

Say Something:

Navigating Challenging
Bladder Cancer Conversations

A Letter from Marilu Henner and Michael Brown

We had met as freshmen in college, and then met again decades later. The second time, we knew right away we were meant for each other.

We had only been together for a few weeks when I noticed spots of what looked like blood in the toilet. Some people might have hesitated to bring up such a potentially embarrassing topic, especially so early in the relationship. But my concern for Michael's health trumped any hesitation, so I asked him about it.

Michael told me he had noticed blood in his urine for two years. His doctor had told him not to worry about it. I wasn't convinced, so he promised to see another doctor. As it turned out, Michael had bladder cancer.

We went to see several doctors, and listened to and evaluated each of their recommendations. Ultimately, we went with the treatment recommendation that was right for us.

We are big believers in the power of healthy living, medical advancement and, last but not least, open communication. Michael allowed himself to be vulnerable and intimate, while I used kindness, sensitivity, humor and strong listening skills; together, we got through a very challenging time by being open with each other.



Photo credit: Jeff Katz Photography

What if I had been too embarrassed or uncomfortable to ask about those spots of blood in the toilet? What if we had held back in talking to our doctors or to each other about Michael's condition and what to do about it?

We are glad we don't have to find out.

If you face bladder cancer, don't try to go it alone or in the dark. Be open about your questions, your feelings and your concerns with your partner, your doctor and others who can give you help and support.

This guide was created to help you do that.

Sincerely,

Marilu Henner and Michael Brown



Navigating Challenging Bladder Cancer Conversations: An Introduction

Like other “below the belt” cancers, bladder cancer can be uncomfortable to talk about because it can cause changes in intimate parts of the body, such as embarrassing symptoms, urinary function and one’s sex life and sexuality. That’s one reason so many people know so little about bladder cancer even though it is the sixth most frequent cancer in the U.S.^{1,2}

Difficulty in discussing bladder cancer can take a direct toll on people living with this disease. To effectively diagnose, treat and manage bladder cancer, it is important for you and your partner, doctor and others close to you to talk about and understand your situation. Without good communication, you may not get the support you need to make the best decisions for your health and well-being.

“It’s important to be open about the issues and not try to hide them.”

This discussion guide will help you talk about bladder cancer with your loved ones, doctors, nurses and others. Two bladder cancer patients, Lou and Kevin, along with their wives, Evon and Marcia, respectively, offered insights regarding their bladder cancer experiences.

“Too many people feel shame or embarrassment about it,” said Kevin, who is living with bladder cancer. “It’s important to be open about the issues and not try to hide them.”

When everyone understands your situation, they can help you make decisions and cope with your condition.

Talking to Your Partner – Where to Start

You may feel embarrassed about discussing with your partner symptoms such as the frequent urge to urinate or spots of blood in your urine. You may think it's not something worth discussing – that it's part of getting older, something you just have to live with. You may worry your partner will be uncomfortable talking about such topics.

Or you may want to protect your partner from potentially scary, uncertain or bad news.

But the sooner bladder cancer is diagnosed, the easier it can be to treat. If you are experiencing worrisome symptoms, tell your partner. If you get a worrisome diagnosis, tell your partner. They are perhaps your most important source of all-around support and can help you cope with your feelings and get the care you need.

Of course, talking about bladder cancer is easier said than done. Here are some tips on how can you have that first conversation with your partner about your symptoms or your diagnosis.



- **Find a place where you feel safe and comfortable.** It could be your home, your car or on a walking path in the woods – any place where you can have a private, honest, uninterrupted conversation.
- **Plan how you start the conversation.** As a conversation starter, tell them you just heard about or were reading about how TV star Marilu Henner helped her husband battle bladder cancer, starting with asking him about the spots of blood in the toilet. Use their story as a realistic, but optimistic, example of what may lie ahead for you.
- **Be open about your condition.** Don't try to sugarcoat it to make them feel better, but don't be overly pessimistic, either. Just talk truthfully – after all, they will likely be your main source of support in getting through it.
- **Utilize resources.** There are many resources about bladder cancer, such as the Bladder Cancer Advocacy Network (BCAN) that can help you and your partner learn more about bladder cancer to better understand the disease, what happens next, and what their role might be in helping you decide – and get through – your course of treatment.
- **Know that everyone reacts differently to the news of cancer.** Your partner may want to dive into research, while some people just want to rely on a doctor's opinion. Some may be optimistic, while others may dwell on the “what ifs” and “whys.” Talk about these differences to get a better understanding of where each of you is coming from in future conversations.

