



Bladder Cancer Basics

Tips for
Caregivers

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Care, advice, and support from the Bladder Cancer Advocacy Network (BCAN)... for caregivers too.

John Quale learned he had bladder cancer in 2000. At that time, people knew little about it—the signs and symptoms, causes, or treatments. John and his wife Diane, his caregiver, knew they had to help others on similar journeys. In 2005, they started BCAN.

We are the only national advocacy organization devoted to advancing bladder cancer research and supporting those impacted by the disease and those that care for them. Sadly, John passed away in 2008. But the mission and vision of BCAN continues.

BCAN thanks the caregivers and patients that helped create the Tips for Caregivers resources.



Tips from BCAN bladder cancer caregivers

Learning someone you care about has bladder cancer can feel overwhelming. Your partner, family member, or friend may need you as a caregiver. Caregiving can be a rewarding and sometimes difficult journey.

Cancer caregivers play many different roles

- ▶ You support and advocate for your loved one during diagnosis, treatments, and follow-up care
- ▶ You provide emotional and sometimes physical support
- ▶ You give encouragement as your loved one makes treatment decisions

Bladder cancer caregivers face a long journey. The treatments and close monitoring of your loved one may continue for many years. Often, a caregiver is not paid. You may not have formal training for this important role. When becoming a caregiver, it helps to know what's involved. Caregivers can:

- ▶ Accompany a patient to appointments
- ▶ Help make medical decisions
- ▶ Coordinate medical and at-home care
- ▶ Manage everyday tasks such as medication schedule, meals, finances
- ▶ Provide transportation
- ▶ Become part of the patient care team as you report observations of the patient's response to medications and treatments

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Anthropologist Margaret Mead said, "Never believe that a few caring people can't change the world. For indeed, that's all who ever have."

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Each year more than 80,000 people in the United States hear the words, "You have bladder cancer." You are not alone as a caregiver. As a caregiver, you are a vital part of the patient care team. What happens at home is just as important as what happens at the doctor's office. BCAN gathered the information in this book to support you as you care for someone with bladder cancer.

Here are some ways to prepare for your caregiver role:

- ▶ Find a support network
- ▶ Gather information about your loved one's diagnosis
- ▶ Plan for the future, accept help and take care of your own health
- ▶ Recognize and accept the "new normal"

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Former First Lady Rosalynn Carter said, "There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver."

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What is bladder cancer?

Understanding the basic information about bladder cancer will help you know what your loved one is experiencing. This Tips for Caregivers booklet comes with a free copy of **Bladder Cancer Basics**. This guide helps you and the person you are caring for understand risks, diagnosis and treatments for bladder cancer.



For more information, visit BCAN.org. Read through our web pages. Learn about treatment and quality of life issues by watching a Patient Insight Webinar.

There are two common types of bladder cancer:

- ▶ Non muscle-invasive bladder cancer is the most common type.
- ▶ Muscle-invasive bladder cancer is less common, but more serious.

Treatment are different based on your loved one's diagnosis. Some need treatment to remove the tumor one time. Others need to have treatment over a few weeks or months.

The best treatment options are based on guidelines for each stage and grade of bladder cancer (please see page 20 in **Bladder Cancer Basics**). Talk to your health care provider about what treatment is right for your loved one.

"As a caregiver you may get thrown into things. If surgery is called for and a cystectomy is necessary (see page 34 in **Bladder Cancer Basics**), it is vital that the caregiver is at ALL appointments, especially the Wound Ostomy Care Nurse appointments. That is when the basics of ostomy and ostomy care are discussed, including supplies and dressing."

— John

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CALL 888.901.BCAN (2226)
OR



[EMAIL INFO@BCAN.ORG](mailto:INFO@BCAN.ORG)

What can I expect as a bladder cancer caregiver?

Many caregivers want to do whatever it takes to help their loved one get better. It is important to recognize that it is not always easy to be a bladder cancer caregiver. Some challenges may include:

- ▶ Traveling long distances or taking time off from work to help your loved one. You may also have work and other family commitments.
- ▶ Bladder cancer treatment and monitoring can be expensive. A financial counselor at your healthcare facility may be able to help.
- ▶ Both you and your loved one may have many different feelings now. You may feel angry, sad, depressed, or stressed. These feelings are normal with a bladder cancer diagnosis. You are not alone.

