual is dedicated to the loving memory of Anne Taguchi

Anne Taguchi was a dear colleague who served as the Center Administrator at USC since the founding of our center in 2018 until 2022 when she began her battle against pancreatic cancer. May her memory be a blessing in hopes of her soul happily rejoicing with the many dogs she raised who have already passed. Her memory will continue to serve as inspiration and motivation to pursue our efforts to find cures for pancreatic cancer.

Acknowledgements

This handbook was developed by the following individuals:

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QR Code for website to find the pancreatic cancer manual.

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How to use this manual:

This manual is designed for community health workers, health promoters, and educators focused on raising awareness about pancreatic cancer among Black/African American communities.

It offers evidence-based data, strategies, and latest statistics to increase awareness and provide information on early signs, prevention, diagnosis, and treatment of pancreatic cancer.

It also offers recommendations on how to advocate for loved ones who want to learn more about pancreatic cancer treatement or cinical trial research designed to identify cures.

All underlined words are defined in the glossary located at the back of this manual. Please refer to the glossary for definitions.

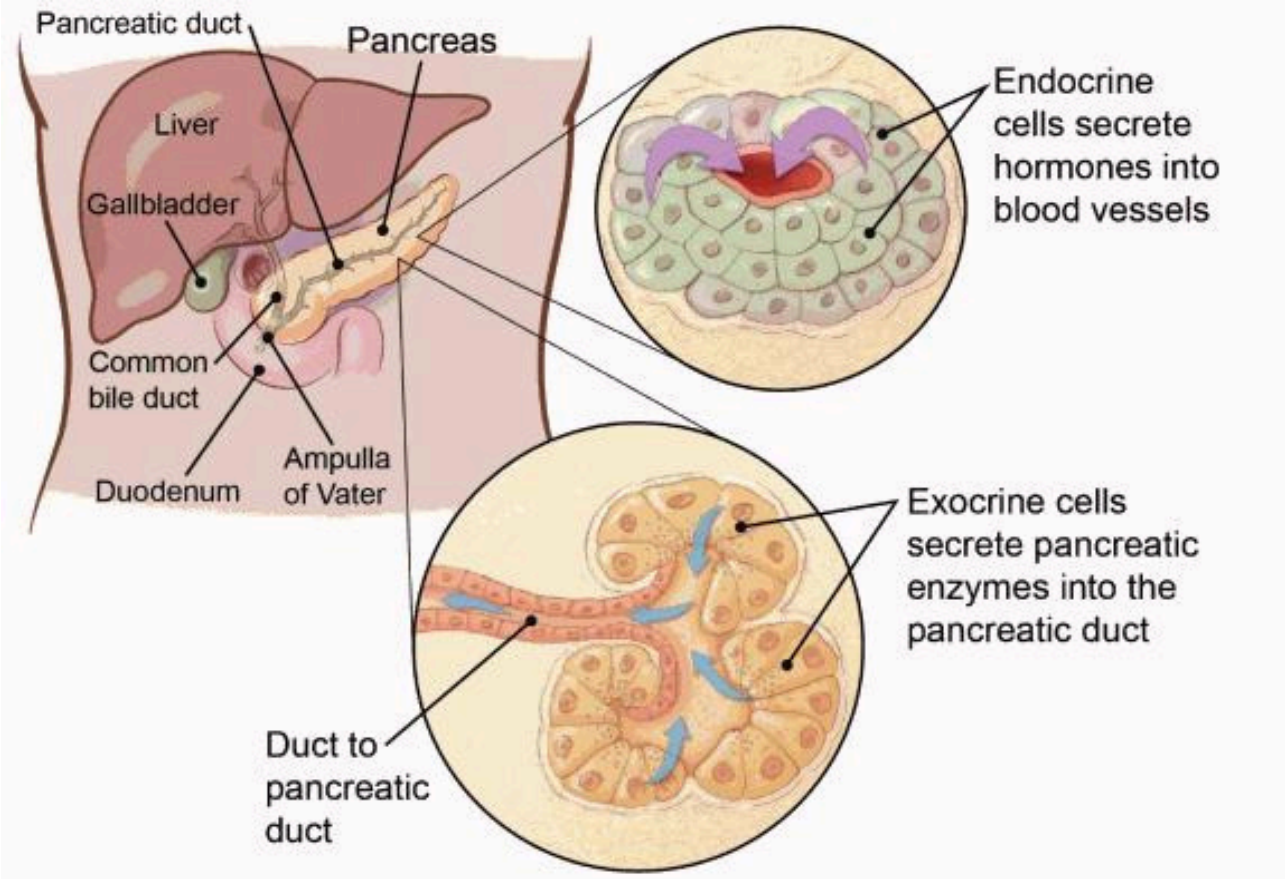
Introduction to Pancreatic Cancer

WHAT IS THE PANCREAS?

