

FREE

WITH LOVE AND SUPPORT



**A GUIDE FOR LATINAS WITH METASTATIC BREAST
CANCER AND THEIR LOVED ONES**

RESOURCES

SHARE/LatinaSHARE
844-275-7427
<https://www.sharecancersupport.org>

American Cancer Society
800-227-2345
<http://www.cancer.org>

National Cancer Institute
800-422-6237
<https://www.cancer.gov>

Cancer and Careers
646-929-8032
<https://www.cancerandcareers.org>

Patient Advocate Foundation
(800) 532-5274
<http://www.patientadvocate.org>

Metastatic Breast Cancer Network
888-500-0370
<http://www.mbcn.org>

Susan G. Komen Foundation
877-465-6636
<http://www5.komen.org>

THINGS TO DISCUSS WITH YOUR DOCTOR

1. Metastatic Site: Size:
2. Subtype: ER PR HER2 TRIPLE NEG OTHER
3. Test and scan schedule:
4. Treatment options:
5. Clinical Trial Information:
6. Expected Patient Decision Date:
7. Possible Treatment Side Effects:
8. Quality of Life (QOL) Concerns:
 - A. Palliative Care (Symptom Management, Complementary Medicine)
 - B. Support Group Information (availability)
 - C. Future Goals (ie; Life Events, Family, Work, Directives, Activities)

Note: Working with your doctor is important throughout your treatment journey. It is important to discuss how you feel and any side effects that you experience because there may be tips to help manage some of them.



Ms. Garcia, where does the sky end?

Ms. Garcia, I need to potty.

Ms. Garcia, look what she did!



Mom, can u pick up Isabelita from school? Sofia is working late, so am I.



What should I cook for dinner?

Something simple. Don't worry. Everything you make is the best, mi amor.



Ay, I forgot the avocado. Now my hip and back hurt too.



DAYS LATER AT WORK



What's wrong?

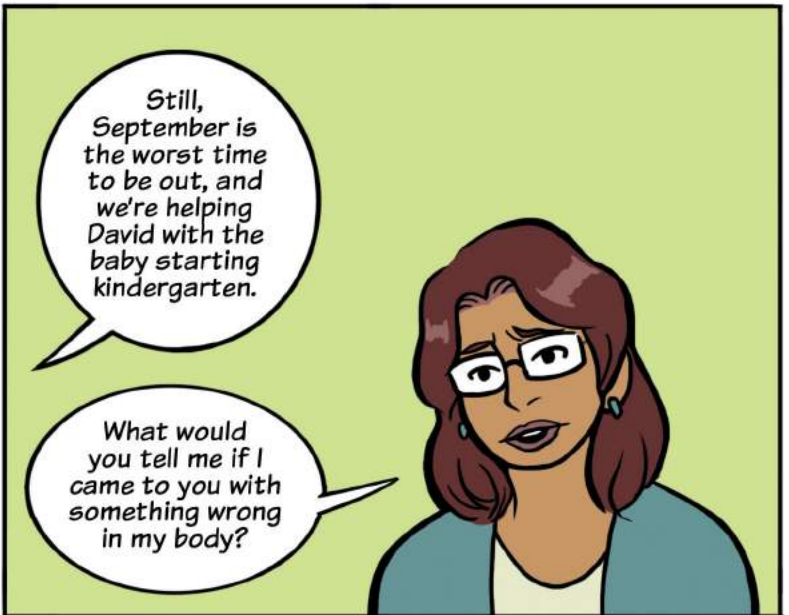
It's nothing. I've been having pain in my back and hip for a few months.

Ana, remember you're a breast cancer survivor. Pain may be a sign something's wrong. Don't ignore your symptoms.



We just came back from vacation. What will Principal Li think if I ask for a day off already?

You've been a teacher's aide here for 20 years. Your job isn't going anywhere.



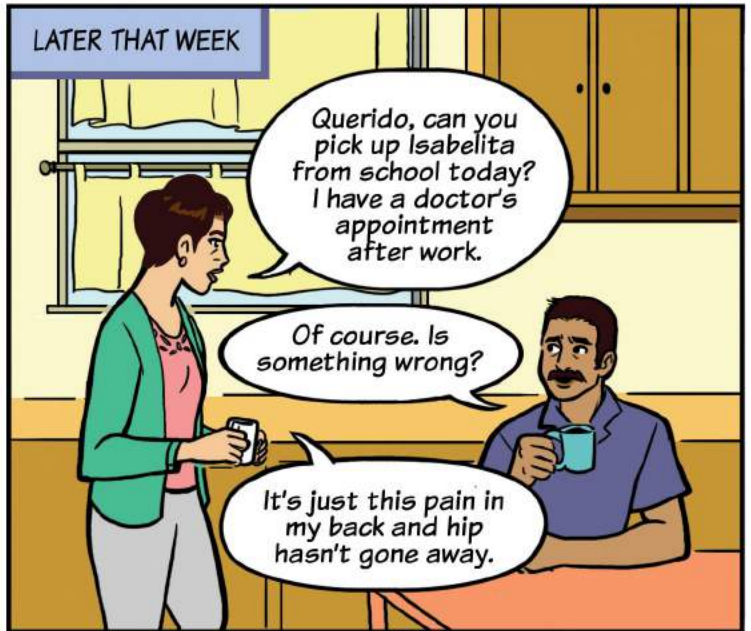
Still, September is the worst time to be out, and we're helping David with the baby starting kindergarten.

What would you tell me if I came to you with something wrong in my body?



To see a doctor. I know, I know. I'll make an appointment for late in the day.

Good. How can you do your job if you're not okay?



LATER THAT WEEK

Querido, can you pick up Isabelita from school today? I have a doctor's appointment after work.

Of course. Is something wrong?

It's just this pain in my back and hip hasn't gone away.

ANA IS REFERRED TO HER ONCOLOGIST AFTER SEEING HER PRIMARY DOCTOR.

Let's do a PET scan and some bloodwork.

For muscle pain?

Well, let's make sure what it is. A PET scan is an imaging test that evaluates your organs, bones, and tissue.

AT THE SPANISH-LANGUAGE BREAST CANCER SUPPORT GROUP

I couldn't sleep last night. What if something is wrong?

You're worrying about what hasn't happened yet.

How can we be there for you?

I just needed to talk. I couldn't worry my family. They went through so much with my breast cancer diagnosis ten years ago.

Ana, here's my number if you feel like talking after your follow-up. Whatever the news is.

Oh, thank you. I might do that.

Thanks for picking up Isabelita from school.

Are you kidding? I love grandma duty. Since you're here, can I ask a favor?

Sure.

Could you come with me to my follow-up appointment? I'm nervous. This is the first time Dr. Khan's asked me to bring a family member.

Of course.

TWO WEEKS LATER

Ana, I asked you to come in for this follow-up with a family member because the back and hip pain you've been having isn't muscular. We found breast cancer that has metastasized.



OH MY GOD!



What?! How? I completed chemo. I took all my medications. I take care of myself now more than ever. Now you're telling me I have breast cancer again?



This is not a recurrence in your breast. This happens when the cancer has metastasized. The cancer cells can spread to other organs.

For example, the liver, bones, lungs and brain. In your case, the bones.



So I have bone cancer now?

Even though the cancer cells spread to your bones, we still treat them as breast cancer.

Since you were previously diagnosed with breast cancer, it's most likely some of those cancer cells survived the hormonal therapy and chemotherapy.

Under a microscope, the cells look like breast cancer cells and respond best to breast cancer treatments.



What if I receive chemo again? Won't it go away?

Having metastatic breast cancer means you probably will be in treatment for the rest of your life, but not necessarily on chemotherapy.



The rest of my life? How long do I have?

Metastatic breast cancer is not curable, only treatable. Treatments are available, but we can't promise how long they will work.



Treatment means we try to shrink or weaken the cancer, stop it from spreading further, and try to manage your symptoms and side effects.

What happens if a treatment doesn't work?



Treatment options can include different standardized treatments and clinical trials. If one stops working we decide together on the next treatment, but first I want a biopsy of your hip.



