

Metastatic Breast Cancer

Questions to Ask if You Are Considering Medical Marijuana

BY ERIC FITZSIMMONS

Jessica* has the kind of story you often hear when asking about medical marijuana, forms of the cannabis plant that are used as a complementary therapy to manage breast cancer treatment side effects such as nausea, pain and loss of appetite. Studies of the effects of medical marijuana and its active chemicals — called cannabinoids — are few, and their findings are mixed. But there are many people like Jessica who say medical marijuana is helpful for them.

The 42-year-old from Massachusetts was diagnosed with de novo metastatic breast cancer in 2013. With the diagnosis came anxiety, a common problem, and she was given the anti-anxiety medicine lorazepam (Ativan) to help manage it. But she did not like how it made her feel.

“We did acupuncture, medication, mindfulness and yoga — so much stuff to get my mind to rest. Nothing worked, so I finally tried medical marijuana. It has been a game changer for me,” Jessica says.

Medical marijuana’s unique legal status makes it difficult to find reliable information about how to get it and how to use it. Because it is banned by the federal government, there is still much that we don’t know about medical marijuana’s effects, from how well it works for different side effects to how it interacts with other medicines and other conditions.

“There is an enormous variety [of types of medical marijuana and marijuana products] and they have different contents of minor cannabinoids, terpenoids, as well as cannabinoids,” says **Mellar Davis, MD, FCCP, FAAHPM**, a medical oncologist and specialist in hospice and palliative medicine at Geisinger Medical Center in Danville, Pennsylvania.



If you are considering medical marijuana, there are important questions you should ask — about the law, about your treatment, about yourself and about medical marijuana — before you begin.

Is It Legal?

Medical marijuana is allowed by law in specific states, but the federal government still considers any form or part of the cannabis plant illegal. While you can generally use medical marijuana in the appropriate states without fear of arrest, the federal law can have effects on other aspects of your life.

Joanna Morales, Esq., CEO of Triage Cancer, says that under federal law, employers have the right to fire you if you test positive for marijuana, even if it’s used for medical reasons. Landlords and organizations you volunteer with may also have rules against marijuana use. Learning the policies of any organizations you are involved with may help you avoid later conflict:

- Check your state’s medical marijuana laws, employee handbook or employment contract to find out what’s allowed at work
- Read over your lease agreement, building or condo by-laws or code of conduct, or ask your landlord how it could impact your rental
- Ask about the policies of other organizations you’re involved with so you know where they stand

*Some identifying information withheld by request



With you, for you.

Correction: In “CDK 4/6 Inhibitors: What’s New and What’s Left to Learn” from the Spring 2018 issue of *Insights on Metastatic Breast Cancer* we reported that abemaciclib can cost \$5,000 a month. Abemaciclib actually runs about \$5,000 for 14 days of medicine, or \$10,000 for a full month. We apologize for the error.

If you have trouble getting a clear answer from documents you have available, you may have to ask your employer, landlord, or volunteer lead directly.

“The other issue people don’t have a good understanding of, is that they hear that medical marijuana is now legal in their state, but it [can be] limited to certain forms of medical marijuana or limited to certain medical conditions,” Ms. Morales says. For example, there are many states that allow medical marijuana only for epilepsy, a common seizure condition, not for breast cancer.

The state can also limit the type of marijuana you can use. Different varieties of the plant have higher or lower levels of two chemicals, called cannabinoids, which have shown some use managing health conditions or side effects: Delta-9-tetrahydrocannabinol, called THC, and cannabidiol, called CBD.

THC and CBD have different effects. THC appears to have more impact on some side effects, but it is also the chemical that gives the feeling of being high.

Ms. Morales says that some states only allow CBD oil, a chemical in marijuana that does not give the feeling of being high, but researchers don’t know whether CBD without THC has an effect on pain, nausea or the other side effects that would help someone in breast cancer treatment.

Can It Help Me?

A long list of possible benefits, plus the mystery left by the lack of research data, has given people high hopes for what could be accomplished by using medical marijuana. But Dr. Davis warns against overemphasizing the benefits.

For the side effects it does seem to help — such as nausea, pain and appetite loss — there are other medicines available that have been well studied and FDA approved. In general, doctors have more information on interactions and side effects of approved medicines than on medical marijuana. “The difficulty is you don’t really know what you’re getting,” Dr. Davis says of medical marijuana. “A physician can recommend it, or certify, but he can’t prescribe it.”

