

ELIMINATING MEDICAL BARRIERS FOR PATIENTS: HEALTH LITERACY

A Toolkit for Patients



Getting the information

you need to make the best decisions

for your health.

CREATED WITH YOU IN MIND

We see you. We hear you. We've got you covered.

After being diagnosed with breast cancer, time is of the essence and it is in your benefit to move quickly and wisely. We have witnessed, heard and personally experienced racial challenges specifically for Black women due to systematic racism within healthcare. For these reasons we've carefully crafted this toolkit with you in mind. Our goal is to help you make more informed decisions by empowering you with the right tools, language, and education to navigate medical systems.



Tigerlily
Foundation
Beauty. Strength. Transformation.



WHAT IS HEALTH LITERACY AND WHY IS IT IMPORTANT?

According to the [CDC](#) Personal health literacy is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others. This is important as having and understanding the right information can save your life and minimize any potential accidental harm. According to [Legacy Health](#) People with low health literacy are:



Are less likely to follow treatment instructions and seek preventive care.



Are also twice as likely to be hospitalized.

Health literacy takes into account not only what the doctor has provided you, but also the ability to apply these learnings as well. This includes understanding how to take your medication, under what conditions do you take your medication, do you understand the documents doctors are sending your way, do you understand your medical coverage. All of these and more are essential considerations for health literacy.



SIGNS OF HEALTH LITERACY

Keep in mind that although you may consider yourself health literate, often times in stressful circumstances, as you are processing difficult news, you may not know to ask the right questions. You also may have not been provided with the information just yet. We all could use some guidance and we are here to provide you with tips to make sure that you are. In order to gauge your understanding your level of health literacy here are a few questions to think through:



I know my type of cancer, what stage it is in, and how aggressive it is



I know what my treatment options are



I know how to interpret lab results



I know what tests I need to take



NAVIGATING CHALLENGES

This toolkit will provide you with the information that you need ahead of time to empower you and allow you to make the best decisions for your health.

Understanding what breast cancer is, is the first step to understanding your diagnosis and your way forward. Not only is the interpretation of the information important, but it's also about access to your information. Having all of the information and facts is critical to a healthy you. After all you are your own best advocate, so let's make sure that you have the tools you need to do what is best for you.

PATIENT CONSIDERATIONS

Clear Understanding

Clarity is key when making decisions in a high-pressure situation. When newly diagnosed with breast cancer, your doctor will provide you with important information regarding your diagnosis, treatment options, and your future. We want you to have all of the information that you need, and we want you to have a clear understanding. On average, patients forget up to 80% of what doctors tell them as soon as they leave the office. 50% of what they recall is remembered incorrectly. If you encounter a situation where you are not understanding what the doctor is telling you, ask for clarification. You want to be sure that you understand everything the doctor tells you so that you are informed to make the best decisions for yourself.

Ask for additional tools and marketing materials since we all learn through different means. These tools can be especially helpful if they contain different ways of explaining information such as graphs and graphics.

Items you want clarity on



Your diagnosis and interpreting results



What treatment means for you and how it will impact your lifestyle



Treatment options



Insurance Coverage



Genetic Testing



Access to clinical trials

Below we have questions that you can ask



Your Lifestyle

Consider your lifestyle when speaking to doctors, researchers, and other health workers. Things will change and understanding how your lifestyle may change is important to understand from the start. This allows for better preparedness for what is to come. Treatment may require a leave of absence from your daily duties. Planning in advance to find a replacement will help you to sustain a new normal life.

Talk about the changes with your doctors about what you can anticipate. Consider your:

- Diet and Exercise
- Mental health (life coach, therapists)
- Fertility
- Intimacy, and your daily activities
- Image (psycho-social)
- Personal Relationships (family, support network, romantic relationships)
- Other Health Issues
- Employment



Clinical Trials

As a breast cancer patient, it is important to know about clinical trials. Not only are clinical trials a critical part of the development of treatments, but your participation helps researchers, patients and advocates learn more about diseases.