The pancreas is an organ located behind the stomach and has a wide head and a narrow tail, it has a light tan / pinkish color (ACS, 2024).

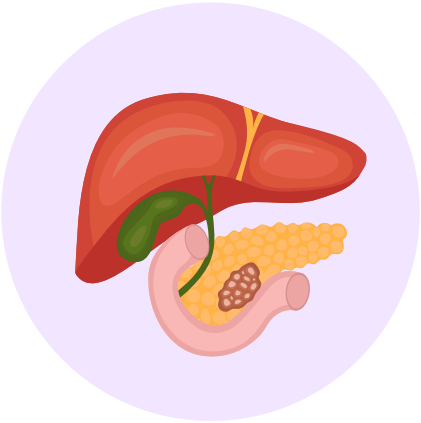
Since the pancreas tends to hide behind other organs, doctors have a difficult time examining it. (Mahadevan, 2019).

This organ is responsible for two main functions: producing and releasing of enzymes that help digest food and control blood sugar.



WHAT IS PANCREATIC CANCER?

Pancreatic cancer is a type of cancer that begins in the pancreas. The cancer starts when cells in the pancreas begin to grow out of control. Our body has many different types of cells, each has specific roles to help our body do everything it needs to do.



There are different types of pancreas cancer depending on which cells in the pancreas grow out of control. The most common type of pancreatic cancer is adenocarcinoma (ACS, 2024).

SIGNS AND SYMPTOMS OF PANCREATIC CANCER

- It is difficult to find pancreatic cancer in the early stages because it usually doesn't cause any signs or symptoms in those stages.
- By the time symptoms show up, usually the cancer has already grown too large or may have spread outside the pancreas (ACS, 2024).
- In fact, about 60% of patients are diagnosed after the cancer has already spread from the pancreas to other parts of the body (Strobel, 2019).

WHY IS IT IMPORTANT TO LOOK AT PANCREATIC CANCER AMONG BLACK/AFRICAN AMERICAN COMMUNITIES?

- The number of people newly diagnosed with pancreatic cancer over the past few years has steadily increased , becoming one of the most frequent malignant tumors that cause deaths (Zhao, Liu, 2020).