Once a patient is diagnosed with bladder cancer, he or she may have many medical appointments. These appointments take time. They also take effort to keep track of.

“Right after my husband was diagnosed, I made a notebook that was dedicated to our bladder cancer appointments. I took notes during each appointment, including the doctors’ and nurses’ names at each appointment. We could go back and look at the recommendations they gave us. It also helped keep our appointments straight.”

— Wanda

“After my husband was diagnosed, I made a list of people to call in case of emergency. I left it in an easily accessible place. It proved to be invaluable when he spiked a fever in the middle of the night. I didn’t have to dig through all our paperwork to find who I should call.”

— Christi

After diagnosis, the time needed for treatment is different for every patient. When treatment is over, people with bladder cancer continue to see their doctor for follow up scans, to be sure the cancer does not come back. The doctor will explain how often this must be done.

Get organized. Keep important information and phone numbers handy. That will help you save time on this journey.

How can I help during bladder cancer treatments?

Some patients won't need the help of a caregiver. They will continue working and going about normal activities. Others will need help getting to and from appointments. They may need help with everyday activities like showering and going to the bathroom or taking over their household activities.

Each situation is unique and may change over time. It is important to be flexible as both you and your loved adjust to this new normal.

You may need to learn new skills to care for your loved one. The medical team can help you learn what you can do to care directly for your loved one.



It also helps to have:

- ▶ **Patience.** Understand that there may be changes in plans. Things do not always go smoothly. Sometimes, there may be hesitation or resistance from the very person you are trying to help.
- ▶ **Compassion.** Try to understand what the person is going through.
- ▶ **Attentiveness.** Be attentive to the needs and changes that are taking place. Notice when there are emotional or physical changes in the person you are caring for.
- ▶ **Dependability.** Show up to provide the care that the person needs and is counting on.

How can I take care of myself too?

The bladder cancer treatment journey can have many ups and downs. As a caregiver, keep this proverb in mind, “Joy shared is doubled, burden shared is halved.” You and the patient are in this together. Many caregivers wish they had let more people help them throughout their loved one’s cancer journey. You may be good at some things, and not as good in other things.

Make a list of tasks and activities that other people could do. If someone offers to help, you will have a better understanding of the kind of help you need. Here are some ideas that may lighten your burden:

- ▶ Make a meal that you can have in the freezer for dinner on a treatment day.
- ▶ Seek help with care for your pets or young children if you have them.
- ▶ Arrange for help with shopping.
- ▶ Ask for help with yard work. Does the lawn need to be cut? Does snow need to be shoveled?
- ▶ Arrange for help in the home. Could someone help with laundry or tidying up?

“When my wife was diagnosed, I went into Superman mode trying to take care of everything at once. I tried to stay strong and do everything myself. What I should have done was let people help us when they offered.”

— John

- ▶ Seek help with driving to or from medical appointments.
- ▶ Ask someone to spend time with the person with bladder cancer so you can just keep up with the rest of your life. Or so you can just do something for yourself. You must also take care of your mental and physical health.

BCAN is here to help, too. Visit us at BCAN.org for more information or to speak to a volunteer in our Survivor to Survivor program.



Survivor to Survivor — Talk to someone who understands

It’s normal to have concerns and questions about bladder cancer. Many people want to know what to expect with a surgery or procedure, or what to expect with treatment. Some want to know how other survivors got back to “normal.” Many just want to talk with someone who knows what they’re going through.

The **BCAN Survivor to Survivor program** offers phone support for people who have questions about bladder cancer. You can speak with a survivor about their journey, as well as what to expect on yours. Would you like to speak with a survivor? Or another caregiver?

Just call 301-215-9099 or email survivor@bcan.org and ask for the Survivor to Survivor program. BCAN will match you with a volunteer. They’ll keep all your information private. To learn more about this program, visit bcan.org/find-support/survivor-to-survivor.

When you travel on an airplane, attendants tell passengers how to use the safety oxygen masks before takeoff. They explain “If you are taking care of someone who needs assistance, put your mask on first.” Follow the same advice when caring for your loved one.



