



Frankly Speaking About Cancer Clinical Trials




**CANCER SUPPORT
COMMUNITY.**
A Global Network of Education and Hope

As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community (CSC) is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community.

CSC achieves its mission through three areas: direct service delivery, research and advocacy. The organization includes an international network of Affiliates that offer the highest quality social and emotional support for people impacted by cancer, as well as a community of support available online and over the phone. The Research and Training Institute conducts cutting-edge psychosocial, behavioral and survivorship research. CSC furthers its focus on patient advocacy through its Cancer Policy Institute, informing public policy in Washington, D.C. and across the nation.

For more information, please call the toll-free Cancer Support Helpline at 888-793-9355, or visit www.CancerSupportCommunity.org.

So that no one faces cancer alone®

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WE HAVE TO TALK: A STORY OF HOPE

This is a book about clinical trials, but it is a story of hope. It's the hope of a young father facing a brain tumor who enters a trial that uses a promising new therapy, of a mother who brings her daughter from Chile to participate in an innovative trial for her advanced breast cancer. It's the optimism the mother of a five-year-old daughter has after being part of a clinical trial for her acute leukemia.

The Cancer Support Community created this special publication as part of our *Frankly Speaking about Cancer Clinical Trials* program. We wanted to hear the voices of people impacted by cancer discussing the issues they face when they decide to participate in a clinical trial. We asked our affiliate in Chicago, Gilda's Club, to help us find people who would agree to be photographed acting out these stories. The people who came forward included patients and caregivers, families and friends and health care providers. They ranged from age five to seventy—white, black, Hispanic—who took time off from their jobs, their lives and from school to help make this book possible.

Hope is the heart and soul of what drives people to participate in clinical trials—hope for more time, and for feeling better in the time they have. Every decision to be part of a clinical trial is rooted in hope for an individual future and for a better future for everyone who faces cancer.

Our journey to create this book took us all around the beautiful city of Chicago—and we found hope in those places as well. We visited a community garden where people come together to grow vegetables, herbs and flowers, and a 130-year-old church still thriving in its proud neighborhood. We spent time in the Chicago History Museum, teeming with children learning from the past to help shape their own futures. We photographed a

young family in Millennium Park on a perfect Spring morning. We took photos and drank coffee in the Hope Cafe, a remarkable community resource dedicated to giving people with rough pasts a second chance, and trying to keep young people from making those same mistakes. We went to two of the fine medical centers that provide care for people facing cancer. At Gilda's Club, we found a place of sharing, connection, learning and love.

Today, there is real hope for the future of cancer treatment. Research is opening the door to new understanding of how cancers arise, grow and spread. These discoveries are rapidly being translated into new therapies that are making a real difference in the lives of many people facing cancer. All of this progress, every step on the journey, results from clinical trials. The success of every trial depends on patients who are willing to participate in these trials.

The Cancer Support Community thanks the patients, family members and friends who participated in this project, as well as the people who shared their spaces and stories with us. We salute the courage, wisdom and determination of every person who faces cancer and makes the commitment to being in a clinical trial. Our hope is that this book helps patients and families who are thinking about being part of a trial, that it answers some important questions and starts some great conversations. Mostly, we hope that it encourages more people to enter clinical trials.

The stories pictured are a blend of many similar stories we ran across in our research and not those of the volunteers pictured. For more information on clinical trials and to watch videos of people telling their own clinical trial stories, go to www.CancerSupportCommunity.org/ClinicalTrials.

CHAPTER ONE: A BETTER TOMATO

Doctors are always looking for better ways to treat cancer. A clinical trial is kind of like comparing two kinds of tomatoes in your garden.

Granddaughter: What are you doing, Grandma?

Grandma: Planting tomatoes.

Granddaughter: Why do you have two rows?

Grandma: They're two different kinds of tomatoes—the ones from last year and some new ones.







**A clinical trial compares
an established treatment to a new approach.**

Granddaughter: Why? Weren't the ones last year good?

Grandma: They were, but this is a new type that might be better.

Clinical trials are done to find out if new treatments work better and are safer than existing treatments.

Granddaughter. Better how?

Grandma: They might make more tomatoes, or taste better.

Granddaughter: What else?

Grandma: Some of the vines got sick. They say that might not happen with the new ones.

Granddaughter: Why not just plant the new ones then?

Grandma: I want to be able to compare them—
so I have to watch both types grow.



Doctors compare what happens in the patients who get the different treatments.

Granddaughter: Why are you planting them in different places?

Grandma: So I can tell the difference in how they grow.

Patients are put on different arms of the trial and can get either the new treatment or the established one.

Granddaughter: Why?

Grandma: You sure ask a lot of questions... So we can see which ones make more tomatoes and are healthier.





Patients on clinical trials get a high level of care.

Granddaughter: But what if the old ones get more sun—or water?

Grandma: That's not going to happen. I'm going to make sure they get the same care. Otherwise, I won't really know which tomatoes are better for us.





Doctors keep careful track of everything that happens to people during a clinical trial.

Granddaughter: I'm going to help. I'm going to count all the tomatoes when we pick them.

Grandma: Yep. We'll keep track of that—and we can look at which ones taste better and how our vines grow.







Patients and
their doctors
are partners in
clinical trials.

Granddaughter:
This is an
experiment, isn't it?

Grandma: Yes, it is.

Granddaughter:
Good. Let's
do it together.

CHAPTER TWO: WE NEED TO TALK





Husband: How did the appointment go today?

Wife: It was okay, but we need to talk. The doctor says he wants me to consider being on a clinical trial.

Husband: Clinical trial... What does that mean? Are you okay?

A clinical trial is a research study that compares new treatments to the best treatments we have available today.



Wife: Well, it's time to make some decisions about my treatment.

There's a new drug they are testing that she thinks could work for my cancer. You can only get it now on a clinical trial.

Husband: Research? You're going to be part of an experiment?

Wife: Don't look at me that way. It's not like I'm some kind of guinea pig. The doctor says this is a promising new drug.

Clinical trials are the engine that drives progress in cancer treatment.



Husband: If it's so promising, why do they need to do a research study?

Wife: That's why they do the clinical trial—to find out whether it works better than, what did she call it... the standard of care.

We do clinical trials to find out if new treatments are effective and safe.

If you're on a trial, you get excellent care. You, your cancer, your health and any side effects will be monitored very closely.

Husband: Will your doctor still take care of you?