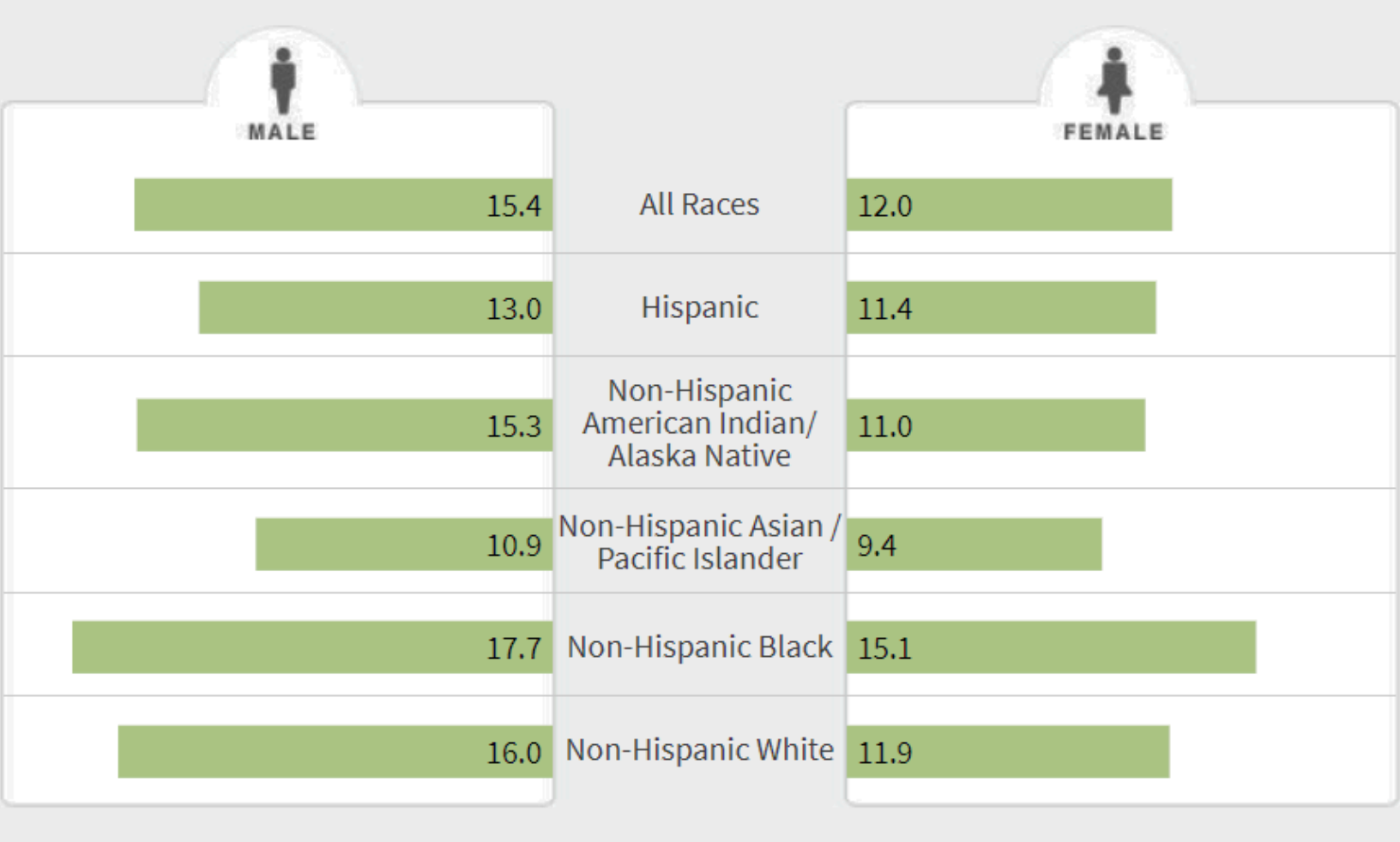
- There are 16 individuals diagnosed with pancreatic cancer per every 100,000 Black/African American individuals compared to 13 people diagnosed with pancreatic cancer per every 100,000 White individuals.

- Black/African American are diagnosed with cancer at later stages, tend to have larger tumors. and are often younger compared to people from other racial groups (Noel, Fiscella, Irfan, 2019).

Module 1

- Black/African Americans face lower surgery rates, tend to be treated in lower resource hospitals, develop more complications, and die more frequently from this disease compared to White individuals.
- Treatment of pancreatic cancer is impacted by an individual's access to health insurance and to socioeconomic status. (Noel & Fiscella 2019).

HOW COMMON IS PANCREATIC CANCER?



SEER 22 2017–2021, Age-Adjusted

Pancreatic cancer rates are 50% - 90% higher in Black/African Americans compared to other U.S. racial groups (NIH, 2022).

Factors Related to Pancreatic Cancer

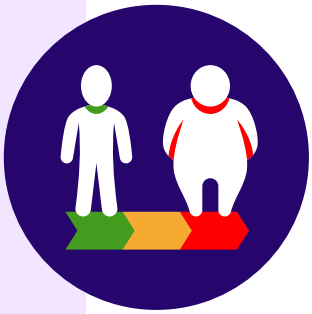
Researchers are still investigating the causes of pancreatic cancer. We are learning more about factors that increase risk for pancreatic cancer. What is also encouraging is that changing behavior can help to reduce one's risk as described briefly described below:

Tobacco Use

Tobacco use including smoking cigars and using smokeless tobacco, is a major risk factor for pancreatic cancer, accounting for about 25% of cases. Quitting smoking lowers this risk.

