

METASTATIC BLADDER CANCER

Tips and tools to help
you take control of your
cancer experience.

By  Dr. Joe
explains™

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About Dr. Joe Explains



Understanding is power, and clarity is confidence.

Board-Certified Oncologist and Hematologist Dr. Joe Hofmeister knows there is more to caring for a patient than just giving recommendations and prescribing treatment. He developed simple, useful analogies to help his patients overcome their fear of the unknown and provide a simplified explanation of their medical condition. When he saw how helpful these analogies were, Dr. Joe put together, what we call, Dr. Joe Explains.

We are a team of medical and non-medical contributors—experts, nurses, patient advocates, writers, and designers—who work together to develop resources for patients and their families, friends, and caregivers.

Dr. Joe Explains is devoted to creating materials that guide patients and loved ones through life-changing diagnoses. We provide essential knowledge, paired with compassion and support, which gives patients the basis to make decisions with confidence.

Dr. Joe Explains offers a full-length book and quick-read booklets that provide patients and their loved ones with basic explanations of medical processes using easy-to-understand language and impactful visuals. They include definitions and pronunciations of terms, take home points, and questions to ask the doctor.

Visit www.DrJoeExplains.com to see the growing list of topics, conditions, and procedures that Dr. Joe and his team address.



SECTION 1:

Getting Started

Communication is key.

You probably know that strong communication is the foundation of any successful relationship. But having good, productive conversations is much easier said than done—they take a lot of work, strength, and courage.

When you face a cancer diagnosis and step into the world of medicine, conversations can get even more challenging. No matter where you are in your journey with metastatic bladder cancer, discussing issues, side effects, and concerns can be uncomfortable. With all the jargon, terms, treatments, and procedures, it's common to get overwhelmed and not know what to say or where to begin.

The good news is, there's something that can make all of this a little less intimidating—understanding the whys, the hows, and the whats.

Why do you need to participate in your care? How do you overcome feelings or concerns? How do you start conversations? What questions do you ask? Who do you ask? *How do you know what matters?*



We're here to answer many of your questions and share some tools and tips to help you navigate your diagnosis. However, as you flip through these pages, we encourage you to keep the following in mind:

1. *Remember you're in charge.* Your support team is there to help you. Don't be afraid to participate and advocate for yourself. If it's important to you, it's important.
2. *Be open.* This book is full of valuable tips and tools to help you feel more confident. Take everything in, and if something sounds useful, give it a try.
3. *Try to be patient.* Speaking up takes courage, but having difficult conversations might become a little easier with patience and practice.
4. *Keep reading.* We firmly believe that knowledge is power, and the more you know, the better off you'll be.

Ready? Let's get to it.





SECTION 2:

Let's Talk

Tips for communicating
with your medical team.

Whether you're managing side effects, making treatment adjustments, or selecting a new medication, having open and honest conversations with your support system is vital.

There's a lot to talk about throughout your journey with metastatic bladder cancer, and you'll want to be prepared. Luckily, we're here to help.

In the next few sections, we're going to share some questions to ask, discussions to have, and actions to take to help reduce your stress and ease your worries. But first, we're going to provide tips to improve conversations with your medical team.^{1,2}

Start with who you know.

Conversations can be easier to have when they're with someone you know and trust. For example, if you have a good relationship with one of your nurses, start the conversation with them. He or she may answer your questions, recommend you discuss the matter further with someone else (like your doctor or social worker), or simply offer words of encouragement.



Slow down the conversation.

Being able to understand your medical team is crucial. If you don't understand something, politely ask the person to pause, repeat what he or she said, or rephrase the information. Slowing down the conversation will get everyone on the same page and can even save time in the long run.



Consider bringing someone to your appointments.

Try to avoid attending appointments alone. Having a trusted friend or family member in the room or on the phone can really help—the more people who hear what gets said, the better. Regardless of who you bring, it's also a good idea to have them take detailed notes you can reference later.

Schedule additional appointments.