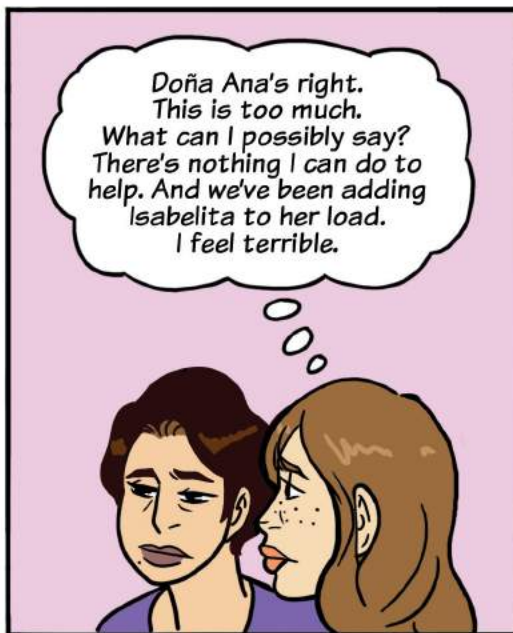


This is too much to process at once.

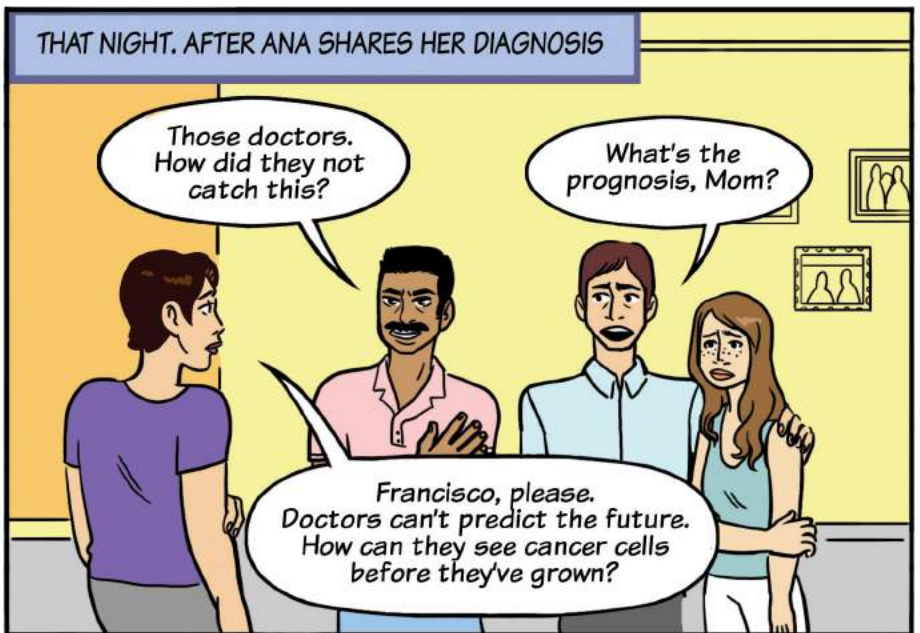
I know this is a shock and overwhelming. Why don't we make a follow-up appointment to discuss treatment and clinical trials? In the meantime, talk to your family.



Take this information with you. It's called the Metastatic Communication Toolkit. It'll help you and your family better understand your diagnosis and treatment options.



Doña Ana's right. This is too much. What can I possibly say? There's nothing I can do to help. And we've been adding Isabelita to her load. I feel terrible.

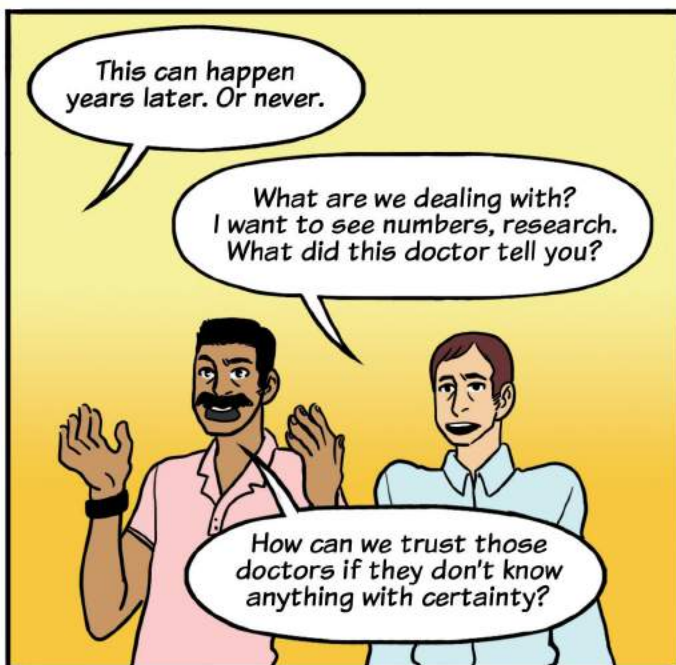


THAT NIGHT. AFTER ANA SHARES HER DIAGNOSIS

Those doctors. How did they not catch this?

What's the prognosis, Mom?

Francisco, please. Doctors can't predict the future. How can they see cancer cells before they've grown?



This can happen years later. Or never.

What are we dealing with? I want to see numbers, research. What did this doctor tell you?

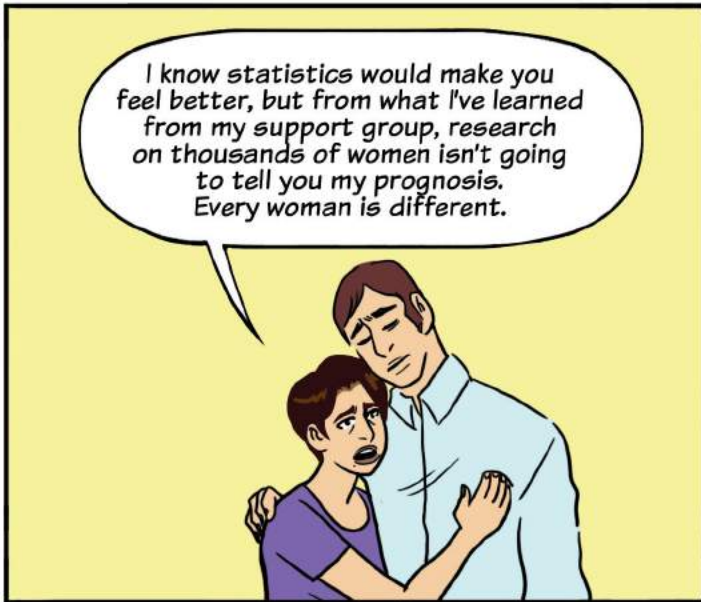
How can we trust those doctors if they don't know anything with certainty?



Why is everyone fighting?

No one is fighting, mi'ja. We're just talking too loud.

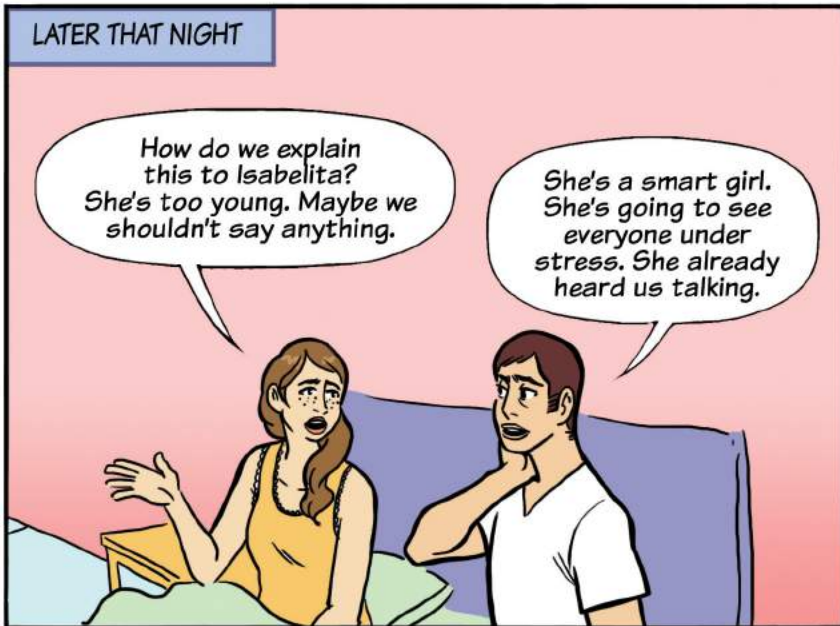
It's past your bedtime anyway. We better get going.



I know statistics would make you feel better, but from what I've learned from my support group, research on thousands of women isn't going to tell you my prognosis. Every woman is different.