Wife: Of course, she says I will get top notch care. They check out everything—and keep close tabs on any side effects.





Husband: Does that mean more doctor's appointments? We're already at that center a lot.

Wife: Well, yes. I will need to do a few more appointments and some procedures, but that's so they can know if it's working and check the side effects. I can handle it.



You will probably need some additional doctor's appointments and procedures.



Husband: Which means more bills?

Wife: No, at least I don't think so.

She said all the costs would be covered, and, if there are problems, we should talk to her and they can help.

The medical costs of clinical trials are covered by insurance or the trial. Talk to your health care team about other costs.





Husband: But, it's a trial, right? What if you don't get the new drug? What if you get a placebo, some sugar pill?

Wife: It doesn't work that way. I will either get the new drug or the best thing they have now.

People with cancer on clinical trials almost never get placebos.





Husband: So, are you going to do it?

Wife: I think so. I feel like it's the best option for me now. And you know, even if it doesn't help me, it might help other people with cancers like mine.

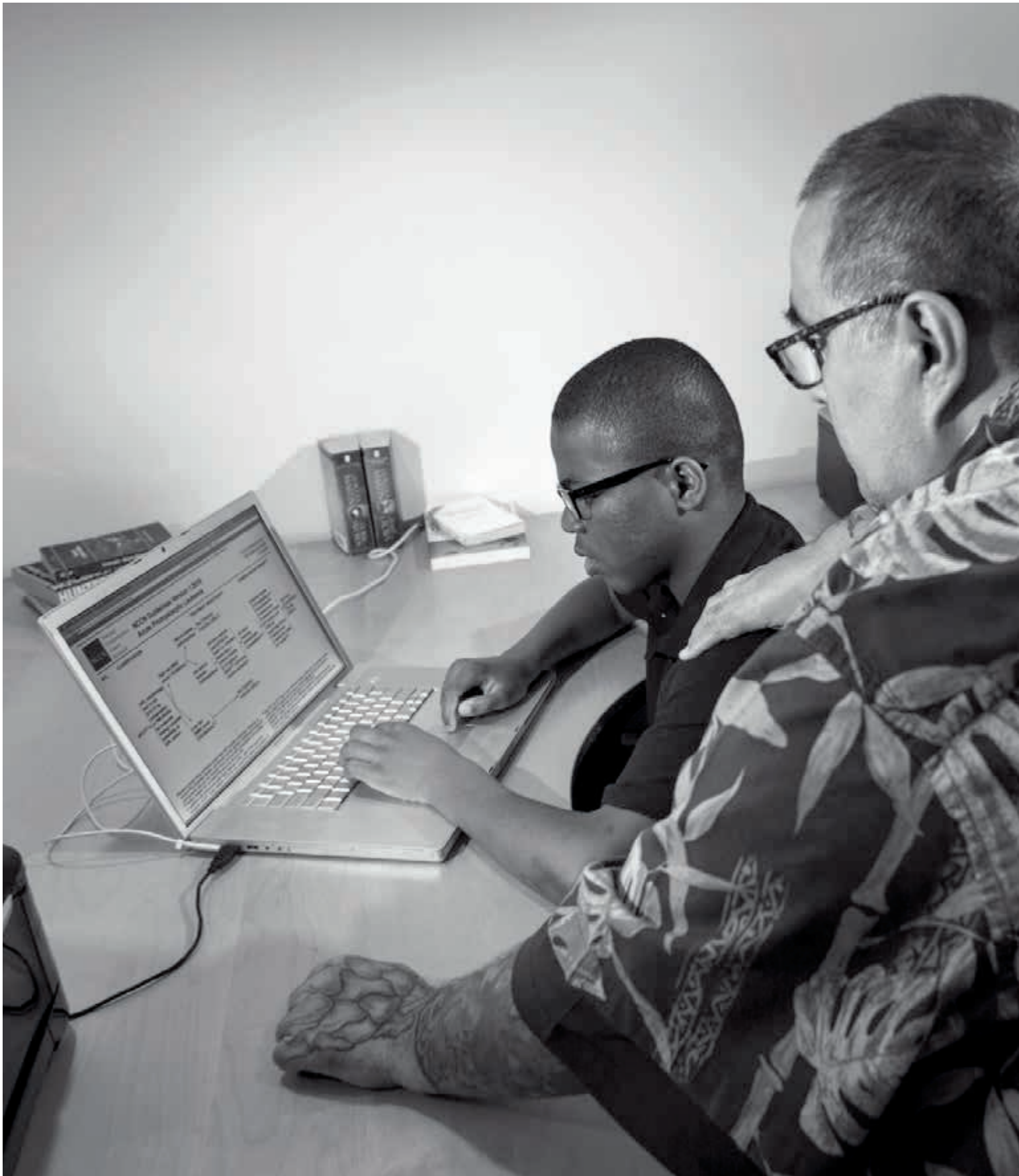
Husband: What if we have questions? I know I do.

Wife: Well, we can go together next time. It would be great if you were there with me—and the doctor says they'll explain everything and we can ask any questions we have. It's called informed consent.

Husband: Okay. I'm there with you every step. You know that, right?

Your doctor will explain everything about the trial, and give you the opportunity to ask all your questions.

CHAPTER THREE: WHAT DOES THIS MEAN?





Cancer is complicated. It can be hard for patients or caregivers to find clinical trials online.

Younger son: What does this mean? This stuff might as well have been written by Martians.

Father: What's the matter, Bud? I thought you were the online search master.