If you feel like everything is moving too fast, you need some time to think, or you still have more questions, schedule an additional appointment with your medical team before leaving the office. You don't need to make big decisions on the spot, and if you want to do some research, get a second opinion, or consult your family and friends, that's okay. Just make sure you understand exactly how much time you have to make your decision.

Remember: Your medical team is there to support you and answer your questions; they don't want you to feel rushed.





SECTION 3:

The Day-to-Day

Speaking up about side effects.

Sharing and discussing your treatment side effects with your medical team can be challenging. However, speaking up about your experience is important to get the best care possible.

Start by being honest with your medical team, caregiver, family, and yourself.

Be honest not only about how you're feeling, but also about your treatment goals. Doing this will give you and everyone you love comfort in understanding your wishes and choices. Your doctor will also be able to adjust his or her recommendations based on these insights.

Keeping a journal or notebook is a great way to track your thoughts and experiences.

Write down your feelings, specific side effects, changes you notice, and any questions you have. Then, remember to bring the notebook to your appointments. It's a lot easier to start conversations when your notes are in front of you. It's also reassuring to know all of your questions were answered at the end of the appointment.

Some questions can wait, but call the doctor right away if you ever experience any of the following, as these side effects can be warning signs of significant issues that may need immediate attention.

Fever over 100.4°F, nausea, vomiting, dehydration, diarrhea, rashes, unusual pain, severe or persistent headaches, significant weakness, abdominal or chest pain, difficulty urinating, burning while urinating, blood in the urine, changes in breathing, changes in thinking, severe depression or anxiety, or feelings of confusion or sleepiness.

Even though that's a pretty long list, it doesn't include everything. Each type of treatment has unique side effects that you may need to know about. *Ask your doctor what else you should add.*

