Caregiving for a Loved One With Bladder Cancer

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Each year, an estimated 81,000 adults in the United States are diagnosed with bladder cancer.

This booklet provides information, guidance and resources for people helping to care for a loved one with bladder cancer. Use this booklet in whatever way works best for you—read it straight through or refer to sections as you need them. Be sure to share the information you find most helpful with your loved one.

The Role of the Caregiver

Caregivers provide important support for a person with cancer. Often, caregivers are family members or friends. They may live with, nearby or far away from the person they support.

Please remember that if you are a caregiver, you should not be alone as you provide support to your loved one. People in your personal network (family, friends, neighbors) will be eager to help, especially if you are specific in your requests. Take some time to think about the people in your life and how they are best suited to help you, and match your request to their strengths—ask a family member who loves to shop to pick up a few things at the store; ask a friend who's a good listener to come over for a chat with you and your loved one.

There are also professional resources available to you, including the oncology social workers at Cancer*Care,* who are specially trained to help people and their caregivers cope with the emotional and practical challenges of cancer. Additional resources are listed at the end of this booklet.

Guidance for Caregivers

The kind of support that a caregiver provides will be different for each person. In general, caregiving support falls into one of three areas: informational, practical and emotional. This booklet provides examples of how caregivers can help in each of these areas.

Informational Support

A person diagnosed with bladder cancer can feel overwhelmed, and may need informational support directly related to their diagnosis and treatment. Here are specific types of support caregivers can provide:

Learn about your loved one's diagnosis and possible treatment options. There is information in this booklet on current treatment approaches for bladder cancer. You will also receive information from your loved one's health care team, and can ask a member of that team what additional resources they recommend.

Understand the potential side effects of the chosen treatment approach. In addition to information on treatment approaches, this booklet lists potential effects of bladder cancer therapy. Your loved one's health care team can provide additional information on potential side effects, based on the specific drug or drugs used in treatment.

Help your loved one communicate with health care professionals. As you help your loved one manage their bladder cancer, it's important to remember that you are both consumers of health care. In addition to educating yourself about the diagnosis and treatment options, get to know the members of their health care team, including doctors, nurse practitioners, physician assistants, nurses, dietitians, social workers and patient navigators.

Here are a few things you, as a caregiver, can do to ensure that communication with the extended health care team is as effective as it can be:

- **Help create a health care journal.** Having a health care journal or notebook (either on paper or in a digital format) will allow your loved one to keep all of their health information in one place. It should include the names and contact information of the members of their health care team and details of their treatment plan. The journal can also be used as a diary to capture their experiences while undergoing treatment, and your experiences as a caregiver.
- **Help prepare a list of questions for their next appointment.** This list should include your questions and concerns as well as those of your loved one. Because the doctor may have limited time, create the list in order of importance.
- **If you can, accompany your loved one to medical appointments or be present during telehealth sessions.** Even if they have a journal and a prepared list of questions or concerns, it's always helpful for them to have support at appointments. You may think of additional questions to ask, or remember details about their symptoms, treatment or overall quality of life that they may have forgotten.
- **Write down the doctor's answers.** Taking notes will help you and your loved one remember the doctor's responses, advice and instructions. If you have a mobile device, ask if you can use it to take notes or record the discussion, which will help you review the information later.

Practical Support

There are many ways that caregivers can help with practical matters (the activities of daily living), including:

Personal care. Depending on how they are feeling, people going through bladder cancer treatment may need help with a number of activities they would normally handle themselves, such as bathing or dressing. Ask your loved one to let you know if they want help with these activities. Some people may want help, but would prefer that it is provided by a paid helper, rather than a spouse, significant other or friend. If that's the case with your loved one, ask a member of their health care team for recommendations on local home health agencies that can provide these services.

Health care. As a caregiver, you may be involved in some health care tasks that are more typically handled by a nurse, such as administering medication and changing bandages. If you need help with these health care needs, ask the doctor, nurse or hospital social worker about local home health agencies that can send in-home nurses to provide these (and other) services.

Organizing medications. Keeping track of prescription and over-the-counter medications can be a challenge under any circumstances. An inexpensive pill organizer (available at most drugstores) allows for the sorting of medications by day of week and time of day. There are also free medication reminder apps available for use on a smart phone or tablet.

Household tasks and errands. If you are a caregiver to a spouse or significant other, you may already be handling a large share of household tasks and errands. This would be a good time to take short-term responsibility for additional chores, if possible.