How did I still end up taking care of everyone else's feelings on a day like today?



LATER THAT NIGHT

How do we explain this to Isabelita? She's too young. Maybe we shouldn't say anything.

She's a smart girl. She's going to see everyone under stress. She already heard us talking.



If we say nothing, we could confuse her even more. And we promised we weren't going to raise her like that, with secrets and shame. If we keep it simple, maybe that's better than nothing.



ANA AT THE SUPPORT GROUP

What if it was me that missed something? Some pain I ignored like I almost did this time. I should've taken better care of myself.



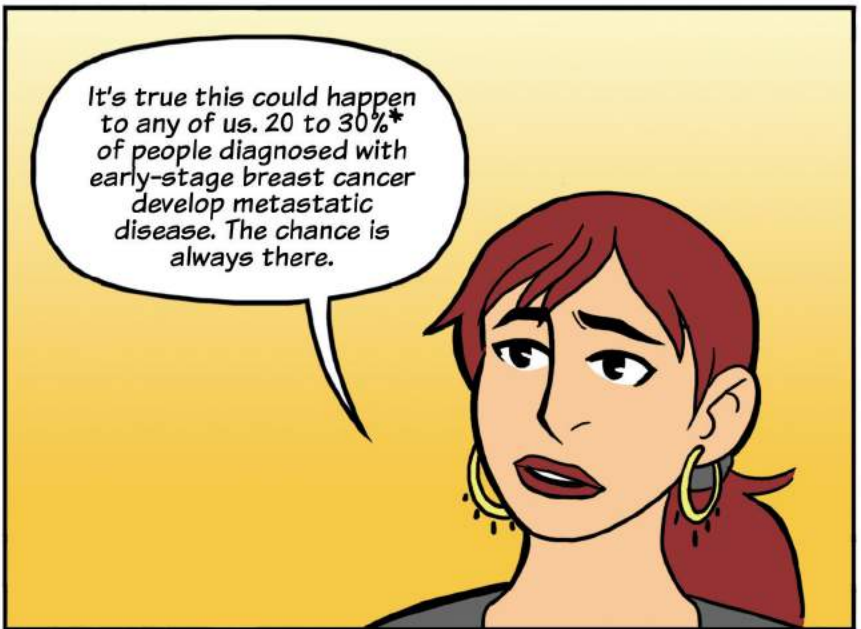
It is not your fault! You didn't do anything wrong.

This can happen to any of us. We're here to support you. Don't blame yourself!

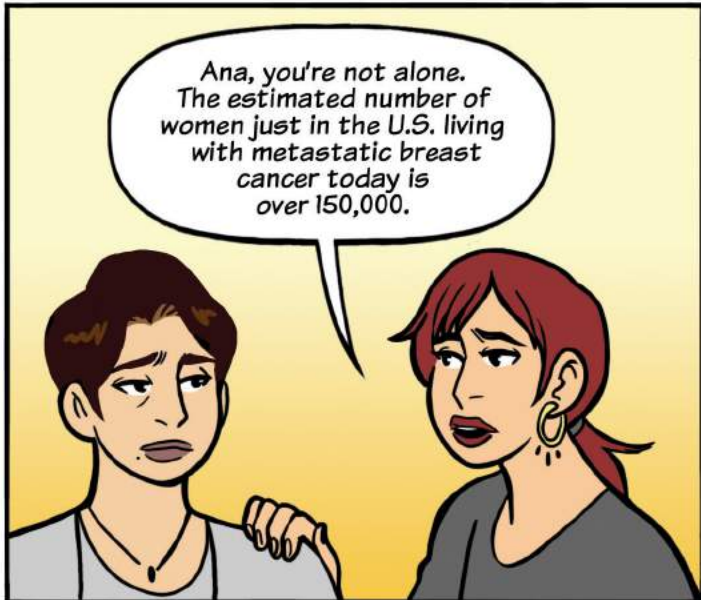


This terrifies me. Don't women die from this disease?

I know this is frightening, but maybe some information would help us deal with our fear.



It's true this could happen to any of us. 20 to 30%* of people diagnosed with early-stage breast cancer develop metastatic disease. The chance is always there.



Ana, you're not alone. The estimated number of women just in the U.S. living with metastatic breast cancer today is over 150,000.



We can't do anything about chances. But we know from experience we can still help each other, right?

Exactly. That's why I keep coming to our group because I don't have to pretend I'm okay if I'm not.



I'm always the strong one for my family. I'm not used to asking them for help, but I did when I was diagnosed last time. It was less confusing and frustrating for all of us.



Ana, here's the information for the metastatic telephone support group. Consider joining. You'd have the support of other women with a metastatic diagnosis in addition to our support group here.

* www.MBCN.org/13-facts-about-metastatic-breast-cancer/

Bendición.

Que Dios te bendiga, mi'jo. This is a surprise. Sofia said she would come with me to my appointment, is she okay?



She's... busy with Isabelita and work. Don't worry. I want to go with you to your appointment.

Oh. Well tell her to call me. I haven't heard from her in days.



AFTER ANA'S HIP BIOPSY

Doctor, my mom has had many tests. My dad is upset, saying that she's being experimented on. I'm pretty educated, but even for me, these terms are like a foreign language.



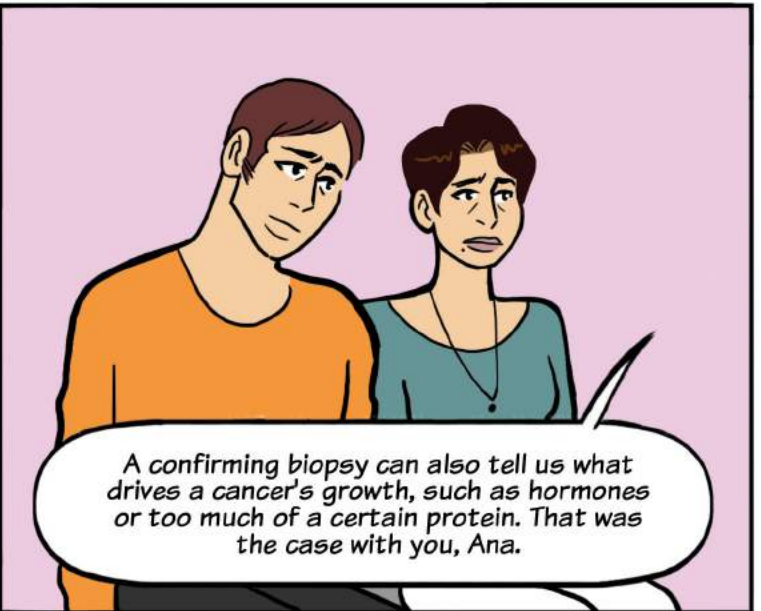
That's your mother's pathology report from the hip biopsy which confirms her diagnosis and helps us figure out how to move forward.




As you know, a biopsy tests a sample of tissue. A **confirming biopsy** of the metastatic site determines the cancer's subtype. Knowing the subtype helps decide on the right treatment.

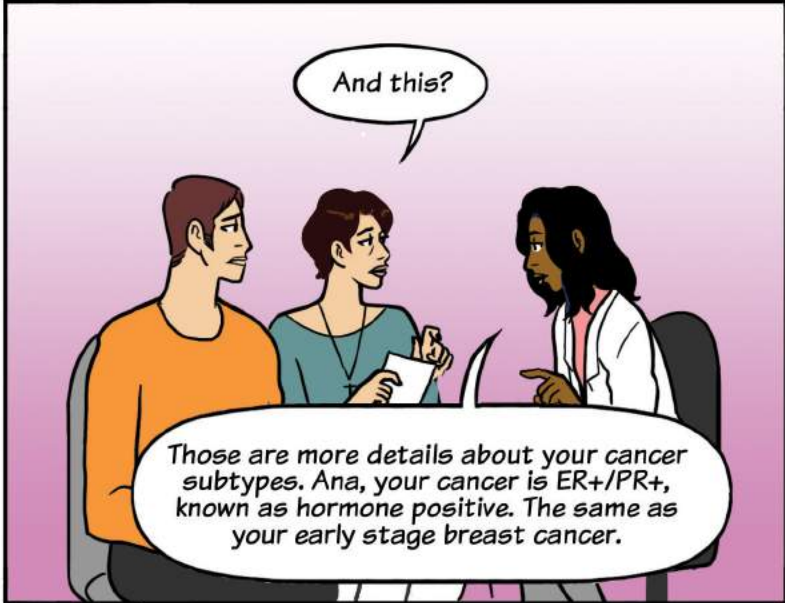


A confirming biopsy can also tell us what drives a cancer's growth, such as hormones or too much of a certain protein. That was the case with you, Ana.






