THE OLANDUS FOUNDATION

Patient & Caregiver Guide

Navigating Your Cancer Journey With Knowledge, Community, and Hope

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This guide was created for patients newly diagnosed with cancer, and for the caregivers and family members who walk alongside them. Whether you are just starting to process a diagnosis or searching for your next step, this resource is here to help you move forward with clarity and confidence.

You are not alone. **Hope lives here.**

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Section 1: You Just Got a Diagnosis — What Now?

Receiving a cancer diagnosis is one of the most disorienting moments a person can face. Your mind races. Your body feels numb. Everything you thought you knew about your future suddenly feels uncertain. That reaction is completely normal.

Take a breath. You do not have to figure everything out today. Here are your first steps.

1. Give yourself time to process.

You do not have to make major decisions in the first 24 to 48 hours. Most cancers allow a brief window to gather information before treatment begins. Use that time.

2. Get a written copy of your diagnosis.

Ask your doctor for the full diagnosis in writing, including cancer type, stage, and any pathology report. You will need this for second opinions and specialist referrals.

3. Seek a second opinion.

This is not disrespectful to your doctor. It is standard practice. A second opinion can confirm your diagnosis, reveal additional options, or connect you with specialists.

4. Build your support circle.

Identify two or three people you trust who can attend appointments, take notes, and help you process information. You should not navigate this alone.

5. Write down your questions.

Before every appointment, write your questions down. See Section 8 of this guide for a full printable checklist.

> **Remember:** A cancer diagnosis is not the end of your story. Tony Williams, founder of The Olandus Foundation, was diagnosed with Double Stage 4 cancer and is thriving today. Your fight starts with information.

Section 2: Understanding Your Diagnosis

Cancer is not one disease. It is a broad category of conditions, each with its own behavior, treatment path, and prognosis. Understanding your specific diagnosis helps you ask better questions and make more informed decisions.

Cancer Staging

Stage	What It Generally Means
Stage 1	Cancer is localized. Has not spread to nearby tissue or lymph nodes.
Stage 2	Cancer has grown but remains in the original area or nearby lymph nodes.
Stage 3	Cancer has spread to nearby tissue or a larger group of lymph nodes.
Stage 4	Cancer has spread to other organs or distant parts of the body.

Common Cancer Types We Address

- Blood cancers: Leukemia, Lymphoma (Hodgkin and Non-Hodgkin), Multiple Myeloma
- Breast cancer
- Prostate cancer
- Lung cancer
- Colorectal cancer
- Cervical and ovarian cancer

If your cancer type is not listed here, The Olandus Foundation can still help you find the right resources and connections. Contact us directly.

Section 3: Building Your Care Team

Your cancer care team is not just your oncologist. It is a group of people, medical and personal, who support every dimension of your treatment and recovery.

Team Member	Role
Oncologist	Your primary cancer doctor. Leads your treatment plan.
Surgeon	Performs procedures to remove tumors or collect tissue for biopsy.
Radiation Oncologist	Specializes in radiation therapy if part of your plan.
Nurse Navigator	Coordinates your care across providers. One of your most important allies.
Social Worker	Connects you to financial, emotional, and community resources.
Pharmacist	Manages your medications and can explain side effects.
Nutritionist/Dietitian	Guides your diet during treatment to maintain strength.
Mental Health Counselor	Supports your emotional health throughout treatment.
Patient Advocate	Helps you understand your rights and navigate the system.
Trusted Family/Friend	Attends appointments, takes notes, provides daily support.

What to Bring to Every Appointment

- A written list of your current medications and dosages
- Your insurance card and any prior authorization documents
- A notebook or a trusted person to take notes
- Your list of questions (see Section 8)
- A copy of your most recent pathology report or lab results
- A support person whenever possible

Section 4: Clinical Trials 101

Clinical trials are research studies that test new treatments, drugs, or approaches to cancer care. They are one of the most underused options available to patients, particularly in underserved communities. That gap is exactly what The Olandus Foundation exists to close.

Why Clinical Trials Matter

- They give you access to treatments not yet available to the general public.
- Many trials cover the cost of the experimental treatment.
- They are conducted under strict safety protocols with regular monitoring.
- Your participation helps future patients from your community.
- Trials exist for every stage of cancer, including early-stage and advanced disease.

Common Myths About Clinical Trials

MYTH: You might receive a placebo instead of treatment.

FACT: In cancer trials, placebo-only treatments are rare. Most patients receive either the new treatment or the current standard of care.

MYTH: Clinical trials are only for people who have run out of options.

FACT: Trials exist at every stage of cancer. Many are open to newly diagnosed patients.

MYTH: Clinical trials are only for wealthy or well-connected patients.

FACT: Trials are open to anyone who meets the eligibility criteria. The Olandus Foundation helps connect underserved patients to trials.