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Evon, wife of Lou, who lives with bladder cancer, admits she was very upset when she heard that her husband had bladder cancer but quickly realized how much he would need her support.

“We were both in a state of shock,” said Evon, when she learned of her husband’s diagnosis. “But there was never a doubt that we would meet it head on and fight it.”

Being open with your partner about your symptoms and how you feel can also be beneficial when communicating with your healthcare team. Kevin said his wife Marcia was better at remembering his symptoms than he was, which is why she always made a point to accompany him on doctors’ visits. People who are reluctant to talk about bodily functions with their doctor can benefit from a partner’s support as well. Remember, it is not only entirely appropriate but essential to your health that you let your doctor know about anything irregular you may be experiencing. Your doctor is trained to handle a wide variety of delicate health issues in a sensitive way – it is an important and common part of what they do.

Talking About Treatment

After 30 years of few medical advances in treating bladder cancer, there are now more treatment options that people can talk to their doctors about, including immunotherapy, which uses your body’s own immune system to help fight cancer. Treatment for bladder cancer depends on multiple factors such as the type, stage and location of the tumor, and include surgery, immunotherapy, chemotherapy and radiation – often in combination. Each treatment comes with its own set of side effects that should be discussed by you and your partner with your doctor before you make any decisions.



Your doctor is instrumental in your battle against bladder cancer, so it is critical to speak openly and honestly about your needs and concerns about treatment. Good communication will help you to have thorough, accurate information and a solid understanding of your bladder cancer in order to make the best decisions.

Here are some tips for talking with your doctor about treatment options.

- **Be ready with questions.** “You should ask questions – you need to understand bladder cancer yourself,” Kevin said. Ask questions about recommended treatments and alternatives so you can understand the risks and benefits and potential side effects of each option. When you ask an important question, make sure the doctor has time to give a thoughtful and complete response. Sometimes it helps to give the doctor questions in advance through email or by giving them to an assistant. This information is crucial to working out a treatment and care plan.
- **Make a record of the conversation.** Take notes or have a companion take notes to make sure you can review what the doctor told you when you’re back at home. Ask in advance if you want to bring a device to record the conversation, which will relieve the stress of writing down what was said. Research shows that recording the doctor’s visit helps patients understand what was said and to communicate that to loved ones.³
- **Ask the doctor to repeat or clarify.** You may want to repeat back to the doctor what was said. Ask the doctor to explain things in terms that are familiar to you, and try rewording your question if you don’t understand the answer. “I needed my doctor to explain what he was saying at a level I could understand it,” Kevin said. “Too many people leave the doctor’s office not understanding what the doctor said.”
- **Don’t be afraid of getting a second opinion.** Bladder cancer is an evolving area of medicine, and there is not always consensus about diagnosis, much less how to manage and/or treat it. Your doctor should be understanding about (and supportive of) your interest in a second opinion. It is a common request by patients with serious diseases like cancer. “Sometimes it’s important to get a second, even a third, opinion,” Marilu said.

Taking your partner or someone you are comfortable with along to medical appointments can be helpful in several ways when learning about and deciding on treatment. Not only can it help relieve the stress of a doctor’s visit, but this person can give you emotional support, accurately remember what the doctor said, and think objectively about the information.

Kevin said Marcia was invaluable in helping him research his condition, treatment options, clinical trials, and top doctors and hospitals in bladder cancer. For instance, Kevin’s doctor told him his entire bladder needed to come out and he would need an ostomy bag to collect his urine for the rest of his life. Marcia researched an alternative called the neobladder, which allows people without a bladder to pass urine through their urethra rather than wear an ostomy bag. She found a doctor and hospital in their city area who had experience with the procedure.

Expressing Your Emotional Needs

Bladder cancer and its treatment can bring some substantial changes to your life. These changes can take not just a physical toll, but a psychological toll as well. To help you cope with these changes, it is important to get emotional support from your partner, particularly during and after treatment.