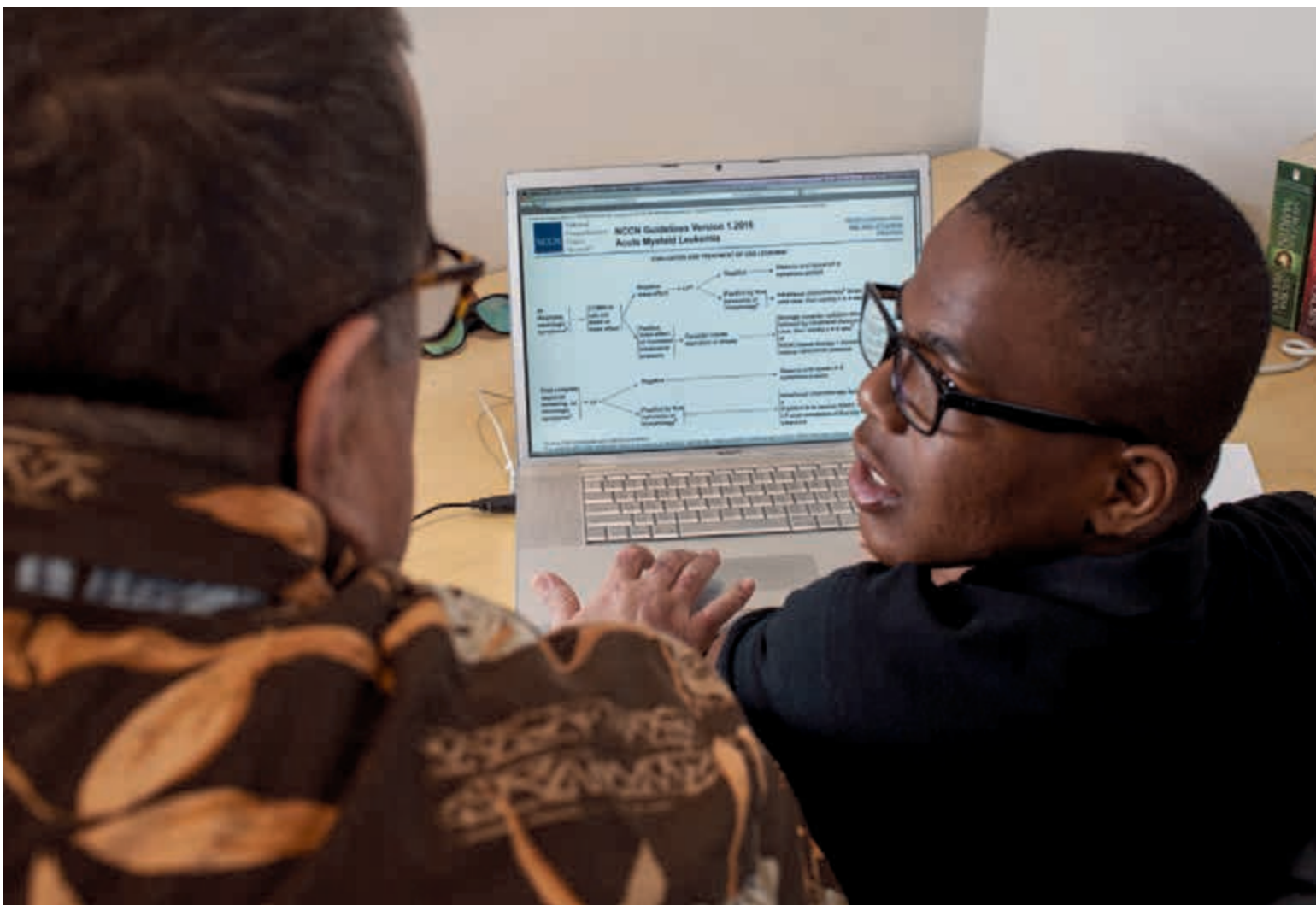
Younger son: I thought so too. But it's not easy to find a trial or know what these words mean, much less if these trials are right for you.

Father: Slow down...we're trying to find a clinical trial that might help treat my cancer...not actually get to Mars. Why is it so hard?

Younger son: Well, there are a lot of trials in a lot of cancer centers. They all seem to be very specific—and they have “eligibility requirements,” so it’s complicated. Very.

Father: Alright, print out what you’ve found. Let’s make a list of questions and we’ll talk to the nurse at my next appointment.

It helps to know your exact cancer type and stage.





Talk to your health care team about finding a trial. If you use the internet, take what you find with you.



Father: We want to talk to you today about me joining a clinical trial.

Older son: We brought some stuff we found on the internet, but we can't figure it out.

Nurse: You're right. It's hard for doctors and nurses, even when we do this every day, to find trials and match them to our patients. But let's look at what you have, and I have some other options we can discuss.



Keep a file on all your medical records, and ask lots of questions when you see your doctor or nurse practitioner.

Older son: So one thing I don't get. How do you decide who goes on what trial?

Nurse: We think about a number of factors.

What kind of cancer do you have? What stage? What treatments have you had and how has your cancer responded?

Father: So you really have to know exactly what you're dealing with when you look up trials online?

Nurse: That's right. It's one reason why we encourage people to get their medical records together and ask a lot of questions.





Your previous treatments and your overall health may influence whether you go on a trial.

**Older son: What do they mean by eligibility requirements?
I feel like we are joining a club.**

**Nurse: Well, no. That usually refers to any treatments you have had,
and whether you are healthy enough to handle taking the drugs.**



**Some trials may be offered at other cancer centers—
which can mean changing doctors.**

Father: How do you find trials?

Nurse: Lots of ways. We offer a number of them here in this center, but we also talk to our colleagues in other centers. I read journals and go to meetings. Sometimes, I look online too, or people like you bring me what they have found.

Older son: Okay. That makes me feel better. We were having a hard time figuring out how to find a trial that might be right for my dad.

Father: It's complicated

Nurse: Yes, but it's a very important part of what we do for our patients.

Nurse: You can always talk to me or your doctor when you have questions about your treatment.