Being Overweight

Being obese increases the risk of pancreatic cancer by about 20%. A person with a Body Max Index (BMI) of 30 or higher is considered obese. Excess of abdominal fat can also raise this risk, regardless of overall weight. Type 2 diabetes associated with being overweight also increases the risk, though the exact cause is unclear.



Nutrition/Food Consumption

High intakes of red and processed meats, saturated fats, high-fructose drinks, sweets, added sugars, caffeine, and alcohol increases risk of pancreatic cancer. Choosing whole grains and colorful fruits and vegetables can help reduce risk.

Other risk factors:

Environmental

Heavy exposure to certain chemicals and heavy metals in the workplace or environment, such as benzene, benzidine, and lead, can increase the risk of developing pancreatic cancer.

Chronic Pancreatitis

Long-term inflammation of the pancreas is linked with an increased risk of developing pancreatic cancer. Chronic pancreatitis is often seen with a history of heavy alcohol consumption and smoking.

Age

The risk of developing pancreatic cancer increases as people age. Almost all patients are older than 45. About two-thirds of people are at least 65 years old with the average age at time of diagnosis being 70 years.

Other things to consider:

Family History

Most people who get pancreatic cancer do not have history of this cancer in their family. For a small number of people, having a family member pancreatic cancer increases their chances of developing this type of cancer. Specific genetic mutations have been identified that can explain this increase risk with more genes yet to be discovered .

Inherited Genetic Syndromes

About 10% of pancreatic cancer cases can be explained by gene changes (mutations) that are passed from parents to children. Sometimes these mutations can also increase risk of other cancers. This is why it is important to share with your doctor if there are close family members with cancer.

Understanding the Risks for African Americans

Research also indicates that sociodemographic characteristics of being a man, having chronic diseases like diabetes all play a role in the development of pancreatic cancer.

There are many factors that contribute to why African American individuals face a higher risk of developing pancreatic cancer, or from dying from it. However, the risk factors listed above are not unique to African Americans where all persons should work to change any risk factor that they can control. Tobacco use is a big reason for deaths that could be prevented.

Detecting and Diagnosing Pancreatic Cancer

HOW DO WE DETECT AND DIAGNOSE PANCREATIC CANCER?

Pancreatic cancer lacks reliable early screening tests. Doctors may detect liver or gallbladder swelling or check for jaundice during a physical exam. Report any symptoms to your doctor promptly.

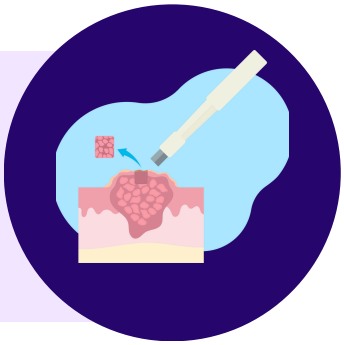
Tests Recommended for Individuals with Strong Family History of Pancreatic Cancer

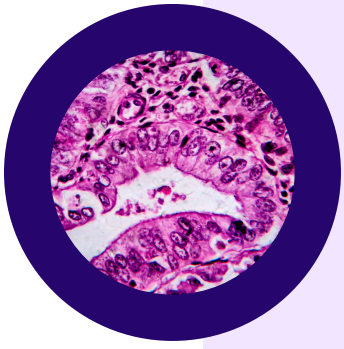
Blood tests

Blood tests can detect a pancreatic issue, but are not enough to diagnose pancreatic cancer. Other tests such as imaging scans and biopsies are necessary to confirm a diagnosis.

Biopsies

Biopsies can be performed through surgery or less invasive methods such as endoscopic ultrasounds (EUS).

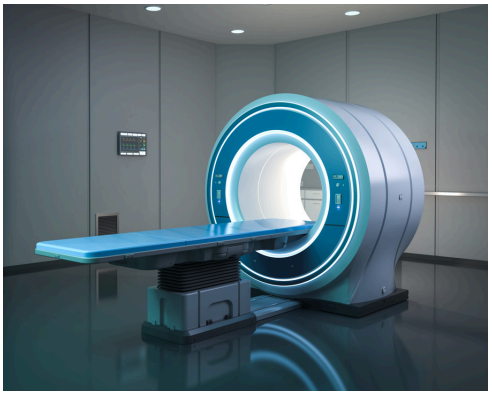




After collecting a sample, a pathologist uses a microscope to:

- Look at tissue samples.
- Study the cells' shape, size, and arrangement.
- Identify if the mass is cancerous and its specific type.
- This process may take several weeks.