Jessica found the information at her local dispensary helpful, but also says that people need to be careful.

“They need to know why they want to use it,” Jessica says. She gets one kind higher in CBD for pain and one higher in THC for sleep, but avoids one popular variety of the plant because it can make anxiety worse.

Your medical team knows your health history and cancer therapies, so speak with them first about side effects. They may suggest another medicine or therapy before marijuana. If you want medical marijuana for a specific side effect, start that conversation with someone on your healthcare team before heading to a dispensary, says Ms. Morales.

How Do I Tell My Doctor?

Some people still feel the stigma of asking about marijuana. It’s best known as a recreational drug and you may fear your doctor not taking you seriously. If you are not comfortable going directly to your doctor, Ms. Morales

recommends finding other members of your healthcare team. A nurse or social worker may be able to help facilitate the conversation.

Kimberly*, a 41-year-old living in Washington, D.C., was diagnosed with stage IV, metastatic breast cancer in her bones 3 years ago, including painful lesions on her spine. Her oncologist referred her to a pain management specialist, but Kimberly found the specialist wasn’t listening to her concerns.

“When you say you’re stage IV and you have nerve pain, all they want to do is give you oxy[codone] or morphine, and when I had taken that initially in 2015 it was awful; I had such bad side effects,” Kimberly says.

Kimberly tries to manage her pain through yoga and acupuncture, which is enough most of the time. Now and then, though, the pain and stress are too much and she wants something to help ease the pain.

She found a pain specialist who better talks through her concerns and suggested some ways to manage pain without opioids like oxycodone. Looking into those options on her own, Kimberly found information on medical marijuana. She decided to apply for permission from Washington, D.C. to get medical marijuana, but has used it only a few times when the pain was too much.

A recent survey of oncologists found 46 percent recommended medical marijuana in the last year, but less than 30 percent said they felt they knew enough to recommend it. Ms. Morales says if your healthcare team doesn’t have answers, ask where they recommend you go to get the information you need. If they are dismissive, bring studies that support your interest. Ask your doctor to discuss them with you.

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How Do I Get It?

Your state government should tell you what you need to do to get medical marijuana, if it is allowed in your state.

In many cases a doctor must certify that you have a disease eligible for medical marijuana in your state. You may have to go to a separate doctor licensed to make that recommendation if your doctor is not certified to do so. The steps to get permission — whether it is called registering, certifying or getting a license — is specific to your state, but you will likely need a document saying you are legally allowed to have and use medical marijuana.

Speak with your doctor and check your state government website for more information.

In Washington, D.C., Kimberly found the process easy, but expensive. Neither the brief appointment with a doctor who specializes in medical marijuana certifications nor the medical marijuana itself is covered by insurance. On top of that, she had to pay a fee to register with the city. It's a process she will have to repeat every year to stay eligible, paying for the appointment and the registration out-of-pocket each time.

After registering, medical marijuana can be bought at a dispensary. Dispensaries are often the place people go to learn how to use medical marijuana. Many dispensaries have information and programs about medical marijuana to help you choose an appropriate variety of the plant and form in which to take it.

Allison*, 60, of Maine, was diagnosed with early-stage breast cancer in 2010 that was found in 2011 to have traveled to her liver. She hesitated to register with the state of Maine, worried about the stigma of being seen at the local dispensary. But once she did, Allison found a dispensary that provided resources and support, which included an educational consultation on her first visit.

Be in contact with your doctors throughout your marijuana use, Dr. Mellar says. Dispensaries, even good ones, do not know your full medical history and are not your doctor.



Medical marijuana interacts with some medicines and often contains a fungus that could be dangerous for people with immune systems that are weaker because of treatment.

Medical marijuana is a tool to help manage your side effects. Your concerns are important and it's OK to push for more information on things you think may be helpful. Kimberly has gone to multiple programs to learn more about medical marijuana and found that she isn't alone. "Every single [program] that I've been to has been packed," Kimberly says. "People want to know." 🍌

*Some identifying information withheld by request

TALKING ABOUT STAGE:

A Q&A With Briana Sykes and Sasha Milicevic

BY NICOLE KATZE, MA



Sasha Milicevic and Briana Sykes

The way people describe a breast cancer experience often differs depending on the stage of cancer under discussion. When it comes to early-stage disease, battle and victory language is prominent: people say things like "fight the fight" and "win the war." But when it comes to stage IV, metastatic breast cancer, those words can take on a different tone and leave people living with the disease feeling left out or alone. The Facebook group **MBC Advocacy and Support — open to all stages and allies!** was founded with the goal of improving communication between those diagnosed with early-stage and metastatic disease so that everyone can "work together to improve and extend the lives of people with MBC."