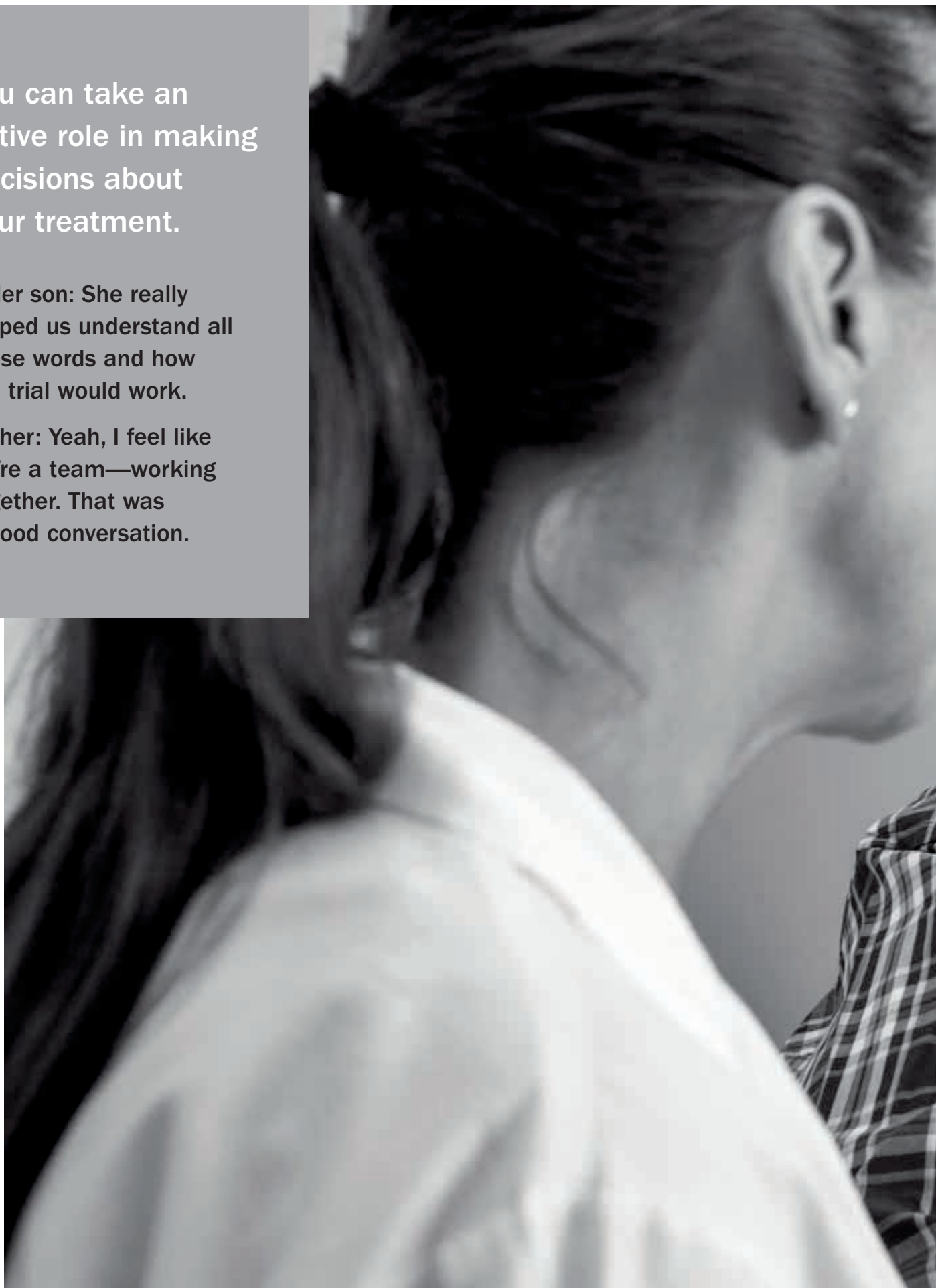
Ask questions. Communicating is key to getting good care.



You can take an active role in making decisions about your treatment.

Older son: She really helped us understand all those words and how the trial would work.

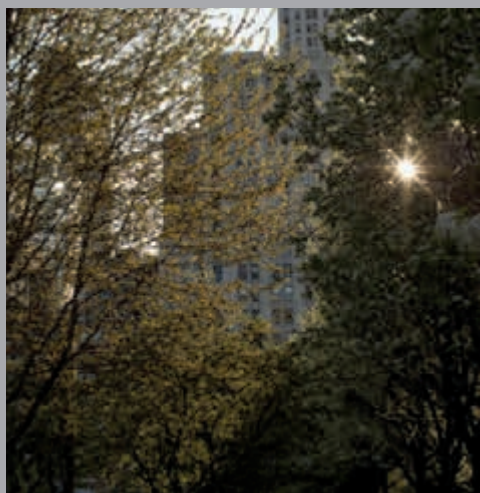
Father: Yeah, I feel like we're a team—working together. That was a good conversation.





CHAPTER FOUR: WHAT NOW?

When cancer spreads or comes back, it is often a good idea to think about a clinical trial.



Husband: I got the scan results back.

Wife: And?

Husband: It's back. The chemo stopped working and the tumor is growing again.

Wife: That's really bad news. What now?





Clinical trials are research studies that compare new treatments to the best that are available today.

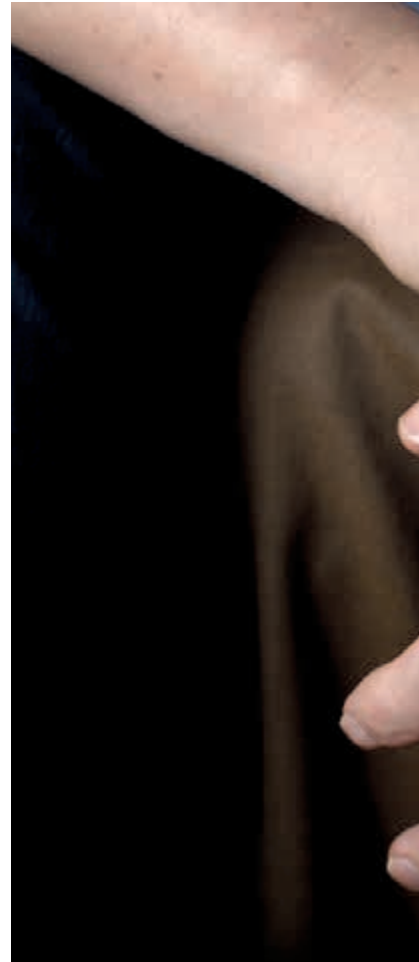
Husband: I'm not sure.

The doctor said something about a clinical trial.

Wife: Oh....is it...that bad?

Husband: I don't see it that way. She said there are some promising new drugs, and this is a good time to try them.

I can only get them by joining a trial.





Clinical trials find out whether new treatments are safe and effective.

Wife: Why can't they just give you the new drugs? Why do the trial?

Husband: Let's ask her, together, when I see her tomorrow.



If you participate in a trial, you will receive either the new drug or the best available treatment.

Husband: How does this trial work?

Doctor: There are two groups. One will get the standard treatment that we know helps some people. The other will get the new drug. The computer makes the decision. It's called randomizing.

Wife: Why not just give him whatever you think will work best?





If you are on a clinical trial, you may benefit from the new treatment. Only drugs that have shown promise are part of these research studies.

Doctor: We know that your cancer is progressing and that the best treatment we have now will, at best, work for an average of a few months. We need better treatments, and clinical trials are how we get those.

Wife: How do you know if he will benefit?

Doctor: We don't. But every drug in a clinical trial has shown real promise.