Every person going through bladder cancer will have different emotional needs. Some amount of feeling depressed, anxious or worried is normal, and some people are affected more than others. Here are tips to get help and support from your partner.



- **Be specific about your needs.** Do you need them to field concerned calls from friends? Talk through treatment options? Talk about your hopes and fears? Just cry? It is helpful to tell your partner in simple, specific terms how they can support you. The kind of support you need may vary from day to day and this is OK.
- **Realistically address the impact of cancer on family and household.** Especially during treatment, you may have to cut back on

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household chores, shopping or work and that can affect how the family and household runs. Your partner may not be able to take on all of these new responsibilities, so an early, frank discussion on where additional support is needed can help address challenges down the road. Talk about what kind of assistance you need, and approach family members, friends or neighbors for help.

- **Remember your partner’s needs.** It is easy for a partner to feel lost or overburdened. What does he or she need to do to recharge? Encourage him or her to go out with friends, get exercise or to keep doing the things they enjoy as much as possible. “Get a support network in place – people to help you and listen to you,” Marcia said. She had a group of four close friends to whom she would express her fears about Kevin’s health that she didn’t want to burden him with.

Addressing After-Care

Life after bladder cancer means returning to some familiar things and also making some new choices. Some people with bladder cancer who undergo surgery need to have their bladder and nearby organs removed. This may require a urostomy, an opening in the abdominal wall that re-directs urine away from a bladder and out of the body into a bag, or pouch, that collects the urine. This requires maintaining and emptying the bag, and at first you may need your partner to help.

“It’s nothing to be ashamed of.”

Lou has a neobladder, but even that has its challenges. When patients like Lou first get neobladders, they have bandages and need to flush out tubes. Once the neobladder heals, maintenance is typically restricted to clearing mucus from the neobladder. “Every day, my wife Evon had to flush my tubes out and change the bandages,” Lou said. He felt bad that Evon had to take on this responsibility, but it is something they both had to accept.

“It’s nothing to be ashamed of,” Lou said.

These are all tough issues to talk about, even with loved ones. They are personal, and may even have psychological or emotional overtones. For example, people may be embarrassed they can’t control the flow of urine or that others may know about their pouch, or they may feel vulnerable or that they are a burden due to the care they require. But being open and honest about these issues can ease these feelings.

“It’s tough advice, but I try to be open about these issues rather than hide them,” Kevin said. Sometimes, combining honesty with humor can be helpful in lightening the emotional load that a person with bladder cancer may face in day-to-day life, he said.

Getting Real About Intimacy

When you first find out you have bladder cancer, you are likely most focused on treatment plans and survival. But after a while, other questions might start coming up. You might be wondering “how will bladder cancer affect my sex life?” Sex and sexuality are important parts of everyday life, yet patients and doctors often do not talk about the effects of cancer treatment on intimacy and how couples can address any problems.

With men, when removal of the bladder is required to treat bladder cancer, the prostate and seminal vessels are often taken out as well and there can be damage to the nerves in the area. This may affect a person’s sexual function, and further steps will need to be taken to help restore sexual activity.

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“When it comes to the intimacy part, you have to be honest and say, ‘Where do we go from here?’” Kevin said.

Women who lose their bladder may also face the loss of their uterus, cervix and even parts of their vagina, which also can affect sexual function. In some cases rehabilitation may help restore sexual activity.

“Many women now give birth in front of their husbands – that’s the kind of intimacy you need when talking about the realities of bladder cancer on your sex life,” Marilu said.

Combined with these physical changes and others such as exhaustion, nausea and pain from the post-surgical period, your emotions and self-image can take a toll on your energy, your sex drive or your enjoyment of sex. For instance, some men may feel emasculated or not whole after they have bladder removal surgery. But finding the right level of intimacy for you and your partner is a key part of your healing, so be sure to be open and honest with your partner about how you’re feeling and get help if you need it.

Sharing Your Diagnosis With Others

You may choose to tell others close to you about your diagnosis, not only because they will be affected by it but also because they are most likely to be a source of emotional and practical support. Or, your friends and relatives may ask questions when you had not planned to share the news of your diagnosis.

Here are tips on how to communicate with other family members, friends and loved ones about bladder cancer.