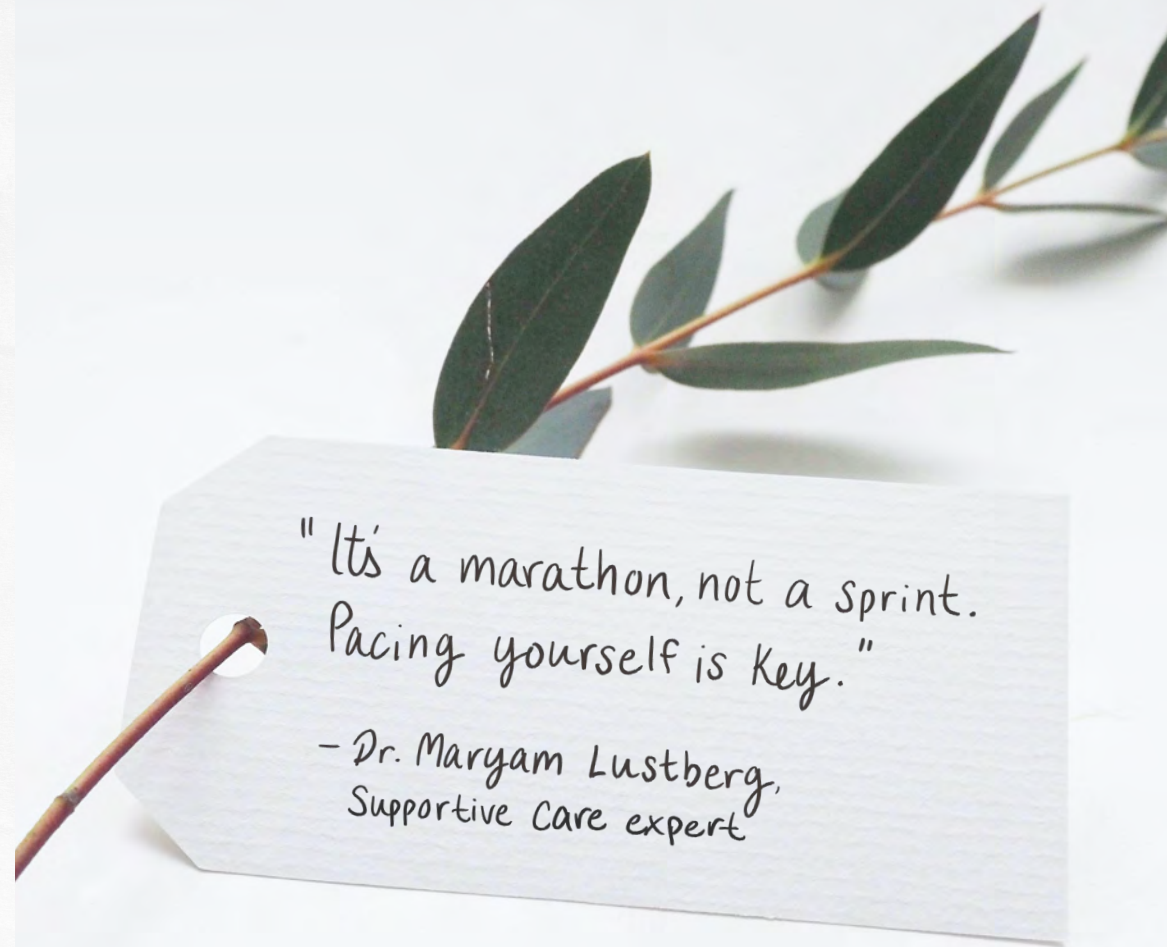


Treatment is about helping you feel the best you can throughout your cancer experience. And while most side effects are mild and tolerable, they can move from annoying to severe and start impacting your day-to-day life.

When this happens, it's essential to speak up. Patients with advanced cancer can be hesitant to tell anyone they're experiencing side effects or problems. Sometimes, they feel like it's their fault (it isn't!). Other times, they feel like if they say something, their medication will get reduced, put on hold, or stopped.

However, your doctor may be able to make everything more manageable by adjusting your treatment plan. Plus, he or she might have some tips to help relieve the side effects.

A dose reduction or pause in treatment doesn't mean that a treatment will stop working. It might just be what you and your body need.





SECTION 4:

Exploring Your Options

How to ask questions and learn more.

Making decisions about your next treatment can be tough, but talking about your options and doing research can really make a difference.

To help you get started, let's go over some important questions to ask, and then we'll give you a few tips to get the most out of your research.

To gain more insight about your options, ask your doctor the following:

- What do you think the best treatment option(s) is for me?
- What are the chances this treatment will control my cancer?
- Will this treatment add any new problems or side effects?
- Am I eligible for any clinical trials?
- Are there any new treatments available that I should consider?

Next, try doing some of your own online research using credible sources to learn more about recommendations, available treatments, and clinical trials. To find the most relevant information, you'll need to know the following key details about your cancer: the type of bladder cancer, stage, biological markers, and line of therapy.

Let's break it down.



Type of Bladder Cancer

There are many types of bladder cancer, but the most common is called transitional cell carcinoma (TCC) (urothelial carcinoma). *Note: Even though we've been using the term "bladder cancer," others might use the newer term "urothelial cancer."*

Stage

Staging is the process of clearly describing how advanced a cancer is using several measurable characteristics. Since you have **METASTATIC BLADDER CANCER**, we can assume that you are in stage 4 (the most advanced stage).

Biological Markers

Your cancer may also have **BIOLOGICAL MARKERS**, such as **MUTATIONS**. To find out if the cancer has any of these markers, your doctor may need to obtain special testing on a sample of the cancer. If specific markers are found, more treatment options may be available to you.

METASTATIC BLADDER CANCER

Bladder cancer that has spread throughout the body

Line of Therapy

If you're choosing your first treatment for metastatic bladder cancer (not including the treatments around the time of your initial diagnosis), then you're most likely selecting a first-line therapy for metastatic disease. As you move from treatment to treatment, your line of therapy will increase. So, you'll move from first-line to second-line to third-line, and so on.