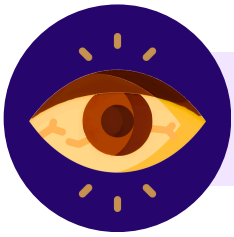
Tests listed below are not typically used for regular screening but may be used for diagnosis of pancreatic cancer:



Magnetic resonance imaging (MRI)

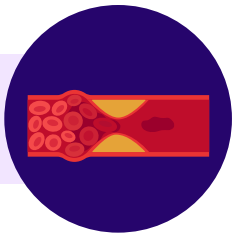
- Imaging tests
- Computed tomography (CT) scan
- Magnetic resonance imaging (MRI)
- Ultrasound
- Cholangiopancreatography
- Positron emission tomography (PET) scan
- Angiography

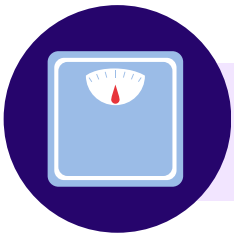
If you physician feels necessary, consider testing if you experience any of the following symptoms:



Jaundice (skin and eyes appear yellow)

Blood clots





Weight loss and/or poor appetite

Nausea and vomiting

Belly or back pain

Tiredness or weakness

Genetic Counseling

Detecting pancreatic cancer early is challenging, but genetic counseling can inform you about your family's history and disease risks.

- It explains how illnesses move across generations in families
- Calculates the risk for other family members
- Provides help and advice on how to manage these risks

Genetic Testing:

- Optional part of genetic counseling
- Examines DNA for any changes (mutations)
- Provides a list of diseases you might be at risk for

Consider Genetic Testing if:

- There have been cases of pancreatic cancer or other cancers in your family

Does Insurance Cover Genetic Counseling & Tests?

- Genetic counseling is often covered by insurance, but out-of-pocket costs may apply
- Genetic counselors can assist in securing insurance coverage
- Health insurance costs won't increase based on high illness risk, and genetic test results are legally protected, ensuring you can't lose your insurance or job

Resources for Genetic Counseling?

- **Primary Care Physicians**
  - **Referral:** Your primary care physician can refer you to a genetic counselor.
- **Insurance Providers**
  - **Coverage and Referrals:** Your health insurance provider can help you find in-network genetic counselors and inform you about covered services.
- **Certified Genetic Counselors**
  - Website: NSGC Find a Genetic Counselor

Here are some places to find genetic counselors		
National Society of Genetic Counselors	https://findageneticcounselor.nsgc.org/	(312) 321-6834
Virtual Genetic Counseling		
Informed DNA	https://informeddna.com/	(800) 975-4819
Genome Medical	https://www.genomemedical.com/	(877) 688-0992
Grey Genetics	https://www.greygenetics.com/	(516) 900-4363
Genetic Labs with Financial Assistance or Accepts Cash Payments		
Invitae Genetic Testing	https://www.invitae.com	(800) 436-3037
Ambry Genetics	https://www.ambrygen.com/	(949) 900-5500
Myriad	https://myriad.com/	(801) 584-3600
Integrated Genetics	https://www.labcorp.com/	(877) 821-7266
Quest Diagnostics	https://www.questdiagnostics.com/	(866) 697-8378
Color Health	https://www.color.com/	(844) 362-6567
Gene Dx	https://www.genedx.com/	(888) 729-1206

Meeting with a genetic counselor does not require genetic testing.
Genetic counseling helps you assess your cancer risk and explore ways to manage it.

Current Treatments for Pancreatic Cancer

Pancreatic cancer treatment plans are personalized based on the cancer stage, patient health, and preferences. The plan includes cancer details, treatment goals, options, side effects, and duration (U.S. Department of Health and Human Services, 2024).

Treatment Options for Pancreatic Cancer:

Surgery:

Whipple procedure , Total pancreatectomy, Distal pancreatectomy

Radiation therapy:

Uses high-energy X-rays or other types of radiation to destroy cancer cells or slow down their growth.

Chemotherapy:

Chemotherapy uses special medications that target fast-growing cells. These drugs are usually given through injections or taken as pills.