To monitor the cancer, I'll order scans and blood tests, including tumor marker tests, which could tell us if the cancer is progressing.

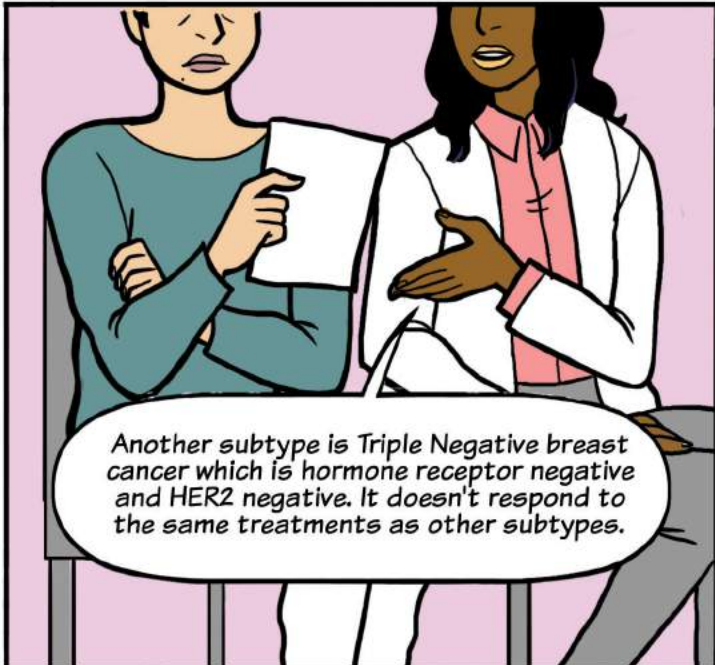


And this?


Those are more details about your cancer subtypes. Ana, your cancer is ER+/PR+, known as hormone positive. The same as your early stage breast cancer.



Another subtype is HER2+. Typically, HER2 receptors help control how a healthy breast cell grows, divides, and repairs itself but in this subtype it's not functioning properly. Sometimes the pathology can be both hormone positive and HER 2+.

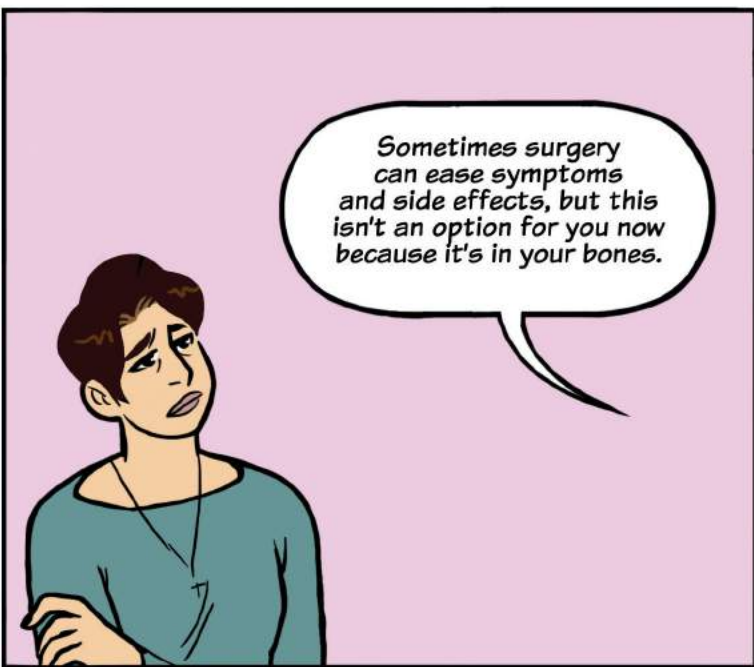


Another subtype is Triple Negative breast cancer which is hormone receptor negative and HER2 negative. It doesn't respond to the same treatments as other subtypes.

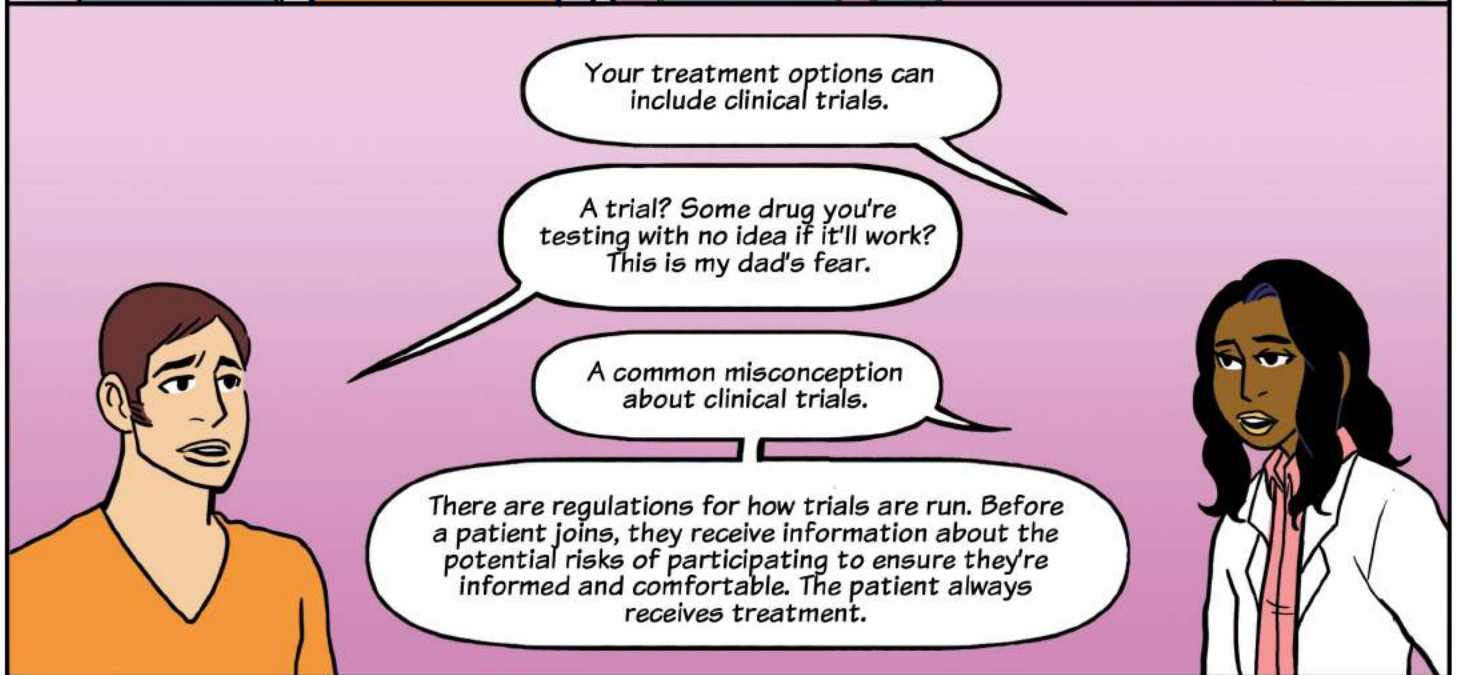
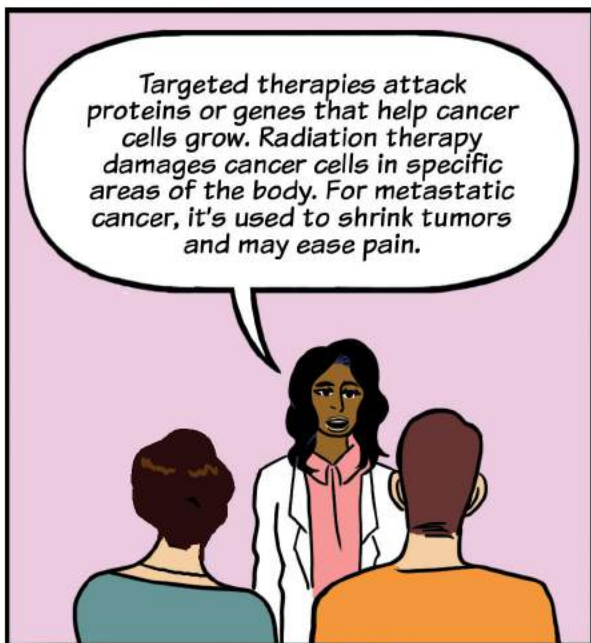
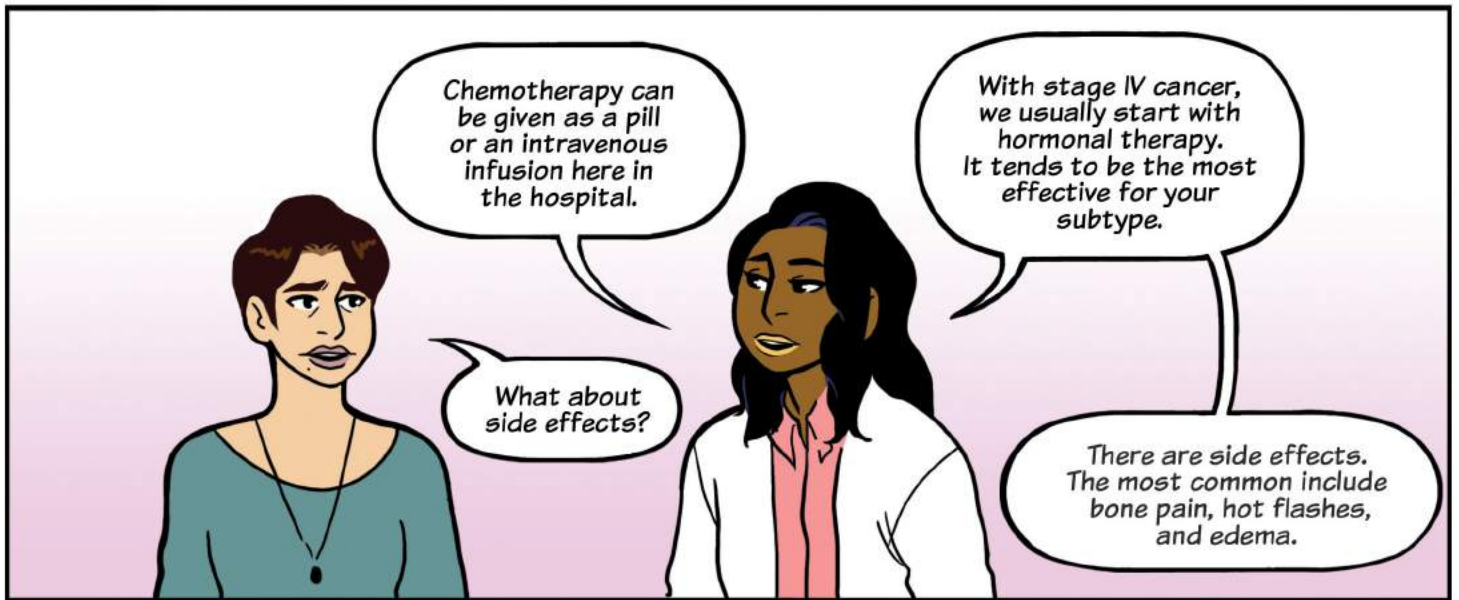