**Nurses and
nurse practitioners
are great resources
when you are
part of a trial.**

**Doctor: I will be here to
answer your questions,
but we also have a nurse
coordinator who will
work closely with you.**





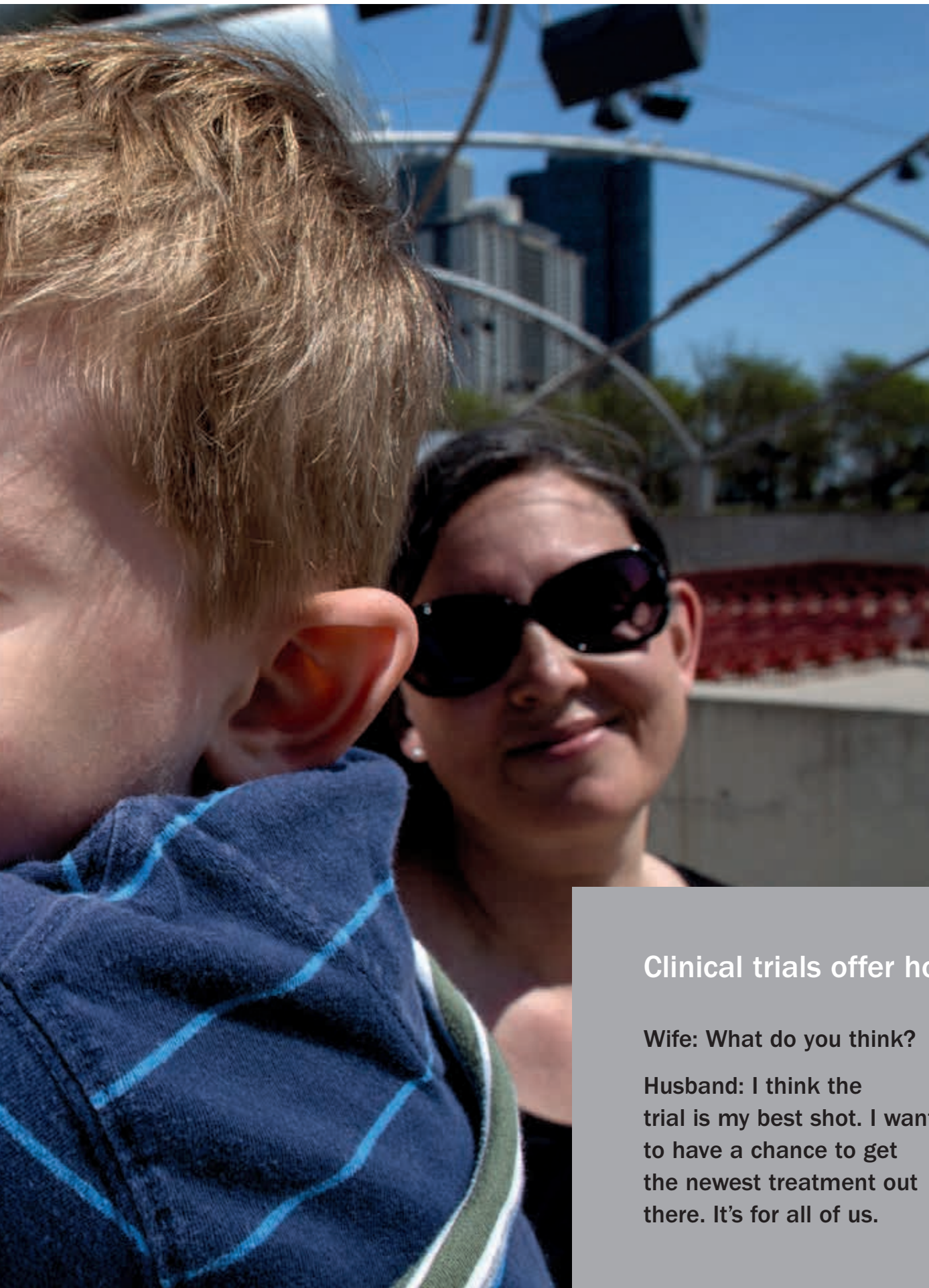
On a clinical trial, you will get very good care. You should tell your doctor or nurse about any side effects of problems you have.

Wife: What about side effects?

Doctor: We will watch those very closely—and I want to be sure you tell us if anything happens, even if it doesn't seem like much.







Clinical trials offer hope.

Wife: What do you think?

Husband: I think the trial is my best shot. I want to have a chance to get the newest treatment out there. It's for all of us.

CHAPTER FIVE: IT'S NOT WHAT YOU THINK





Friend: Is it okay if I ask—how's the chemo coming?

Patient: I'm doing okay. I'm tired, a lot, but there are only a few more treatments.

Friend: Why are you getting chemo before you have surgery?

Some clinical trials are done to help prevent cancers from coming back.

Patient: It's a clinical trial—
They want to shrink the tumor
or make it go away—before
the surgery.

Friend: But why
go through all that?

These are
called neoadjuvant
trials. Adjuvant
trials are done right
after surgery.





Patient: There were things about my cancer that the doctors said put me at higher risk for having the cancer come back.

Friend: That's scary.

Doctors can often identify high risk features in a tumor that make it more likely to come back or spread.



Treating a cancer effectively the first time gives you the best chance for a good outcome.

Patient: That's why I agreed to be on the trial. It can improve my chances that the cancer will not come back—and that's worth it.





All drugs to treat cancer have side effects, but you will receive excellent care in the trial.

Friend: What about the side effects?

Patient: I've got some, for sure, but they are taking good care of me.







Clinical trials are done for many reasons and for patients with many types and stages of cancer.

Friend: How will you know if it works?

Patient: If the tumor goes away or even gets smaller, that's a good result.



Doctors measure these trials by whether the cancer shrinks or disappears completely.

Friend: I feel better. When I heard you were on a clinical trial, I was really worried.

Patient: It's not what you think. I'm glad I joined the trial. I'm getting the best possible care. It's for my future.





Many people are able to live their lives while they are on a clinical trial.

Friend: Are you up for a walk?

Patient: Sure, let's go.

CHAPTER SIX: IT'S DIFFERENT TODAY



Aunt: Tell me again. What did the doctor say? A clinical trial?

Nephew: Yes. My doctor says it's a great option for me right now.

Clinical trials are often a good option for cancer treatment.



Every cancer patient should talk to his or her doctor about clinical trials. If your doctor doesn't bring it up, ask if clinical trials are an option for you.

Aunt: Hold on a second. I don't know about that. Does this mean you will be a guinea pig?