Chemoradiation Therapy:

Chemoradiation therapy combines chemotherapy and radiation therapy to increase the effectiveness.

Targeted Therapy:

Targeted therapy is using drugs or other substances to attack specific cancer cells. Erlotinib is a drug used to treat pancreatic cancer (U.S. Department of Health and Human Services, 2024).

Addressing Cancer Treatment Hesitancies

It's normal to feel hesitant and fearful about cancer treatments, but don't let that stop you from seeking help. Here are some tips to help manage your fear.

Tips to Address Cancer Treatment Hesitancies

1. Talk to your healthcare team about your fears.
2. Be proactive and well-informed.
3. Name your fears & confront them.
4. Get emotional support.
5. Get a second opinion.

Life as a Pancreatic Cancer Survivor

Finishing cancer treatment is a milestone, but many pancreatic cancer survivors worry about the cancer returning. The cancer might not fully disappear or could return in other areas. It is important to learn to:

Keep an Eye on Symptoms

Pancreatic cancer survivors should inform their healthcare team of any new symptoms or issues during follow-up appointments. (American Cancer Society, 2024).

Attend Follow-up Appointments

After treatment, doctors recommend follow-up appointments every three months, including CT scans and blood tests. Later, visits are spaced to every six months. (American Cancer Society 2024).

THE IMPORTANCE OF CLINICAL TRIALS

Clinical trials are tests to see if new medical treatments considered safe will work in real people better than existing treatments. Black/African Americans are underrepresented in these trials. By joining, you help clinicians and researchers understand how cancer affects Black/African Americans and improve future treatments.

HOW TO JOIN CLINICAL TRIALS

- Search for trials at clinicaltrials.gov
- Search for trials at NCI-designated Cancer Centers near your area
- Talk to your doctor about any upcoming clinical trials and learn if they are right for you
- For more information: Scan the QR code to access Clinical Trials Manual

MAIN TYPES OF CLINICAL TRIALS:

Treatment Trials:

Test new treatments, new combinations of drugs, or new approaches to surgery or radiation therapy.

Prevention Trials:

Look for better ways to prevent diseases in people who have never had the disease or to prevent a disease from returning. These approaches may include medicines, vaccines, or lifestyle changes.

Screening Trials:

Test the best way to detect certain diseases or health conditions.

Tissue Donation

Tissue donation transfers biological tissues to restore function or save lives. It involves consent, screening, removal, and storage. Donors may be living or deceased. For pancreatic cancer patients, it increases treatment options and supports research to improve future care.

Scan the QR code to watch a short video on tissue donation

Palliative Care for Cancer Survivors

WHAT IS A CANCER SURVIVOR?

A cancer survivor is anyone who has been diagnosed with cancer and is still alive. A cancer survivor starts from diagnosis and includes not just the patient but also family, friends, and caregivers affected by the diagnosis.

EARLY SURVIVORSHIP

Right after diagnosis and during treatment.

EXTENDED SURVIVORSHIP

After treatment ends but while regular check-ups continue.

LONG-TERM SURVIVORSHIP

Years after treatment, when health issues from cancer or treatment may still need managing.

PANCREATIC CANCER SURVIVOR PAIN

PAIN CONTROL:

- If you are experiencing pain talk to your doctor about pain control options
- Physical therapy, acupuncture, and relaxation techniques may help
- Pain can sometimes be a sign of cancer recurrence, so ongoing monitoring is essential

CHRONIC PAIN POST-TREATMENT:

- **Fatigue:**
  - Stay active with physical activity and adjust sleep schedules
- **Appetite loss and weight loss:**
  - Seek nutritional support
- **Emotional and psychological symptoms:**
  - Address anxiety, depression, and distress with counseling and medication when needed

Palliative Care in Pancreatic Cancer

What is Palliative Care?

Palliative care provides comfort and support for people near the end of their life by managing pain and symptoms and offering emotional support to improve the quality of life for both patients and their families.

Physical and Symptom Management

- Palliative care eases symptoms like pain, nausea, and fatigue
- Uses medications, therapies, and other methods to reduce discomfort
- Aims to help people feel better and improve daily comfort

Emotional Support

- Offers emotional and spiritual support to help patients and families cope with serious illness
- Ensures clear communication about treatment options and goals
- Helps families make informed decisions that align with their values

Cancer Research Advocacy

What is Advocacy?