TALKING TO LOVED ONES

- **Tell people only as much as you want them to know.** Don’t feel as if you need to explain everything about your cancer to everyone who asks. Sometimes, a clear, brief answer is all that is necessary. It’s also OK to simply say that you prefer not to talk about it at this time.
- **Script out what you want to say before you reach out to loved ones about your news.** Be truthful about your diagnosis and course of treatment, even with children. Focus on the facts they need to know and that you want them to know. “You need to frame the narrative,” Kevin said.

TALKING TO LOVED ONES (CONTINUED)

- **Set limits on how you want your cancer to be communicated.** You likely have a circle of friends and family that you communicate with regularly, and a wider circle that you stay in touch with only occasionally. Sometimes it gets to be too much to have to explain over and over how you are feeling and where you are with treatment or recovery. Although you may want to stay in touch with your closest friends and family, you can set limits on check-up calls and communications. “We texted some groups, and let the word get out from there,” Marcia said. There are a variety of online tools and resources that can help you communicate when and how you want to family and friends.
- **Ask for help.** When people hear of your cancer diagnosis, they will often ask if there is anything they can do to help. Don’t hesitate to take them up on the offer. Whether it’s meals, help running errands, or some other task, you will find the support welcome and they will feel good they are doing something to ease your burden. Anticipate what you might need and keep a list of assignments. Marcia said Kevin’s parents helped take charge of their children while she and Kevin were at doctors’ appointments, and her church brought meals for her family nearly every day for more than a year.

COMMUNICATING WITH EMPLOYERS AND COWORKERS

You need to communicate with your employer about your health situation, especially if it affects your ability to work. If you are concerned about telling your boss your diagnosis for fear you could lose your job, know that federal laws protect people with cancer from discrimination. Employers are legally required to provide reasonable accommodations during or after cancer treatment. (To learn more about your rights, contact the [U.S. Equal Employment Opportunity Commission](#), which enforces Title I of the Americans with Disabilities Act.)⁴

Before you speak with your employer, consider these tips that might help your conversation.

- **Talk with your doctor about how your diagnosis and treatment will impact your work.** For instance, will you need time off for treatment and recovery? Are there certain tasks required of your job that you may not be able to do, at least temporarily?
- **Think ahead on needs and potential solutions.** Make a list of work-related needs you think might be necessary while you’re in treatment. For example, will you need to work part-time after recovery? Is there someone who may be able to cover certain responsibilities? When you’re back at work, go over this list with the human resources department as well as your boss.

If you decide to tell coworkers about your diagnosis, you can follow the same tips for sharing your diagnosis above. Remember, everyone reacts differently to news of cancer, and that people may need time to think about and adjust to this information, so their initial response may change as they learn more.

FINDING CONFIDANTS OUTSIDE YOUR CIRCLE

Finally, it can help to talk to someone who understands what it is like to fight bladder cancer. This could be a survivor, nurse, caregiver or clergy member. It can be especially helpful to talk to survivors who have the same stage diagnosis as you. They will have faced similar treatment choices and therefore, understand the specific questions and challenges you face. Bladder cancer discussion groups can be found through your healthcare provider or online through the [Bladder Cancer Advocacy Network](#).

Conclusion

While it may not be easy to talk about your bladder cancer, open and honest communications with partners, doctors, friends and family is crucial for your health and well-being – and it's also important to those you love.

- 1 SEER Stat Facts Sheets: Bladder Cancer. National Cancer Institute website. <http://seer.cancer.gov/statfacts/html/urinb.html>.
- 2 American Cancer Society. Cancer Facts & Figures 2017. Atlanta: American Cancer Society; 2017. <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2017/cancer-facts-and-figures-2017.pdf>.
- 3 Hsieh, P. Why You Should Record Your Doctor Visits. Forbes, Feb. 16, 2015. <https://www.forbes.com/sites/paulhsieh/2015/02/16/why-you-should-record-your-doctor-visits/#6cc0f8603ef1>.
- 4 U.S. Equal Employment Opportunity Commission. Questions & Answers about Cancer in the Workplace and the Americans with Disabilities Act (ADA). <https://www.eeoc.gov/laws/types/cancer.cfm>.