If you feel burnout, exhaustion, or too much stress, you may be unable to help. Don't skip your own medical or self-care. It is important that you stay healthy for both of you! Here are some tips from BCAN caregivers:

- ▶ **Set aside time for yourself.** This can be as simple as reading a book while your loved one is in treatment. Perhaps take a few hours a week to meet up with a friend. You may be able to go away for a vacation if someone checks on or stays with your loved one.
- ▶ **Ask for help.** Ask your healthcare provider or other family members about respite care options. Respite care helps you to take a much-needed break from the demands of caregiving. Whether a few hours a week or an extended vacation, respite care can help ease the burden of family caregiving. It can help to relieve stress, restore your energy, and promote balance in your life as a caregiver. It can also prevent you from feeling exhausted, isolated, or even burned out. Respite care can benefit the person you're caring for too. Having someone else step in to help can give them variety, stimulation, and a welcome change of routine.

- ▶ **Get enough sleep.** If you find yourself having trouble sleeping, talk to your doctor.
- ▶ **Eat well.** A balanced diet can help both you and your loved one feel as good as possible.

Learn more about caring for yourself at bcan.org/find-support/caregiver-resources

Are my feelings and emotions normal?

Many caregivers say that they feel a sense of competency and joy when they care for their loved one. They feel pride because they can do some care tasks well. Being a caregiver can be very rewarding. Celebrate these moments and enjoy them. You are making a difference!

“During my wife’s cancer treatment, I felt very competent, especially when I was able to change her ostomy bag (see page 36 in *Bladder Cancer Basics*) better than the nurses in some cases. I felt well equipped and I was happy to care for my wife out of the love I felt for her.”

— John

Every situation is different, and you may experience many other feelings as well. Talking to a friend or a mental health professional can lighten the emotional load when you are a caregiver. Here are some common caregiver feelings and what you can do to help manage them. If you don’t take care of yourself, you may have a hard time taking care of someone else.

▶ **Burnout is emotional (feelings), physical (body), and mental (thoughts) exhaustion.** It can happen with prolonged stress. You may feel overwhelmed and emotionally drained. You may feel unable to meet the constant demands on your time, energy, or financial resources. Burnout can only be relieved by giving yourself a break. Ways to help prevent burnout also include:

- ▶ Ask for help with tasks, such as taking your loved one to medical appointments. Or ask if someone can stay with your loved one while you take a day off.
- ▶ Practice self-care. Self-care can take many forms. Maybe it is just taking a walk or exercising. Whatever it is, it should be something you enjoy and that can help you relieve stress.

The singer Lena Horne said, “It is not the load that breaks you down. It’s the way you carry it.”

- ▶ **Stress is a feeling of emotional or physical tension.** It can come from any event or thought that makes you feel frustrated, angry, or nervous. Stress is your body’s reaction to a challenge or demand. In short bursts, stress can be positive, such as when it helps you avoid danger or meet a deadline. Long term stress can come with being a caregiver for a cancer patient. It can have a negative impact on your physical or mental health.
- ▶ **Anxiety is your body’s natural response to stress.** It’s a feeling of fear or apprehension about what’s to come. Anxiety feels different to each person. Those feelings can range from “butterflies in your stomach” to a racing heart. It might feel like you are out of control, like there’s a disconnect between your mind and body.

Other ways people experience anxiety include nightmares, insomnia, panic attacks, and painful thoughts or memories that you can’t control. You may have a general feeling of fear and worry, or you may fear a specific place or event. Physical symptoms of general anxiety include:

- ▶ Increased heart rate
- ▶ Rapid breathing
- ▶ Restlessness
- ▶ Trouble concentrating
- ▶ Difficulty falling asleep

Talk to a mental health provider if feelings of anxiety:

- ▶ Are extreme
- ▶ Last for longer than six months
- ▶ Interfere with your your daily functioning

▶ **Depression is a feeling of sadness and loss of interest that doesn't go away on its own.** It affects how you feel, think and behave. Depression can lead to a variety of emotional and physical problems.

You may have trouble doing normal day-to-day activities. Some people with depression may feel as if life isn't worth living. It is more than just a bout of the blues. Depression isn't a weakness and you can't simply "snap out" of it. Depression may require long-term treatment. Don't get discouraged, many people with depression feel better with medication, psychotherapy or both.

▶ **Anger is a basic human emotion.** Long term anger may be harmful to relationships and to your overall health.