A clinical trial is a type of medical research study that determines whether an intervention – a new drug, medical device or diagnostic tool – is safe and/or effective. The investigators leading a clinical trial develop a protocol – a detailed document that describes how the study will be performed. A clinical trial recruits volunteer study participants to test the intervention. Clinical trials are conducted by government agencies, universities, hospitals, and drug companies.

With your doctor, you may want to consider early on if clinical trials may work well for you. Clinical trials also help us learn more about diseases and other health conditions.



Genetic Testing and Counseling

Genetic testing examines your DNA to reveal changes in your genes that may cause illness or disease such as breast cancer. Genetic testing is voluntary, and the results are confidential but you may consider testing if you have questions if breast cancer may affect anyone else in your family. Physicians can order testing for mutations in many genes and there are over 1000 tests in existence today. Genetic testing creates peace of mind and provides you and your family with necessary information to preemptively impact lives.

Wellness

After a cancer diagnosis, your wellness routine may change. It may be worth consulting with your medical provider around diet, exercise, and lifestyle choices to ensure healthy living.

Support & Communication

Getting a better understanding of what others have gone through with breast cancer can be another avenue to pursue when learning about what you may experience. Peer communication can be beneficial as they can offer insight and provide clarity and support on what you can expect during treatment.





QUESTIONS TO ASK YOUR HEALTH CARE TEAM

Diagnosis

- What is my diagnosis?
- What is my cancer type?
- Where is my cancer located?
- Has my cancer spread?
- What is my cancer stage and what does that mean?
- Do I need to have additional tests?
- Can I have a copy of my pathology report?
- Do I have access to a patient portal?
- Do you have any other handouts, videos, content or sites that you can provide to me so that I can be sure that I understand?
- Do you recommend genetic testing?
- What is a patient navigator and can I have access to one?
- What does follow-up care look like?
- What does life look like for me after this diagnosis? What can I expect to change?
- Who should I call during non-business hours if I have a question?
- Do you offer any solutions for transportation to my appointments?
- Will my cancer return?



Treatment

- What is my treatment plan?
- When do we start?
- Is this treatment my only option? What are the side effects?
- Do I need to have surgery or chemo first?
- How can I get a second opinion?
- What does this mean for my breasts? Do I have to have them removed?
- How long will treatment last?
- Do I need any specialists for my treatment?
- Anything that I should do before to prepare for treatment?
- How will treatment affect my daily life?
- Where will I go for treatment?
- How long will I need treatment for?
- Can I come to my treatment sessions alone or should I bring someone with me?
- What side effects are normal and when should I call you?
- Will medications and supplements that I am currently taking for other medical reasons affect my cancer treatment?
- What will life look like after treatment is over?
- Do I still need to have tests after we wrap up treatment?
- What symptoms should I notify you about during treatment?
- What symptoms should I notify you about after treatment?
- What does follow-up care look like?
- How often will I have treatment appointments?



Clinical Trials

- What are clinical trials?
- How can I participate?
- Where do I find out about clinical trials?
- Are they safe?
- What is the drug or drugs being tested?
- What is the time commitment for me?
- How many people have been exposed to it?
- What evidence do we have that it works and how does it work?
- What are the safety concerns so far?
- What do the appointments consist of (how long, frequency, tests included, etc)?
- What will the cost be to me if I participate?
- Are there any patient support programs to offset financial burdens like travel, childcare or pet care?
- If the drug helps me, will I continue to have access to it after the trial?
- What happens if I have a side effect?
- What happens if my tumors don't respond to the study drug?
- What if I change my mind about participating part way through the trial?
- Who do I call from the study team if I have a question or concern between appointments?
- Will the researchers be working with my oncologist?