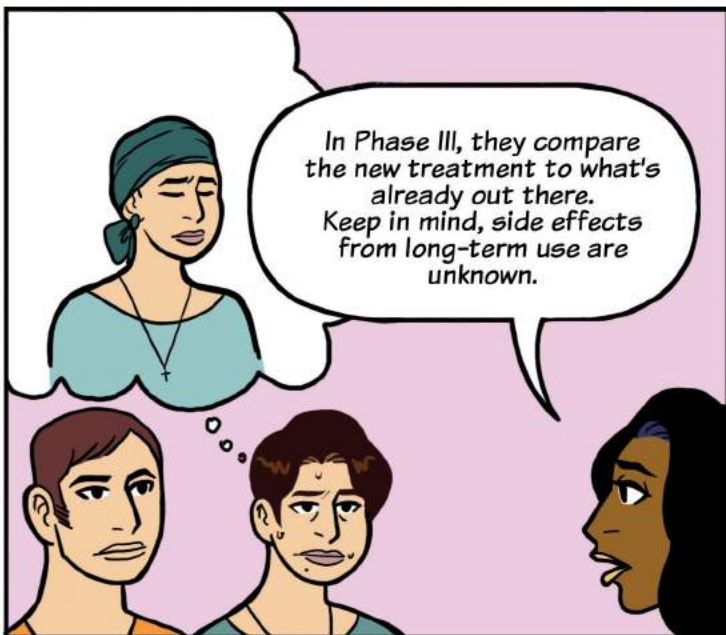
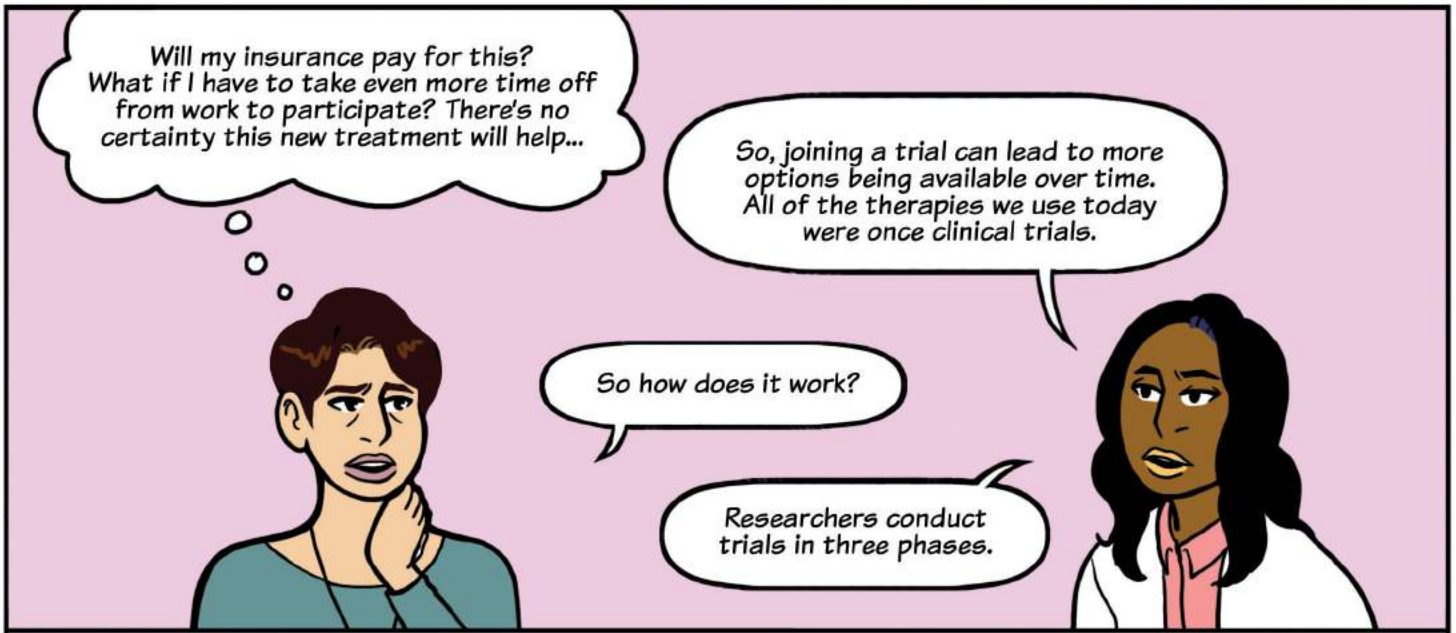
So what are my treatment options? Which one do you recommend for me?