▶ **Grief is the acute pain that accompanies loss.** It is deep, because it reflects what we love. It can feel all-encompassing. Grief is complex; it does not follow rules. Grief has no set end date.

Some experts feel there are clear stages of grief—denial, anger, bargaining, depression, and acceptance. Others believe grief is an individual emotion. Grief can follow the loss of a loved one, the loss of a job or another important role in life. It can include the loss of freedom with becoming a caregiver.

If you or the person with bladder cancer take medicine to manage your own mental health, you might also experience mood changes or other side effects from your medications. Mood changes from medication may be fast or happen over time. Speak with your healthcare provider if these mood changes are a problem.

"From the moment of diagnosis, we looked at it from the perspective of "How do we make the best of this situation?" Using that frame of mind made our cancer journey so much less stressful."

— Christi

Ways to adjust to the new normal:

Dealing with caregiving emotions - You and the person with bladder cancer may experience **mood changes**. Mood changes can also come from the stress of a bladder cancer diagnosis or treatment. They can come from all of the feelings previously listed. Part of being a caretaker is learning how to manage mood changes.

Remember, these emotions are normal and feelings can range from minor to overwhelming. It is important to recognize them and talk to someone if you begin to feel overwhelmed. You and your loved one may just need time to adjust to the changes you are experiencing. We sometimes call this the *new normal*.

Some people will project their feelings onto those who are closest to them. While caregivers can provide emotional support, sometimes a patient directs their negative feelings toward you, the caregiver. This can



be upsetting. As a caregiver, you may be your loved one's safest outlet. You may even be feeling the same emotions. Below are some tips and ideas that other caregivers have used to provide emotional support.

- ▶ Being together, listening, and touching are important ways of **caring and comforting** your loved one.

“One thing I noticed with Dave is, it was better for me to ask him: ‘What are you feeling?’ and NOT ‘How are you feeling?’ It is important for a caregiver to be a sounding board and just listen without trying to make everything better. Caregivers need to understand that it is okay to let him/her to feel sad and upset at times as they learn to live with their ostomy. This is a new normal for two people.”

— Wanda

- ▶ Encourage him/her to openly **talk about concerns**.
- ▶ Practice **positive coping skills** with your loved one. This includes meditation, prayer, relaxation techniques, and humor.
- ▶ Seek **activities** that he/she values as an individual. Reinforce their self-worth with positive comments. Plan activities you both enjoy, like watching a movie, shopping, or visiting with family and friends. Encourage your loved one to resume normal activities when they are ready.
- ▶ Engage in **exercise** as his/her healthcare team allows.
- ▶ Find a local **support group** or an online community that you can participate in. Visit inspire.com/groups/bladder-cancer-advocacy-network
- ▶ Respect a patient's **need for alone time** but let him/her know you are available to talk if needed.

If many of these feelings that caregivers sometimes get interfere with your everyday activities or last longer than three months, we recommend that you seek help from a professional. Your health care provider may be able to recommend someone who specializes in helping bladder cancer patients and their loved ones.

What are some other issues bladder cancer caregivers should think about?

The cost of bladder cancer

A caregiver may take on the role of being in charge of the finances for the household or for the patient. This can be stressful if it is a new task for you. There may be added financial stress if you have a job that does not have flexibility that allows you to take time off to care for a loved one. The Family and Medical Leave Act (FMLA) helps many workers balance their work and family responsibilities.

FMLA allows caregivers to take up to 12 weeks of unpaid leave for certain family and medical reasons. Learn more at dol.gov/agencies/whd/fmla

You may need to navigate health insurance or oversee making sure that treatments are paid for. Many caregivers keep a notebook with all medical bills and insurance payment statements. This can be useful when speaking with financial or insurance agents.

Bladder cancer is expensive to treat. This can place a lot of stress on you and the patient. Treatment expenses contribute to “**financial toxicity**.” This means the treatment is costing more than the patient is able to afford. Some people must make choices between everyday living expenses and paying for bladder cancer treatment.

There are places where patients can apply to receive assistance to pay for some cancer treatment expenses. Ask to speak to a financial counselor either in your doctor’s office or at the local hospital. He or she may be able to tell you about different payment options or available grants. Many drug companies offer help paying for patients’ portion of the payments. Check the website of the pharmaceutical company to see how to apply for help with co-payments.