MYTH: You cannot leave a trial once you start.

FACT: You can withdraw from a clinical trial at any time for any reason.

How to Find a Clinical Trial

1. Visit clinicaltrials.gov and search by your cancer type and location.
2. Ask your oncologist if any trials are available at your treatment center.
3. Contact The Olandus Foundation. We connect patients directly with trial opportunities.
4. Reach out to major cancer centers like Duke Cancer Institute, UNC Health, and Wake Forest Baptist Health.

> **The Olandus Foundation can help you.** We provide direct connections to clinical trial opportunities for patients in underserved communities. Contact us at twilliams@theolandusfoundation.org or call (919) 539-0948.

Section 5: Resources and Support

You should not have to search alone for help. Below are trusted resources for patients and caregivers at every stage of the cancer journey.

Financial Assistance

- Patient Advocate Foundation (patientadvocate.org) — copay relief and financial aid
- NeedyMeds (needymeds.org) — prescription assistance programs
- Cancer Care (cancercare.org) — financial help for treatment-related costs
- HealthWell Foundation (healthwellfoundation.org) — insurance premium support

Transportation Support

- American Cancer Society Road to Recovery — free rides to treatment
- Local faith communities — many offer volunteer driver programs
- Contact The Olandus Foundation — we help connect patients to local transportation options

Emotional and Mental Health Support

- Cancer Support Community (cancersupportcommunity.org) — free support groups
- 4th Angel Mentoring Program — one-on-one patient mentoring
- Stupid Cancer (stupidcancer.org) — support for young adult cancer patients
- Local church and faith networks — a core partner of The Olandus Foundation

Information and Education

- National Cancer Institute (cancer.gov) — comprehensive cancer information
- Blood Cancer United (bloodcancerunited.org) — blood cancer-specific resources
- The Patient Story (thepatientstory.com) — real patient stories and medical guidance
- American Cancer Society (cancer.org) — general cancer support and education

Section 6: A Guide for Caregivers

If you are reading this as a caregiver, this section is for you. You are one of the most important people in this fight. Your role is real, it is demanding, and it matters more than you may realize.

What Caregivers Actually Do

- Attend medical appointments and take detailed notes
- Manage medications, schedules, and insurance paperwork
- Provide emotional support and a steady, calm presence
- Coordinate communication between family members
- Research treatment options and clinical trials
- Handle daily household tasks so the patient can focus on healing
- Advocate on the patient's behalf when they cannot speak for themselves

Taking Care of Yourself

Caregiver burnout is real and it can compromise both your health and the quality of care you provide.

- Set boundaries around your time and energy. You are allowed to say no.
- Accept help when it is offered. Delegate specific tasks to others.
- Stay connected to your own support network.
- Sleep. Eat. Move your body. Your health matters too.
- Look into respite care services for temporary relief.
- Consider a caregiver support group. Blood Cancer United and Cancer Care both offer these.

> **You are not invisible.** The Olandus Foundation sees caregivers as equal partners in the healing process. Our programs include support and resources specifically designed for the people who show up every day.

Section 7: Voices From Our Community

These are real people. Real journeys. Real proof that you can face cancer and come out the other side.

“The Olandus Foundation gave me hope when I felt most alone. Their community understood my experience as a person of color navigating cancer care.”

— Eleanor D., Cancer Survivor

“Connecting with others who share my background and cancer journey has been healing in ways I never expected. We've become family.”

— Tim J., Lymphoma and Prostate Cancer Survivor

“The educational resources and support from the Olandus Foundation empowered me to make informed decisions about my treatment. Their cultural sensitivity made all the difference.”

— Delmus M., Community Member

“After my diagnosis I did not know where to turn. The Foundation connected me to a clinical trial that changed everything. I am still here because of that connection.”

— Community Member, Wake Forest, NC

Your story matters too. The Olandus Foundation is always looking for community members willing to share their journey. Contact us to learn how you can become a voice for others walking this road.

Section 8: Questions to Ask Your Doctor

Print this page and bring it to every appointment. Check off questions as you ask them.

About Your Diagnosis

[ ] What is the exact name and type of my cancer?

[ ] What stage is my cancer and what does that mean for me?

[ ] Has the cancer spread to other parts of my body?

[ ] Should I get a second opinion and can you refer me to a specialist?

About Your Treatment

[ ] What treatment do you recommend and why?

[ ] What are the goals: cure, control, or symptom relief?

[ ] What are the side effects and how will we manage them?

[ ] Are there other treatment options besides the one you are recommending?

[ ] What happens if the treatment does not work?

About Clinical Trials

[ ] Am I eligible for any clinical trials?

[ ] What trials are available at this center or nearby?

[ ] Will my insurance cover the costs of a trial?