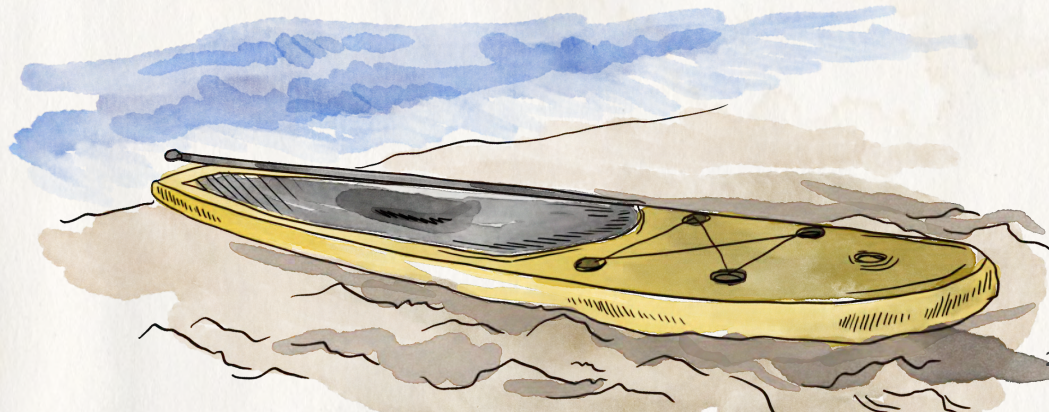
If you're confused or have questions about any of these details, ask your medical team. They can clear it all up for you.

BIOLOGICAL MARKERS

Tumor characteristics used to determine the best treatment options and predict outcome

MUTATION

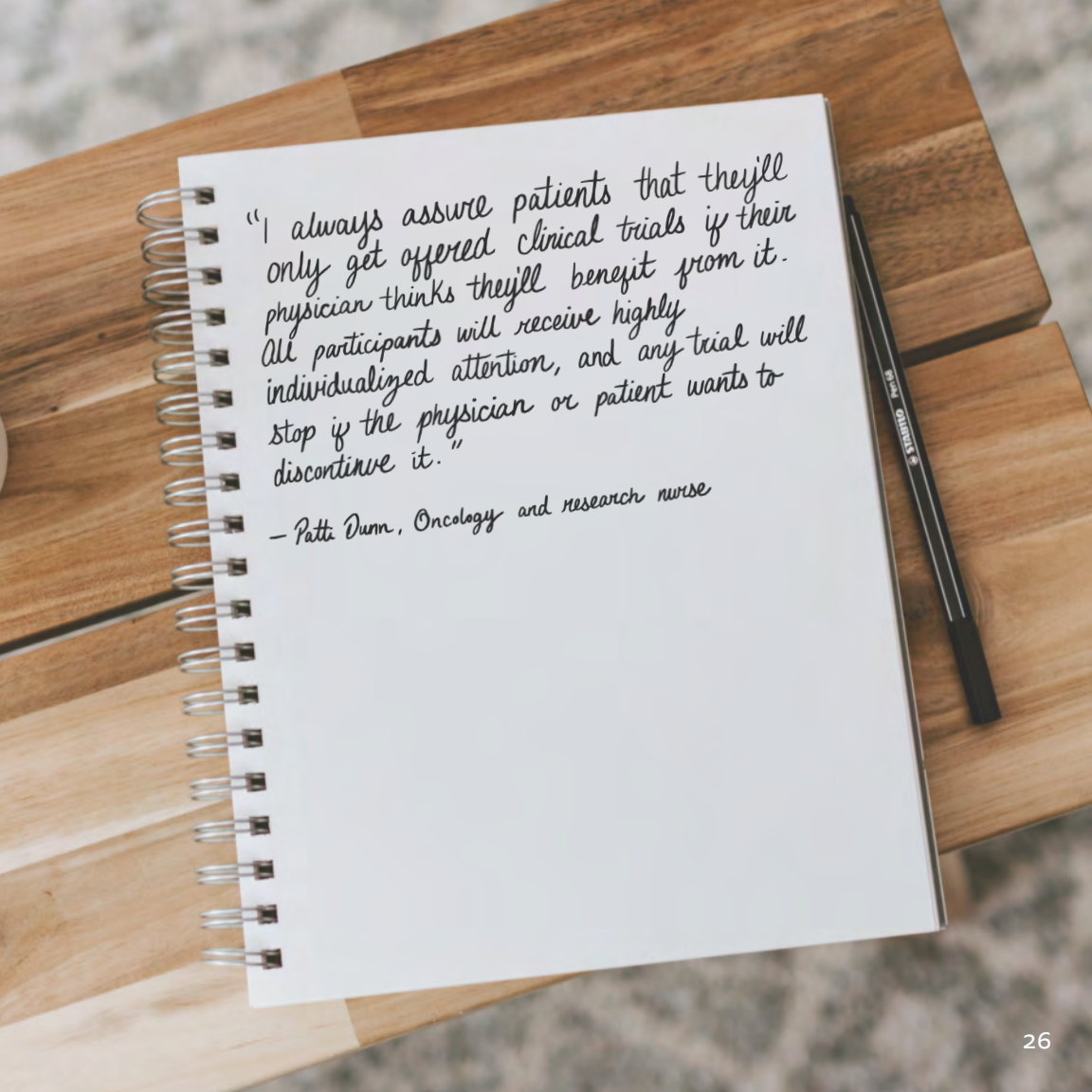
A change in DNA that can lead to or cause cancer