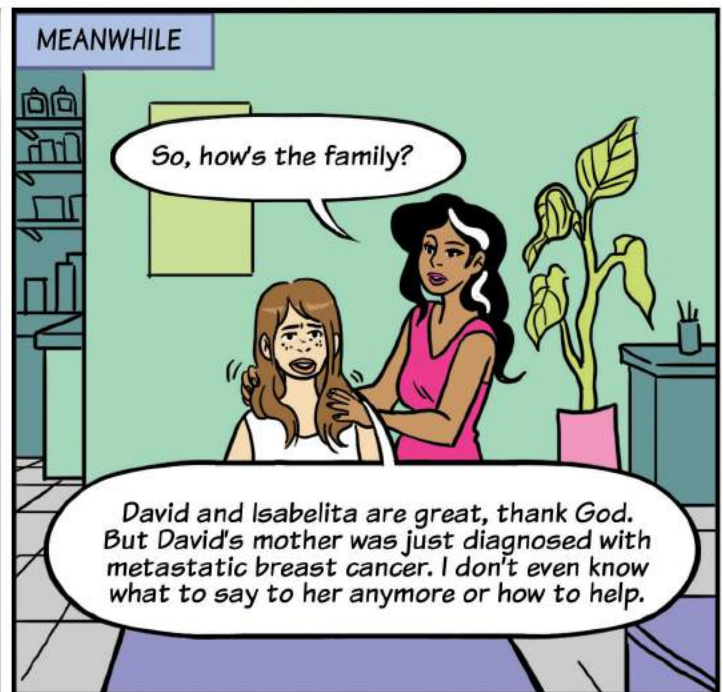
The most common treatments are hormonal therapy, other targeted therapies, chemotherapy, radiation, clinical trials, and sometimes surgery.

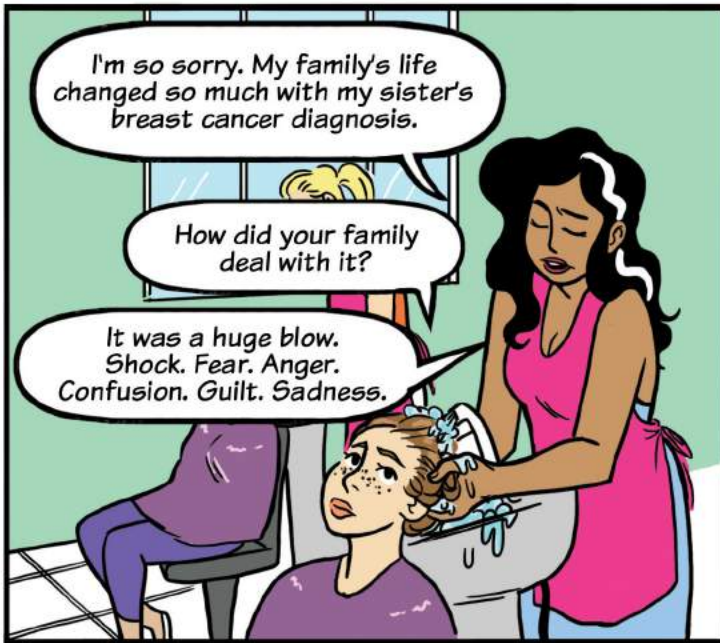


Sometimes surgery can ease symptoms and side effects, but this isn't an option for you now because it's in your bones.











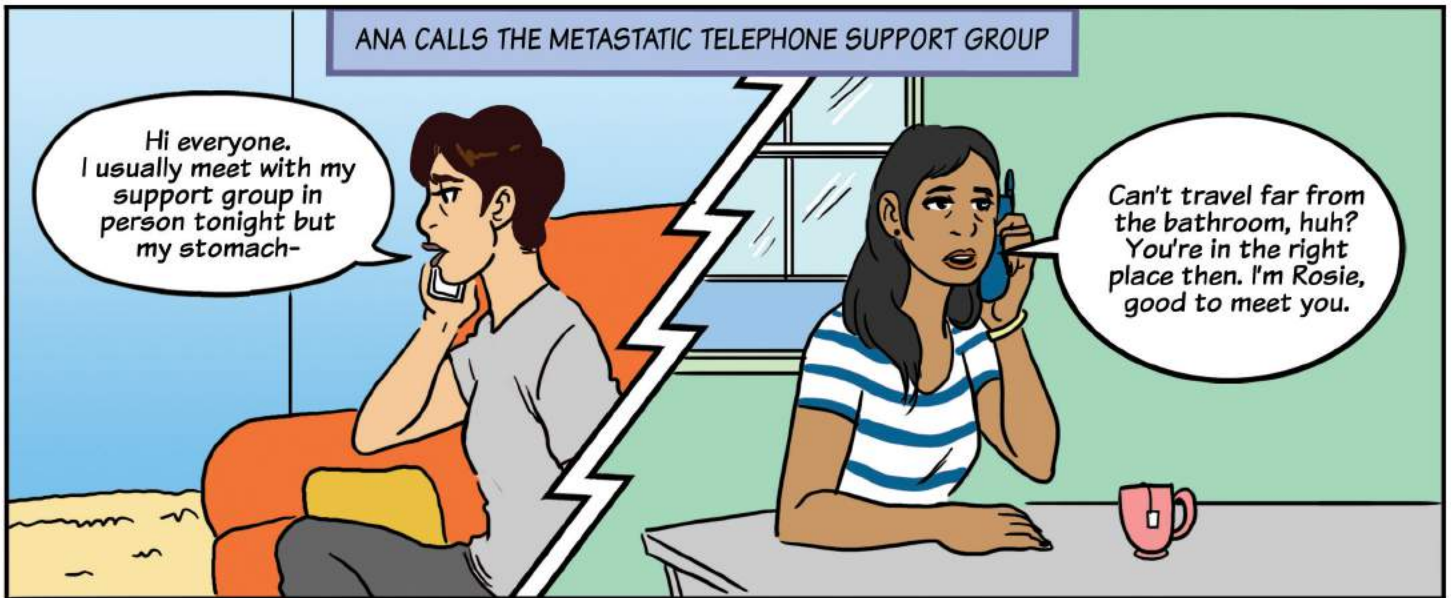
I shouldn't be nervous, but it's different undergoing treatment this time.

How can I help?

You already are. I'm overwhelmed, but I'm glad we talked and that you're here for me.

So am I.

ANA CALLS THE METASTATIC TELEPHONE SUPPORT GROUP



Hi everyone. I usually meet with my support group in person tonight but my stomach-

Can't travel far from the bathroom, huh? You're in the right place then. I'm Rosie, good to meet you.

NEXT DAY AT WORK



How are you feeling?

Pretty good today. I've been able to adjust my work schedule to participate in this clinical trial.

You're going to beat this Ana. When is your last treatment?

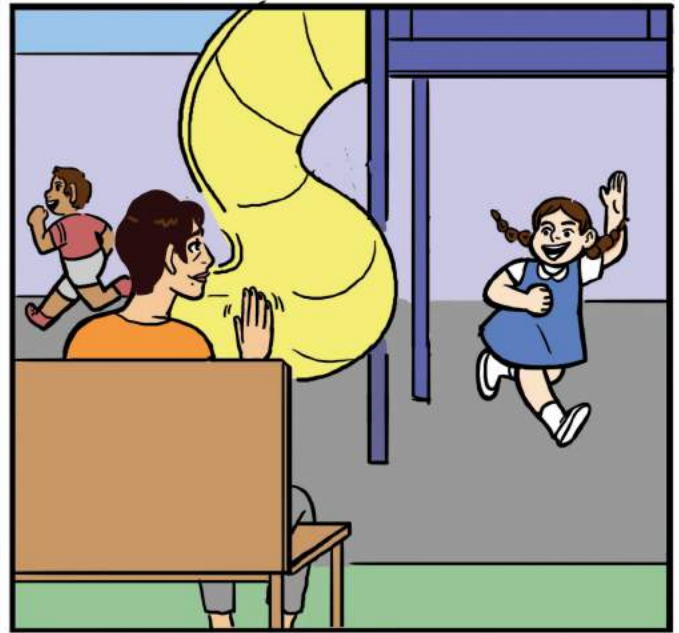
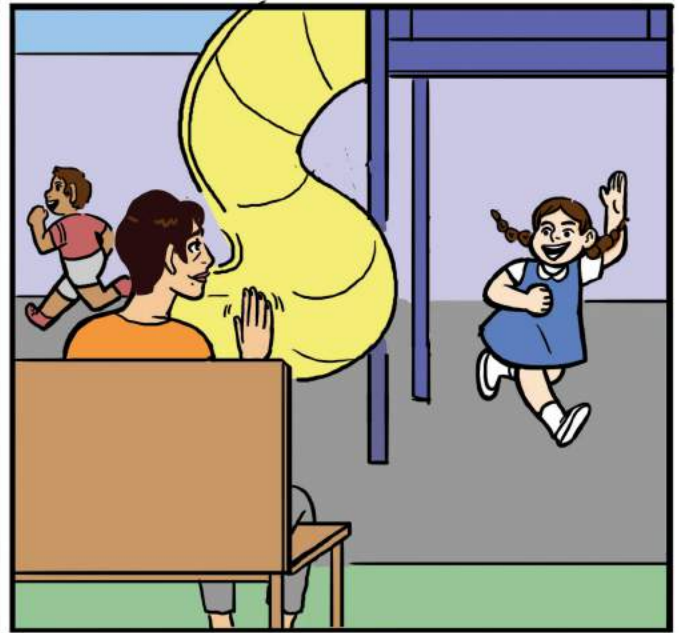
Umm, well actually, metastatic breast cancer doesn't work that way. It's not beatable, it's treatable. I'm on treatment for the rest of my life.