Lifestyle

- I want to have a baby, what does this mean for me?
- Will I be able to breastfeed?
- Will I be able to keep my fulltime job?
- Will I lose my hair?
- Will I lose my breasts?
- How will this affect my physical appearance?
- Do you recommend any support groups or educational programs?
- Are my family members at risk?
- Do I need to change my diet?
- Can I still exercise during treatment?
- What can I do now to be in the best possible shape?
- What can I do to be as healthy as possible?
- How often will I have appointments after treatment is over?
- Will this diagnosis prevent me from being able to get insurance in the future?





TIGER TIPS



Get your doctor to advocate for you. When scheduling appointments or booking tests have your doctor speak to the scheduling team about your appointments as opposed to calling to set up an appointment. This will save you time and ensure that you are being prioritized. Secretaries will work with more urgency when getting direction directly from a doctor.

Act with urgency. You are a priority and your life is a priority. Don't put off testing, treatment or even research. Time is of the essence and the sooner you do things the more likely the better the outcome will be.

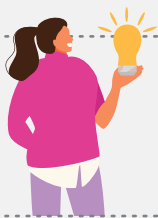
Write down or ask your doctor for a summary or recording of what was discussed during your appointment. According to "[Patients' memory for medical information](#)" by Roy P C Kessels, people forget up to 80% of what doctors tell them as soon as they leave the office and 50% of what they recall is remembered incorrectly.



"Ask, ask, ask". We can't say it enough. Low health literacy is linked to higher rates of hospitalization and higher use of expensive emergency services.

Tell the truth. It can be tempting to hold back the truth or parts of the truth, but when asked, do your best to answer wholly.

Don't struggle with a language barrier. If you need an interpreter, do request one. If you are struggling to understand even as an English speaker ask your provider to explain it differently until you completely understand.



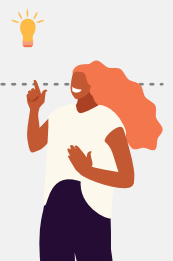
Bring support if you can. If someone cannot come with you you can ask the doctor if they can call in. Having someone there that can help you to listen and take notes is beneficial.

Go with your gut. If you have any doubts about your doctor, the institution or quality of care, do pursue a second opinion. No ONE doctor who has all the answers, so asking someone else is no big deal. We want to emphasize that there is NO retaliation when you ask for a second opinion, everyone should feel empowered to take control of their situation and find the answers they need. Pay attention to how the institution, quality or care. Even treatment by the staff is another key indicator.

Make a list. Make a list of any comments, concerns, and questions that you might have away from the appointment. Aggregate them and bring them to your next appointment.

Repeat what the doctor says. Repeat what the doctor says during an appointment to allow them the opportunity to correct you in case you misunderstood.

Ask the doctor if you can voice record them.





WHAT THE LAW SAYS – KNOW YOUR RIGHTS



A second opinion

You have a right to take control of your health and you have a right to a second opinion. Legally, medical facilities must provide you with your medical records if you request them.

Federally you also have a right to a copy of your medical records and health information. Keep in mind that there may be a cost associated with this.



Right to a translator

Federal laws across all 50 states require hospitals to provide language access services. This is great news for you if you are in need of an interpreter.

Access to patient navigator/advocate

While there are no federal laws about the access to patient navigators often times hospitals do have them on staff. If not, your health insurance can be another avenue to pursue in search of one.

According to [cancer.gov](https://www.cancer.gov) a patient navigator is a person who helps guide a patient through the healthcare system. This includes help going through the screening, diagnosis, treatment, and follow-up of a medical condition, such as cancer. A patient navigator helps patients communicate with their healthcare providers so they get the information they need to make decisions about their health care.



Access to social worker

Although not mandatory, oncology social workers are an added benefit.



BARRIER RESOURCES

At Tigerlily we are committed to providing you with the most up to date information along with resources to help you on your journey. We know that this is a challenging time and we want to provide you with resources not only Tigerlily offers, but also our partners. Check out our Barriers Resources page to find additional resources available to you.