Nephew: It's not like that. My doctor explained how closely they will watch me. I think this is my chance to get the newest treatments.





Some African Americans distrust clinical trials because of what happened in the past. Today, review boards and federal laws help protect patients.

Aunt: Did he explain some of the medical experiments done in the past, like Tuskegee? I remember learning about that in college.

Nephew: Of course, but things are different today—there are more safeguards in place. And I really do trust my doctor.



Nurses and nurse practitioners are great resources when talking about clinical trials.

Aunt: Did you talk to your nurse about this? She answered all my questions when we went together.

Nephew: I did, in fact. She was great. She agreed that it was a really good choice for me right now.



Aunt: What's it going to cost? You've already missed a lot of work.

Nephew: The costs of the trial are covered—completely. We talked about that too.

Medical costs should be covered by the trial or insurance. Check with your insurance and talk to your doctor or nurse about any cost issues you have.



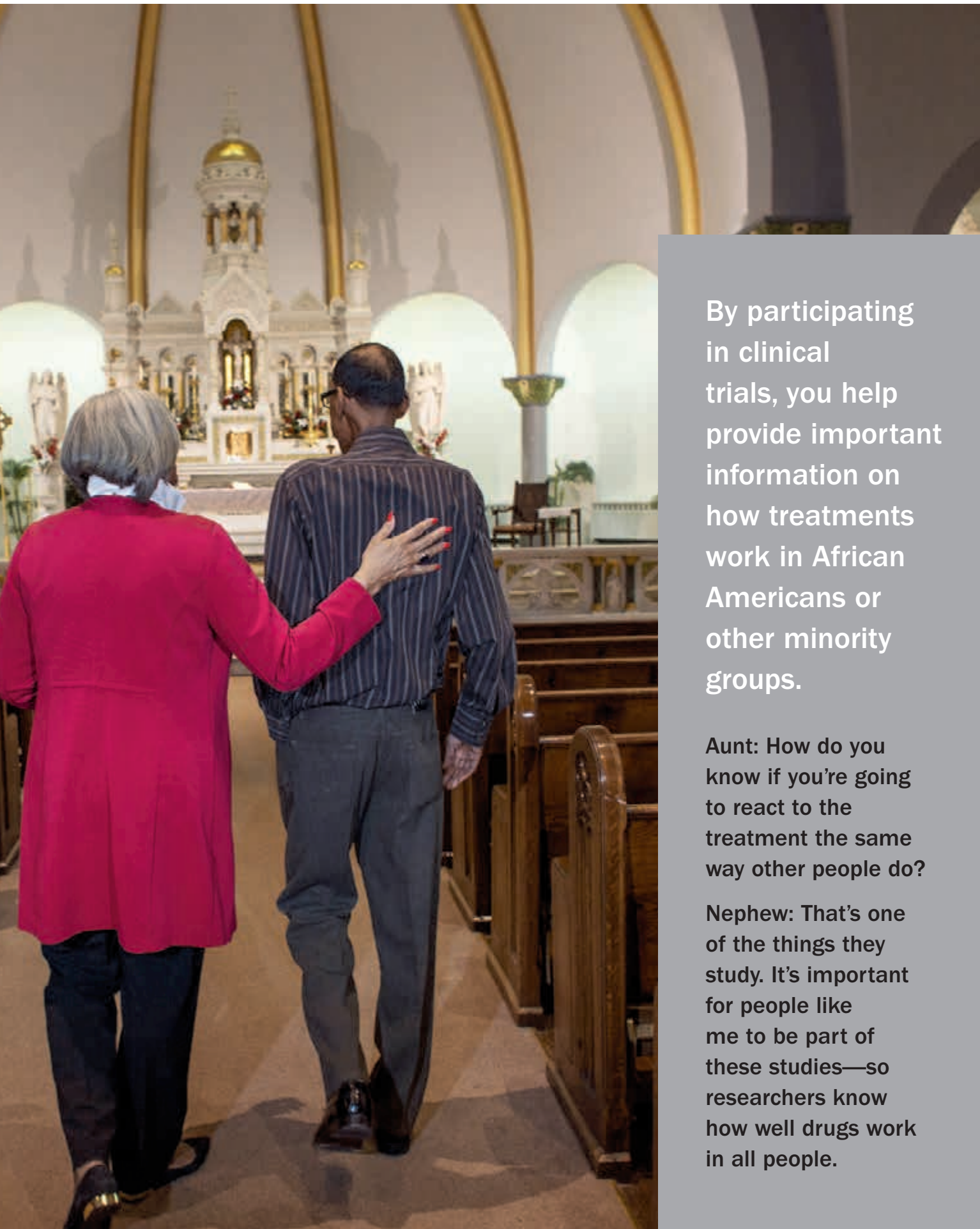
Clinical trials are for everybody—of all races and backgrounds.



Aunt: Do you know that most trials used to only let white men join them? No women, blacks or Hispanics?

Nephew: Yes, but by taking part, I'm helping change that. These days everyone with cancer should be offered the option of a clinical trial. It's good medicine.






By participating in clinical trials, you help provide important information on how treatments work in African Americans or other minority groups.

Aunt: How do you know if you're going to react to the treatment the same way other people do?

Nephew: That's one of the things they study. It's important for people like me to be part of these studies—so researchers know how well drugs work in all people.

A photograph of a church interior. In the foreground, the back of a person's head and shoulder is visible, wearing a red garment. The background features a large stained glass window with a central figure in blue and white, and a smaller stained glass window to the right. The church pews are visible in the lower half of the frame.

Clinical trials
improve cancer
treatment—
for everyone.

Aunt: You're going
to do this?

Nephew: I am.
I think it's the right
thing for me and the
right thing to do.
It's how cancer
treatment gets better
—for all of us.



CHAPTER SEVEN: FOR THEM

Mom: You look tired, dear. Is everything okay?

Daughter: Well, yes, but the treatment is getting to me. The last scan looked pretty good though.

Most people participate in a clinical trial because they hope to benefit from the treatment.







Mother: So, does that mean you're getting better?

Daughter: It means I'm not getting worse.

For some people, a cancer that does not progress is a good outcome.



Mother: Is it worth it? Being on the trial?

Daughter: I think so. It gives me hope.

**Patients can choose to
stop being on a trial at any time.**





Mother: What if...it doesn't work?

Daughter: Then, I guess we'll try something else, another trial. We have to keep looking at the options.

There are often other options, including other clinical trials, for patients who do not respond.