LBBC's editor and manager of content development, **Nicole Katze, MA** interviewed **Briana Sykes** and **Sasha Milicevic** about bridging the gap. Briana is a volunteer in LBBC's Hear My Voice outreach volunteer program. Sasha is a co-founder of the Facebook group with **Beth Caldwell**, a graduate of Hear My Voice who died in 2017. Sasha was treated for early-stage disease 5 years ago. The group now has 1,200 members.

Nicole

Describe the tension between "metsters" and "early-stagers." Why is this an important issue?

Briana

Some people with metastatic breast cancer feel ghosted by those with early-stage disease. I have noticed this when someone with early-stage is done with their treatment. They want to move on with their lives and celebrate their survivorship. There are all kinds of events and rallies celebrating their fight with no mention of those of us who are dying.

I have [also] heard that those with early-stage find those with metastatic disease scary, [because] it is their worst nightmare. I recently spoke with an organization that developed a support group that was mainly early-stage. They admitted that the group doesn't have any metastatic men or women in it and [that] they realize they offer minimal support to those with metastatic disease. The director of the organization told me, "[the people with MBC] make everyone uncomfortable, but we can't kick them out." It just seems like there is less support for those of us with metastatic disease, [and] it infuriates us because we want to live and we need help. Sometimes that may come off as angry or bitter, but can you blame us?

Sasha

Briana touched upon quite a few things. Most oncologists don't tell early-stagers that 1 in 3 will eventually develop metastatic disease. They emphasize high survival rates and low mortality. If your doctor is telling you that your chances of recurrence (let alone metastases) are low, other patients contradicting that can indeed come off as scary, negative or bitter. What many of my early-stage sisters don't understand is that those women [already diagnosed with MBC] are providing us with knowledge that we need. It is unsettling to hear that 1 in 3 early-stagers will develop mets and that nothing you do changes your odds. It is a scary notion to adjust to because we want to be in control, but once you accept it you can actually start working on making a difference.

Nicole

What would you like to see people from these stages doing differently when they interact with each other?

Briana

I do think that sometimes those of us who are metastatic are hard on early-stagers. I knew nothing about metastatic

breast cancer before it happened to me, and not all doctors [educate] their patients on the statistics of becoming metastatic or what that means. I remember when I wasn't staged yet I wasn't willing to look up what stage IV meant, because clearly that wasn't going to happen to me and I didn't want to know. I think we need to give early-stagers a little more grace and be willing to educate them, and hope that when they know more they will be willing to fight for us, too. Support research! Make sure we are not ignored.

Sasha

At this point I have quite a few friends from the MBC community, and I have never been met with anything but kindness and support [from them.] There are so few early-stagers advocating for the MBC community. My messages are mostly for women like me, early-stagers:

- Learn as much as you can about MBC. Knowledge is power and it can happen to you as well.
- Supporting our metster sisters means supporting ourselves because we don't know what's ahead of us. It's entirely unfair to let metsters fight the fight [alone] when they most likely will not benefit, but we might.
- Most important: listen to what they have to say. Ask what you can do to help.

Nicole

What's the benefit of building a stronger, more unified breast cancer community?

Briana

We already know that the breast cancer community can raise big dollars. [But] in the past couple of decades that money has been devoted to early detection, awareness or other questionable ventures. Early detection and awareness don't help people who are already metastatic. We are left in the dust. If we could just work together to make sure the money is going to research to save lives, it would benefit everyone. Call me selfish, but I would much rather donate for better treatment options to help people live longer than donate for a more comfortable mammography machine.

Sasha

A stronger community can influence public policies and direct money where it is needed: toward finding the cure for metastatic breast cancer. A strong community can educate the public about important issues. There's a lot that we can learn from the LGBT community and their struggle to redefine AIDS and fund research on HIV/AIDS.

A stronger community that includes not only [diagnosed] women but also women who never had breast cancer will emphasize that we are all in this together and that we can make a difference. 🍷