Caring from far away

Not all caregivers live in the same house, or even the same state as their loved one. What does caregiving from a distance include? Typically, it means helping your loved one find information on treatment options. You may help set up doctors’ appointments. Many caregivers call loved ones on the phone regularly to make sure they have the support they need, both practically and emotionally.

You can research their disease and treatment online. You can also research clinical trials that offer new treatment options.

To help find a clinical trial, visit clinicaltrials.bcan.org. You can search for trials by the type of bladder cancer by different states.

Contact friends and family to arrange visits to the patient and provide basic support with day-to-day tasks. This includes arranging for food deliveries, making appointment lists, or organizing documents either in a notebook or in online files. You may need to get permission from your loved one to access his or her medical records.

Talking About Your Loved One’s Diagnosis

Many bladder cancers are diagnosed after the age of 70, but younger patients are also diagnosed. You and your loved one may have to talk to your children or parents about the bladder cancer diagnosis. If you or the patient are working, you may want some tips on talking to your employer. You can find some resources that have strategies at bcan.org/find-support/caregiver-resources.

What happens when my loved one is no longer in treatment?

There may be a point when the person with bladder cancer is no longer in active treatment. Because bladder cancer can come back, he or she will need regular checkups to make sure they are cancer free. The doctor will explain how often they want your loved one to come in for monitoring with cystoscopies, urine tests, scans, or other tests (see p. 18-19 in Bladder Cancer Basics). This may decrease as time goes on.

It is normal for you or your loved one to feel anxious or stressed before these tests. You may also feel calm and prepared. Each person will react differently, and your feelings may change over time. It is important to recognize these feelings. Some people create routines around these visits to the doctor. They may go for a walk in their favorite park or eat a special meal before they go in for testing.

There is no clear end date to needed bladder cancer surveillance. Some patients will see their urologist or other doctor regularly for the rest of their lives. Others may get to a point where a shared decision is made to only see the doctor if they start having symptoms or other problems.

Your loved one may not need as much active care during this time in the bladder cancer journey. Or they may need care in different ways. After you have adjusted to this new schedule, there may be hiccups along the way. You should also talk about the future with your loved one.



Difficult conversations about end-of-life

Many bladder cancers are non-muscle invasive and do not progress. Some are invasive and spread to other parts of the body (metastatic). Thinking and planning for what could happen is hard for some people to talk about. Talk to your loved one and make decisions together about options if treatments don't work. Knowing their wishes for end-of-life decisions can help you to help them. A legal counselor may be helpful. Having all legal documents completed is a relief for the caregiver and the patient.

Talk about:

- ▶ A living will
- ▶ Advanced medical directives
- ▶ Life Insurance
- ▶ Property Memorandum
- ▶ Don't forget to include things stored digitally

For more information, visit the National Institute on Aging: nia.nih.gov/health/getting-your-affairs-order

You can find additional links to online resources to help you plan for end-of-life at bcan.org/find-support/caregiver-resources



BCAN caregivers share these tips:

"My husband was an attorney. We already had wills, living wills, healthcare surrogates and powers of attorney established before his diagnosis. We were young at 54 and 51! It was a blessing not to have to think about those things as we got deeper in the weeds of worsening health.

Also, my husband lost the ability to speak about two months before his death (brain metastasis, chemo fog, overall weakening.) He was still working up to that point.

If we had waited to discuss legal issues, whether and when to ask for hospice, funeral arrangements, etc., those conversations would not have happened. Of course, these are very difficult conversations!" — Christi

"When it became clear that my mom's illness was terminal, I asked her if she would like to receive visits from family and friends.

I contacted everyone and coordinated a visiting schedule that wouldn't be too overwhelming for my mom." — Linda

"When my husband was first diagnosed, one of the first things we did was review and update wills, trust, executor of estate, health directives, power of attorney and funeral planning. We made a list with phone numbers of who to call when the time is appropriate. We have begun the passing on of family treasures to our extended family members. It brings a sense of joy to share a legacy with those who will treasure and keep them within the family. We also discussed celebration of life songs, poems, and stories to share. My husband currently has no evidence of disease, but we both have a peace of mind knowing that we have already taken care of this." — Wanda



FOR MORE INFORMATION



[**BCAN.ORG**](https://www.bcan.org)



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