Mother: What keeps you going?

Daughter: You and Dad. And, well... Life! There is so much joy to be had. I want to stick around for more. But there's also something else.

Patients who join trials hope for longer, better lives.



Mother: Like what?

Daughter: I want what I'm going through to mean something.

**Many cancer patients
want their experience to mean something.**



Doctors learn from every clinical trial, even those that do not seem successful.

Mother: What do you mean?

Daughter: My being on this trial will help other people. They'll learn from it—even if it doesn't work.



Mother: I never thought of that.

Daughter: I think about it all the time—I don't want other people to have to go through this. It's about a better future for everyone.

For many people, helping future generations means a lot.





CHAPTER 8: THE WHOLE PERSON





There are many reasons for having clinical trials—and for participating in one.

Doctor: I want to talk to you about being on a clinical trial.

Patient: Another clinical trial? I thought I was doing well. You said there was no sign of the cancer. What's this about?

Doctor: Whoa, slow down. You're doing fine. This trial is to study whether exercise helps with your emotional and physical health.

Patient: Exercise? What does that have to do with clinical trials?

Some trials are focused on improving mental and physical health.





Doctor: We really want to focus on the whole person, not just your cancer—and we need to know more about whether exercise can make you less tired, or have less anxiety.

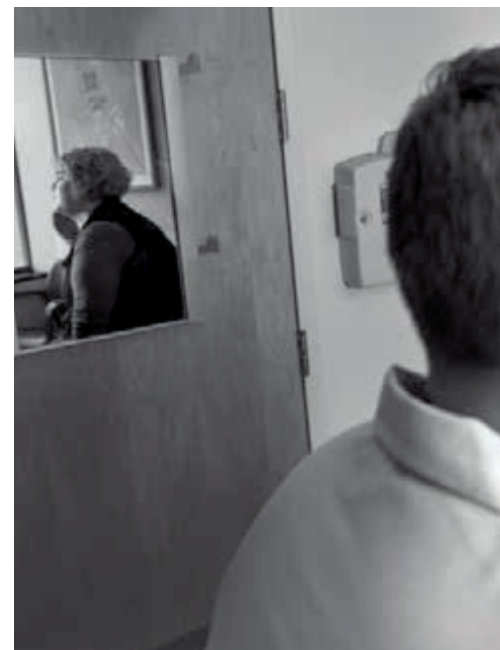
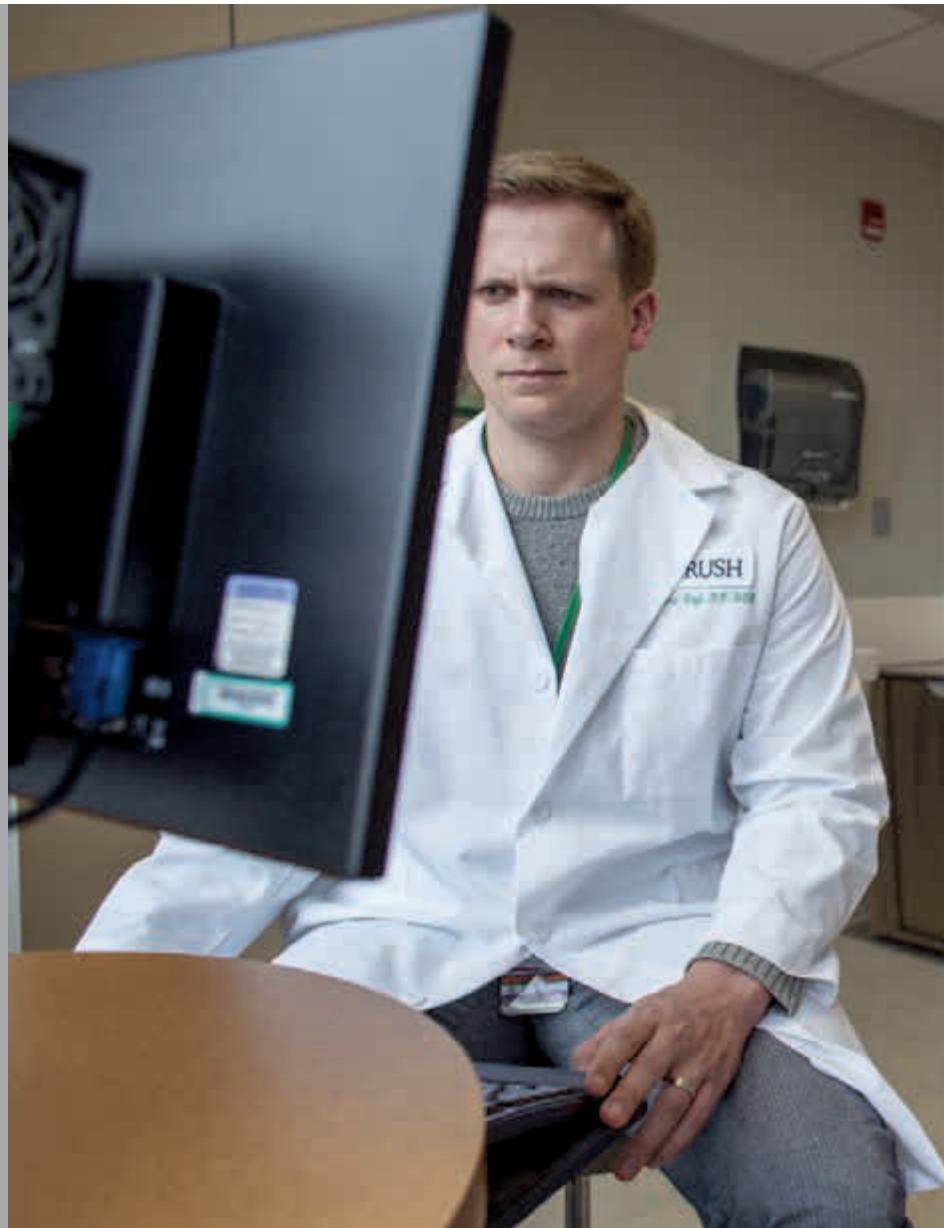
Patient: That sounds interesting. I'm into exercise, or I was before this happened. Tell me more.

We need evidence to know the best ways to address all the issues that people with cancer face.

Doctor: It's like other trials. You'll be randomized into either a group that does supervised exercise, or one that doesn't. It lasts for three months.

Patient: Okay.

Researchers compare the results of the two groups in many ways.