A FEW MONTHS LATER

How are you feeling, Ana?

Some days are better than others. I've been feeling a bit tired lately.

Your tests show no progression, so I recommend you continue your current course of treatment.



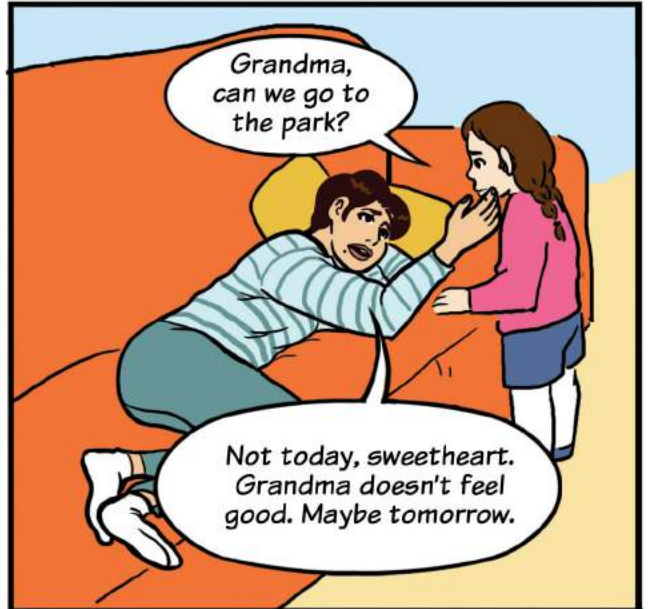
What's wrong? Our cooking isn't as good as yours, but--

No. No. Everything was wonderful. It's the swelling in my hands.



Grandma, can we go to the park?

Not today, sweetheart. Grandma doesn't feel good. Maybe tomorrow.



MONTHS LATER

Ana, I just received results from the last tests. The cancer is showing signs of progression. I'm afraid your treatment has stopped working.

What? But I feel fine!

What happens now?

You'll have to discontinue participating in the clinical trial and we'll see how you respond to a second line of treatment. Let's go over your options.



METASTATIC TELEPHONE SUPPORT GROUP

I finally stopped feeling hopeless about this disease and then my treatment stopped working. How can I live on this rollercoaster?

It ain't fair, honey. I was on my first line of treatment for 16 months before it stopped working.

Ana, did your doctor present new options?

She did. My son is gathering a list of medications and clinical trials we want more information on too. I just don't know if I can keep going through these ups and downs.

Living with metastatic breast cancer feels like it puts the future right in front of me. You have to live in the moment and ride the waves. Next weekend, I'm planning a trip to the beach.

What's one thing you're looking forward to?

My granddaughter's kindergarten graduation. I'm tearing up just thinking about being there.

Sounds like a reason to keep going and continue with your treatment.

WEEKS LATER

I'm heartbroken to announce that Rosie passed away over the weekend.

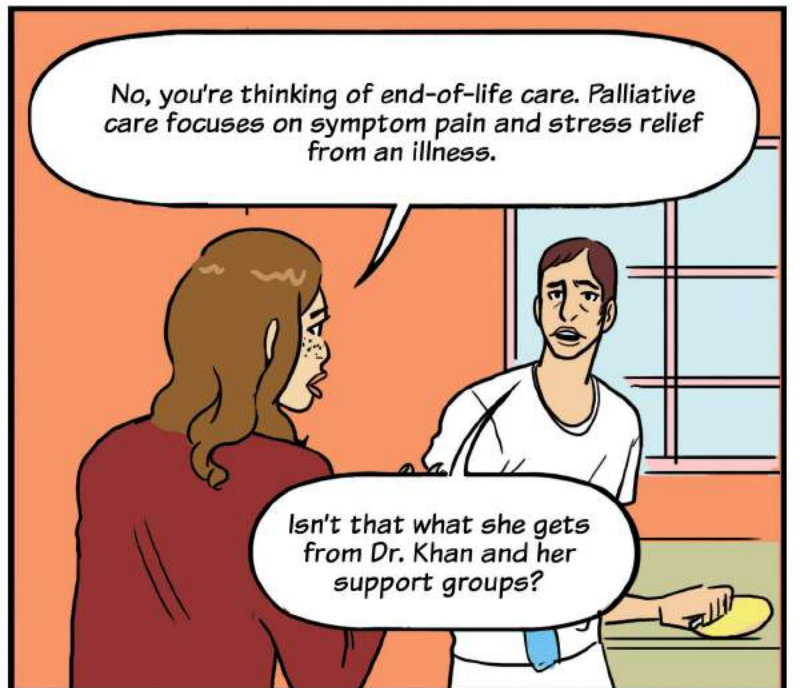
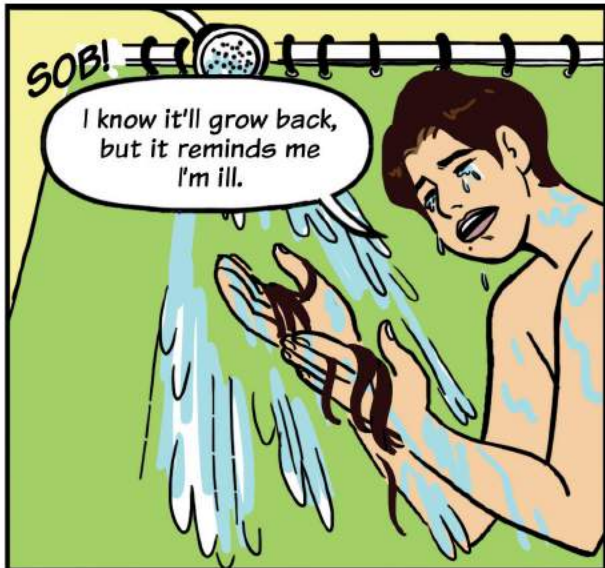
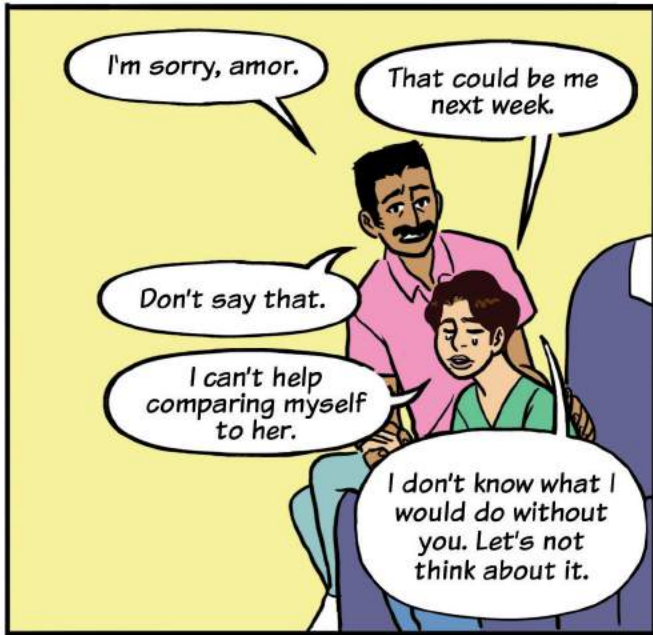
Oh no!