[ ] Can you connect me with a trial navigator?

About Practical Support

[ ] Is there a nurse navigator or patient advocate I can work with?

[ ] What financial assistance programs are available to me?

[ ] What should I do if I have questions between appointments?

[ ] Who do I call if I have an emergency or sudden change in symptoms?

Section 9: Glossary of Key Terms

Medical language can feel like a foreign language. Here are plain-English definitions for terms you are likely to encounter.

Term	Definition
Adjuvant therapy	Treatment after primary treatment to reduce risk of recurrence.
Benign	A growth that is not cancerous and does not spread.
Biopsy	Removal of a small tissue sample to examine for cancer cells.
CAR-T therapy	Immunotherapy that reprograms your own immune cells to fight cancer.
Chemotherapy	Drugs used to kill or slow the growth of cancer cells.
Clinical trial	A research study testing new treatments in human patients.
Complete remission	No signs of cancer can be detected after treatment.
Immunotherapy	Treatment that helps your immune system fight cancer cells.
Infusion	Delivering medication directly into the bloodstream through an IV.
Lymphoma	Cancer that begins in the lymphatic system.
Metastasis	The spread of cancer from the original site to other parts of the body.
Oncologist	A doctor who specializes in diagnosing and treating cancer.
Palliative care	Care focused on relieving symptoms and improving quality of life.
Pathology report	A lab document describing the exact nature of cancer cells found.
Prognosis	The expected outcome of a disease based on available evidence.
Protocol	The specific plan for how treatment will be administered.
R-CHOP	A common chemotherapy combination used to treat certain lymphomas.
Radiation therapy	Using high-energy rays to destroy cancer cells or shrink tumors.
Remission	A decrease in or disappearance of signs and symptoms of cancer.
Targeted therapy	Treatment targeting specific genes or proteins that help cancer grow.

Section 10: About The Olandus Foundation

The Olandus Foundation was founded by Tony Williams, a Double Stage 4 Cancer Thriver and advocate for health equity. After facing his own diagnosis with two rare and aggressive forms of lymphoma, Tony saw firsthand what too many people already know: your zip code, your race, and your income can determine whether you live or die from cancer. That reality drove him to act.

Our Programs

Healing Forward Initiative — Our national umbrella initiative uniting communities for equitable cancer care.

The Power of Us Program — Bridging gaps in healthcare access, clinical trial participation, and cancer education.

Lunch and Learn Sessions — Monthly educational events with oncologists, specialists, and survivors.

Coffee with the Doc — Informal conversations with cancer specialists in community settings.

Community Forums — Expert panels, group discussions, and direct resource connections.

Our Program Goals

- Reach 300 community members through our programs
- Facilitate 200 cancer screening appointments
- Connect 60 patients to clinical trial opportunities
- Ensure 90% of program participants report learning something new

We are here for you.

Email: twilliams@theolandusfoundation.org

Phone: (919) 539-0948

Website: www.theolandusfoundation.org

Hope Lives Here.

My Care Team & Contact Sheet

Fill in this page and keep it with you. Bring it to every appointment.

My Oncologist

Name: _____

Practice/Hospital: _____

Phone: _____

Next Appointment: _____

My Nurse Navigator

Name: _____

Phone: _____

Email: _____

My Primary Care Doctor

Name: _____

Practice: _____

Phone: _____

My Social Worker / Patient Advocate

Name: _____

Organization: _____

Phone: _____

Emergency Contact

Name: _____

Relationship: _____

Phone: _____

My Diagnosis Notes

Use this page to record key details about your diagnosis and treatment plan. Having this information in one place saves time and reduces stress at appointments.

My Diagnosis

Cancer Type: _____

Cancer Stage: _____

Date Diagnosed: _____

Treating Hospital/Center: _____

Pathology Report Date: _____

My Treatment Plan

Recommended Treatment: _____

Treatment Start Date: _____

Estimated End Date: _____

Treatment Location: _____

Treatment Goal (Cure/Control/Symptom Relief): _____

Key Decisions Made

Second Opinion Obtained (Yes/No): _____

Clinical Trial Discussed (Yes/No): _____

Clinical Trial Name (if applicable): _____

Other Notes: _____

My Medication Tracker

List every medication you are taking, including supplements and over-the-counter drugs. Bring this page to every appointment and update it whenever something changes.

Medication Name	Dosage	Time of Day	Purpose	Prescribed By

Always tell every member of your care team about ALL medications you are taking, including vitamins, herbal supplements, and anything purchased over the counter. Some supplements can interact with cancer treatments.

Scan to Visit Our Website

Register for upcoming events, access additional resources, and connect with The Olandus Foundation community.

www.theolandusfoundation.org

This guide is for informational purposes only and does not constitute medical advice. Always consult your healthcare team for guidance specific to your situation.