Don't forget to look into clinical trial options too.

Clinical research trials are so valuable for so many reasons.³ First, they may give you an additional treatment option that you may not have had if you didn't participate. Second, it gives you an opportunity to help others by proving if new treatments work. Lastly, clinical study patients get a lot of attention and care.

Clinical trials can be very beneficial, but they aren't for everyone. Your medical team will be able to provide more information and address any concerns you may have about clinical trial options.



"I always assure patients that they'll only get offered clinical trials if their physician thinks they'll benefit from it. All participants will receive highly individualized attention, and any trial will stop if the physician or patient wants to discontinue it."

- Patti Dunn, Oncology and research nurse



SECTION 5:


Keeping it Straight

Tips for staying on track with treatment.

It's common for patients with metastatic bladder cancer to take several medications to manage multiple conditions.

Whether you're taking medication to treat the cancer, relieve side effects, or control another condition, it's crucial to follow your doctor's directions.

If you're confused about treatment scheduling or dosages, always check with your doctors, nurses, or pharmacists. They'd much rather prevent or address a problem early on than fix one later.



We know it can be challenging to keep everything straight. Luckily, we have some simple tips to help you stay on track.



Keep a treatment calendar.

Create a calendar with all doctor and treatment appointments, as well as the timing and dosages of your oral medications (including supplements and over-the-counter medications). If calendars aren't for you, at the very least, you should try to have a list of all of your medications and the timing for each dose. *Keep this information on a piece of paper, your phone, or use another creative method—whatever works for you!*

Whip out the sticky notes.

Write what each medication is for, how much to take, and when you need to take it on a sticky note and attach it to each pill bottle. *Don't forget to identify which medications are only taken as needed—you can even color code the paper to easily differentiate the two types.*

Use a pillbox.

Consider using the details from the sticky notes to fill a pillbox with all your scheduled medications. No matter how organized you are, the last thing you want is to take the wrong pill, the wrong amount, or forget you already took it. *Life is busy, things happen, and calendars, sticky notes, and pillboxes can be great tools to help simplify your life.*

Bring important information to appointments.

Bring a medication list, your pill bottles, contact details for all your providers, and any other important medical information to your appointments. Doing this will help keep your doctors on the same page and prevent mishaps. Make sure your medication list includes all current prescriptions, supplements, over-the-counter medications, and treatments that aren't pills. *If you need assistance with this task, ask your caregiver or a friend to lend a hand.*

Don't run out of medication.