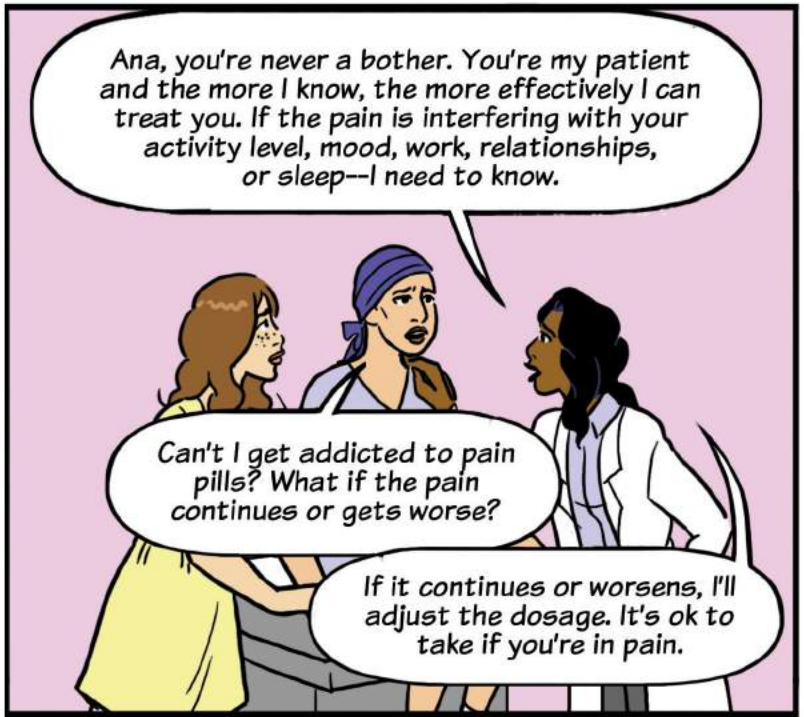
Let's remember our friend and share how this affects us. Remember, we're in this together.

What?

What's wrong?

Ay, Francisco. One of the women in the telephone support group died. She was so sweet and funny. She really helped me when my treatment stopped working.







We're going to miss you, Ana.

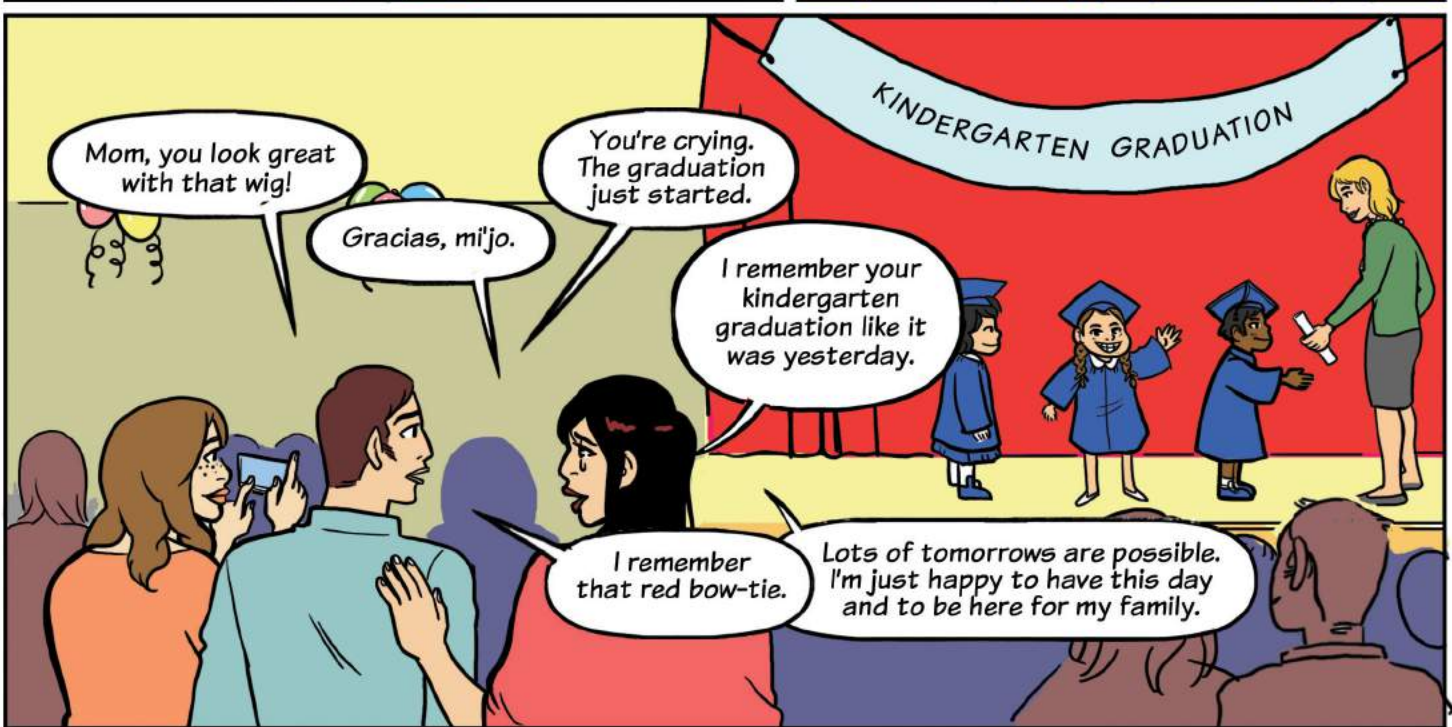
Me too. There are so many things I want to do. Spend time with my family, take care of myself, and travel if I feel up to it. Now seems like the right time.

HAPPY RETIREMENT ANA



We've missed you. How have you been?

There are good days and not so good days, but today I felt good enough to come to the support group.



Mom, you look great with that wig!

Gracias, mi'jo.

You're crying. The graduation just started.

I remember your kindergarten graduation like it was yesterday.

I remember that red bow-tie.

Lots of tomorrows are possible. I'm just happy to have this day and to be here for my family.

KINDERGARTEN GRADUATION

GLOSSARY

Alternative or Complementary Therapies: therapies such as acupuncture, reflexology, aromatherapy, reiki massage, meditation, and homeopathic remedies found to be beneficial by some patients with chronic disease, but have not been fully evaluated.

Biopsy: surgical procedure in which a small piece of tissue is removed from a patient.

CT Scan (Computed Tomography Scan): digitized, detailed, spatially accurate, serial, three-dimensional body images, created by a narrow beam of X-rays.

Chemotherapy: treatment that attacks all cells indiscriminately in the hope of reducing the growth of rapidly dividing cancer cells. Available intravenously or via pill form, this treatment can be prescribed alone or in combination with other treatment.

Clinical Trial: research study using consenting human participants that tests the effectiveness and safety of a treatment.

Diagnosis: process of determining the nature and cause of a disease or injury through evaluation of patient history, examination, and review of laboratory data.

First Line Treatment: the initial, preferred, or best treatment for a disease.

Hormone Therapy: prevents cancer cells from receiving estrogen, thus halting their growth. This is usually the first treatment option for hormone receptor-positive patients.

Hospice or End-of-Life care: a program that provides palliative care and attends to the emotional and spiritual needs of terminally ill patients at an inpatient facility or at the patient's home.

Informed Consent: a patient's consent to a medical or surgical procedure or participation in a clinical trial after being properly advised of the facts and risks involved.

Metastatic Breast Cancer (also called Stage IV or Advanced Breast Cancer): breast cancer that has spread to other organs in the body (usually the bones, lungs, liver or brain). Despite spreading to another part of the body, it is considered and treated as breast cancer.

PET Scan: a computerized diagnostic technique that uses radioactive substances to examine structures of the body.

Palliative Care: an approach to health care that is concerned primarily with attending to physical and emotional comfort rather than a cure.

Pathology Report: a document that contains the diagnosis determined by examining cells and tissues under a microscope.

Prognosis: a forecast of the probable course and/or outcome of a disease.

Progression: the process of spreading or becoming more severe.

Quality of Life: a person's well-being, which may include physical, emotional, and social dimensions, as well as stress level, sexual function, and self-perceived health status.

Radiation Therapy or Radiotherapy: targets the tumor to kill the cancer cells and can provide relief from the pain associated with the cancer.

Second Opinion: a patient privilege of requesting an examination and evaluation of a health condition by a second physician to verify, revise, or challenge the diagnosis and proposed treatment by a first physician.

Subtype: the smaller groups that a type of cancer can be divided into, based on characteristics of the cancer cells.

Targeted Therapy: Medications that help stop cancer from growing and spreading by targeting specific genes or proteins.

Tumor Marker: substances found at higher than normal levels in the blood, urine, or body tissue that can indicate cancer.

DEDICATED EXPERIENCED SUPPORT

SHARE

for women facing breast and ovarian cancers

SHARE/LatinaSHARE

844-275-7427

www.sharecancersupport.org

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