Advocacy supports a cause by influencing opinions and decisions for social change. Pancreatic cancer survivors can advocate by raising awareness, sharing their stories, and seeking policy changes

What is Patient Advocacy?

Patient advocacy supports and protects patients' rights, interests, and well-being in the healthcare system, aiming to empower patients and enhance healthcare outcomes.

What Is Research Advocacy?

Research advocacy is the active promotion and support of scientific research to impact public policy, funding choices, and societal views.

Research Advocacy

Key aspects of research advocacy include:

Research Funding and Awareness: Advocates work to increase funding for pancreatic cancer research to improve understanding, develop better treatments and raise awareness.

Policy Advocacy: Advocates and policymakers work together to get more funding, simplify drug development rules, and encourage new research for pancreatic cancer.

Partnership Building: Advocates form relationships with other organizations, advocacy groups, and stakeholders to increase advocacy efforts and share resources.

Roles for Cancer Research Advocates:

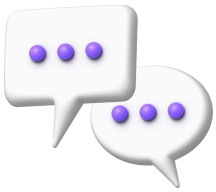
- Community Educator
- Participate in clinical trials
- Donate tissue
- **Become a member of:**
  - A grant review group (study section)
  - Institutional Review Boards
  - Research advisory boards
  - Research advisory committees
  - Research team as investigator, staff, or an advisor

Resources

- Free trainings & recorded webinars for more information: https://pancan.org/facing-pancreatic-cancer/patient-services/educational-events/

- Scan the QR Code for the CaRE2 Contact Registry

Patient Advocacy



Key aspects of patient advocacy include:

Education and Awareness: Advocates inform & educate patients, caregivers, and the public about pancreatic cancer.

Support Services: Advocacy groups offer services like helplines, support groups, and online forums for patients and caregivers.

Patient Rights: Ensuring that patients' rights are respected, including the right to informed consent, confidentiality, and respectful treatment.

Community Engagement: Advocacy engages the community through events, fundraisers, and partnerships with healthcare organizations.

Resources

- To find in-person support groups, go to:
  - https://pancan.org/facing-pancreatic-cancer/resources-support-and-research/support-groups/in-person-support-and-networking-groups/
- To find online support groups visit:
  - https://pancan.org/facing-pancreatic-cancer/resources-support-and-research/support-groups/online-support-groups/
- Patient and Caregiver services. Highly trained and compassionate Case Managers provide free, personal one-to-one support and information about the disease. (877)-272-626

Glossary

1 Enzymes- are proteins that help speed up our bodies chemical reactions.

2 Cells- are the units in our body that perform all important functions in our organs and other tissues.

3 Body Mass Index [BMI]- is a measure of body fat based on height and weight that applies to adult men and women.

4 Diabetes- is a chronic disease marked by high blood sugar levels. In Type 1 diabetes, the pancreas produces little or no insulin, a hormone that enables glucose(type of sugar) to enter cells for energy. Type 2 diabetes, the most common form, occurs when blood sugar levels are too high.

5 High fructose- a common type of added sugar that is used in packaged foods and beverages.[1]

6 Biopsies- involving taking a small tissue sample and examining it under a microscope, is necessary to confirm if these masses are cancerous.

7 Pathologist- a specialized physician who interprets and diagnoses the changes caused by disease in tissues and body fluids.

8 Adenocarcinoma- affect the release of enzymes used for digestion; whereas neuroendocrine tumors are less common, and affect the regulation of blood sugar in the pancreas.

9 Whipple procedure- is a surgery that removes the head of the pancreas, the gallbladder, parts of the stomach, a section of the small intestine, and the bile duct. After the surgery, there is enough pancreatic tissue left to keep making digestive enzymes and insulin.

10 A total pancreatectomy- is a surgical procedure designed to remove the entire pancreas, along with parts of the stomach, small intestine, common bile duct, gallbladder, spleen, and nearby lymph nodes.

11 Distal pancreatectomy-is a surgery to remove the body and tail of the pancreas. If the cancer has spread to the spleen, it might also be removed during this procedure.

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Contact Information

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https://care2healthequitycenter.org

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