To continue taking your medications, you need to have enough of them. When you're running low on medication, tell your medical team or pharmacist sooner rather than later. If you're comfortable, you can try to use your online patient portal to ask for refills or have your pharmacist send a request. If you don't hear back, call someone on your medical team—this is especially important for pain medications. And if you aren't able to afford medications, you can talk to someone on your medical team about that, too—they might be able to enroll you in a patient assistance program. *You aren't alone; there are plenty of options and organizations available to help!*





SECTION 6:

Asking for Help

Who to turn to for additional support.

While we've covered a lot of information and provided many tips and tools, we're guessing you still have a few more questions.

The good news is, there are plenty of people and resources who can help you along the way.

Your medical provider and team—which can include your oncology nurse, nurse navigator, nurse practitioner, physician assistant, and physician—are always a great place to start. They can answer ongoing questions about your disease, treatment, expectations, and more.

Other professionals can provide more focused support for your specific needs as well.

If you're struggling with symptom management (like pain or depression), quality of life issues, or establishing treatment goals, consider talking to a palliative care specialist, psychologist, psychiatrist, mental health counselor, or non-profit organizations (like Cancer Support Community). Additionally, you may feel more comfortable discussing concerns about sexual function with a urologist or gynecologist.

If you have questions that aren't related to medical care—like financial concerns, billing, estate planning, or insurance—there are people who can help with that too. Social workers, financial counselors, and lawyers are all experienced professionals who can assist with many common issues.



What you're going through might be very challenging, but the most important thing to remember is that you aren't alone. You have an entire medical team and support system ready to help and encourage you. *Asking for help can be tough, but strong communication, good conversations, and reliable knowledge are power.*



Take Home Points

- Remember you're in charge. Your support team is there to help you. Don't be afraid to speak up and advocate for yourself. *If it's important to you, it's important.*
- To improve conversations with your medical team, start by talking to someone you're comfortable with, slow down the conversation, consider bringing someone to your appointments, and schedule additional appointments if you need them.
- Bring a journal with notes about how you're feeling, specific side effects, changes you notice, and any questions you have to all appointments.
- If your doctor suggests a change in treatment, ask why he or she made this recommendation and talk about clinical trial options. You can also try doing some of your own online research using credible sources.
- To stay on track with your treatment, consider keeping a treatment calendar, attaching important information and instructions to each pill bottle, using a pillbox, and bringing important information to all your appointments.
- Asking for help can be tough, but strong communication, good conversations, and reliable knowledge are power.

What Should I Ask My Doctor?

1. Is there any additional information I need to know?
2. Can we discuss this topic further before I make a final decision?
3. Do I qualify for any clinical research trials?
4. Do you have any tips for managing my side effects?
5. Who should I call if I'm having problems?
6. What other people, support groups, and resources are available to me?



What I am thinking...

My notes, questions, and thoughts.





Resources

Our favorite resources for bladder cancer

Bladder Cancer Advocacy Network
bcan.org

Cancer Support Community
cancersupportcommunity.org

CancerCare
cancercares.org

Triage Cancer
trriagecancer.org

Cancer + Careers
cancerandcareers.org

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Living with metastatic bladder cancer can be hard. Sometimes talking about it is even harder.

What should you ask? Who can you turn to for support? How do you keep it all straight? These are just some of the questions that might be swirling around in your mind, making it difficult to see a clear path forward. A little more understanding about your options and some practical suggestions can help give you clarity and a better sense of direction. Find out how to ask about treatment options, speak up about your experience, and have better conversations with your medical team. The road ahead may seem overwhelming, but you aren't on this journey alone.

Inside this booklet, you'll learn:

- How to communicate better with your medical team
- Ways to keep track of medications and appointments
- When to speak up about side effects
- Where to go for additional support



Learn more at www.DrJoeExplains.com



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