Patient: Will this help make sure my cancer doesn't come back?

Doctor: No, it doesn't treat the cancer.

Trials of this kind do not treat the cancer. They help people live a better life.





Your costs in a clinical trial are covered by the trial.

Patient: What does it cost?

Doctor: All your expenses will be covered—just like in any clinical trial.

Patient: Will I get to know the results?

Doctor: Absolutely. You're a partner in this trial.

Patients are partners in all clinical trials.







Patient: This is way different than how I thought clinical trials work. I'm in.

Doctor: Great. It's so important to learn more about how to help people survive with cancer.

More and more people are surviving cancer, or living with it. These trials help improve quality of life.

GLOSSARY

Doctors often use medical terms to talk about clinical trials. This is a list of some of the terms you may hear or read when you are thinking about being in a clinical trial.

A CLINICAL TRIAL or CLINICAL STUDY is a research study to test how well new medical treatments work in people. Each clinical trial tests new ways of screening, preventing, diagnosing or treating cancer, or improving the quality of life for people with cancer.

ADJUVANT TRIALS: Research studies done after primary treatment for cancer, such as surgery or radiation therapy, to reduce the chance the cancer will recur or come back.

ADVERSE EVENT: Any unfavorable change in a patient's health. This includes abnormal lab findings, side effects of the treatment and health problems that may not be caused by the trial but happen during or after a person participates. Doctors use adverse events to decide whether a treatment is safe and help set the dose.

AGENT: In a clinical trial, a substance that produces or can produce an effect that treats cancer.

ARM: A group of participants in a study who are receiving the same treatment.

BIAS: Any factors, such as human beliefs or choices that affect a clinical trial's result.

BLINDING: Setting up a study so that neither the doctors nor the participants know who is getting which treatment.

CHEMOTHERAPY: The use of drugs to treat cancer.

CLOSED STUDY: A trial that is no longer recruiting or open to new patients.

COMBINATION THERAPIES: Studies or treatments that use more than one drug or agent.

COMPLETE PATHOLOGICAL RESPONSE (CPR): The total disappearance of a cancer following neoadjuvant therapy. CPR is an important way for researchers to measure the outcomes of a neoadjuvant clinical trial.

CONTROLLED TRIAL: This is a study in which the new treatment is compared to a control (usually the standard of care).

DATA: Information from a study.

DISEASE-FREE SURVIVAL: The time from when a person with no detectable cancer begins a treatment until the cancer appears or returns.

ELIGIBILITY REQUIREMENTS: Every clinical trial has certain standards that participants must meet in order to participate. These usually are related to the kind and stage of cancer, any previous treatment you have had and your overall health.

ENDPOINT: This is a way that researchers measure the results of a clinical trial.

EXCLUSION CRITERIA: Factors that can make a person not eligible or able to participate in a clinical trial.

EXPERIMENTAL: Any research study that is designed to test whether a new drug or treatment is better than the available best treatments.

FOOD AND DRUG ADMINISTRATION (FDA): The federal agency responsible for assuring that all drugs and medical devices available in the United States are safe and effective. The FDA reviews—but does not conduct—clinical trials.

HUMAN SUBJECTS REVIEW BOARD: See Institutional Review Board.

INSTITUTIONAL REVIEW BOARD (IRB): The group at a medical center that reviews all proposed clinical trials taking place in that center to make sure they are safe and effective for patients and that all patients' rights are protected.

IMMUNOTHERAPY: Treatments that use the body's own natural immune system to fight cancer.

INCLUSION CRITERIA: The factors that allow a person to participate in a study.

INFORMED CONSENT: The formal process researchers use to make sure patients understand a clinical trial and fully agree to participate in it. This is an important way of communicating with patients and caregivers about the goals of the study, possible results and side effects. It is also a time to ask questions.

INTERVENTION: Any drug, agent, medical device or procedure that involves a patient. Surveys, interviews and education programs can also be interventions.

INVESTIGATIONAL NEW DRUG: A drug or agent that is being used in a clinical trial but has not yet been approved by the FDA.

INVESTIGATOR: The researcher who is conducting the clinical trial.

NEOADJUVANT TRIALS: Studies done to test treatments before the primary treatment for a cancer, such as surgery or radiation therapy. This is done to eliminate or reduce the amount of cancer.

OPEN STUDY: One that is actively recruiting new participants.

OUTCOME MEASURES: The ways that researchers decide if the new treatment is safe and effective. These are set before a study begins and can include measures of survival and quality of life.

OVERALL SURVIVAL: The length of time a person lives from the beginning of treatment.

PHASE: There are four basic stages of clinical trials:

PHASE I trials are the earliest. They are often small and are designed to establish the safety and effectiveness of a new treatment. They may involve people with many kinds of cancer.

PHASE II are studies designed to see if a new treatment works in people with specific types of cancer. These trials are often larger and usually involve comparing the new treatment to the standard of care.

PHASE III are the large studies that establish how a new treatment will be used. These trials may involve hundreds or even thousands of patients and take place in many hospitals in this country and around the world.

PHASE IV trials study the long-term side effects and results after a treatment is approved by the FDA.

PLACEBO: An inactive substance, sometimes called a “sugar pill.” Placebos are almost never used in cancer clinical trials. Most studies involve getting the standard of care for the specific cancer type.

PRECLINICAL STUDIES: Research done on new drugs and treatments before they are used in humans.

PROGRESSION-FREE SURVIVAL: The time from when a patient begins taking a treatment until the cancer begins to grow or spread again.

PROTOCOL: The written plan or design for a trial that tells doctors what treatments and doses patients get on a study. It is the doctor’s recipe for conducting the trial.

QUALITY OF LIFE: These are ways of measuring treatments and the patient experience that focus on a patient’s overall health, ability to live and enjoy life and sense of well-being.

RANDOMIZED: Many clinical trials involve assigning participants to treatment groups by letting a computer choose who will get which treatment. This is done to make sure that there is no bias in the study and assures that every patient has an equal chance of getting either the standard of care or the new treatment being tested.

SINGLE AGENT TRIALS: Studies that test one drug.

STAGE: The extent of the cancer.

STANDARD OF CARE: This is the currently accepted and widely-used treatment for any specific type of cancer. Clinical trials compare new treatments to the standard of care to learn if they work better and are safe for patients.

TARGETED THERAPY: Treatments that target specific genetic mutations or changes in a cancer.

TOXICITY: Harmful side effects that result from an agent being tested.

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