Emotional Support

It's hard to watch someone you care about go through the difficult emotions that may arise with a cancer diagnosis, which can range from denial to sadness to anger. There are things you, as a caregiver, can do to help both of you cope:

Listen to your loved one. It's important to listen without judging or "cheerleading." Simply listening to and validating what your loved one is expressing can be one of the most important contributions you make.

Support your loved one's treatment decisions. While you may be in a position to share decision making, ultimately it is your loved one who bears the impact of their bladder cancer and its treatment.

Get information about support groups. Joining a support group gives your loved one a chance to talk with others coping with cancer, and learn what they do to manage difficult emotions. Ask a hospital social worker for a referral, or contact Cancer*Care*. Cancer*Care* offers free face-to-face, telephone and online support groups for people affected by cancer.

Continue your support when your loved one's treatment is over. The end of treatment means fewer meetings with the health care team, whose support you have likely relied on. You may also have questions about how to transition away from being a caregiver, so getting support during this transition can be helpful.

Remember to Take Care of Yourself

Taking care of a loved one can be a positive experience, but it can also feel like a full-time job, and be very stressful. Many caregivers tend to put their own needs and feelings aside; however, it's important for you to take good care of yourself. Here are some tips to help you do so:

Ask for help. Consider using My Cancer Circle™ (mycancercircle.net) to organize help from friends and family. My Cancer Circle is a free, private and customizable online tool that enables people facing cancer to organize and coordinate a circle of family members and friends to provide practical and emotional support. This tool provides caregivers of people facing cancer a simple, effective answer to a question they are constantly asked, "What can we do to help?" In addition to family, friends and neighbors, look for professional or volunteer resources in your community.

Stay active. Experts recommend at least 150 minutes (2.5 hours) of moderate-intensity aerobic activity per week, preferably spread throughout the week. Aerobic activity includes the use of cardio machines, walking, running, hiking, swimming and dancing.

Pay attention to what you're eating. Keeping a balanced diet is an important part of taking care of yourself. Include fruits and vegetables in your meals. Nuts, yogurt, and peanut butter are easy snacks with lots of protein that will keep your energy level up. Pack snacks if you know you will be with your loved one at the doctor's office or the hospital for an extended period of time.

Get enough sleep. Caregiving can be emotionally and physically draining, and you should try to get enough sleep. The Centers for Disease Control and Prevention (CDC) recommends at least seven hours per night for adults. Also, take naps during the day if you need them.

Keep up with your own checkups, screenings and medications. Your health is very valuable. Stay on top of your own medical appointments, and have a system for remembering to take any medicines you need to stay healthy.

Get emotional support. Caregiving is hard work that can affect your emotional well-being. Taking care of yourself includes coping with many of your own feelings that come up as you care for your loved one. Here are some tips to help you cope:

- **Take a break.** Take some time for yourself regularly. Even if it's just for a few minutes, doing something you like can help you recharge.

- **Open up to friends and family.** Ask friends or family members if they would be willing to be "on call" in times of stress. You can also plan a regular "check-in" time. And be sure to make time for socializing with friends or family, preferably outside of your home.
- **Talk to a professional about your feelings and concerns.** Many caregivers feel overwhelmed and alone. Speaking with a counselor or oncology social worker may help you cope. Cancer*Care's* oncology social workers are just a phone call away.
- **Join a support group for caregivers.** Cancer*Care* offers free face-to-face, telephone and online support groups for caregivers. These groups provide a safe haven where you can share your concerns and learn from others who are going through a similar situation.

Bladder Cancer

About 95 percent of bladder cancers are classified as "transitional cell" (also called urothelial carcinoma), meaning that the cancer (carcinoma) arises mostly from the cells that line the inside of the bladder. Transitional cell carcinomas can also arise from cells in other places along the urinary tract, including the inner lining of the kidneys, the ureters and the urethra.

In approximately 70 percent of transitional cell carcinomas, the cancer is contained within the superficial lining of the bladder. The remaining cases are classified as "muscle invasive," meaning that the cancer cells have spread beyond the inner lining of the bladder into the muscle layer or has spread outside the bladder.

Treatment Options

The course of treatment for bladder cancer is often determined after consultations with a urologist, a medical oncologist and a radiation oncologist. Each doctor brings a perspective unique to their specialty.

Non-invasive bladder cancer

If the cancer cells are non-invasive (contained within the lining of the bladder), the treatment approach is decided with a number of factors in mind, including what was seen on diagnostic imaging tests and other health issues the person may have.

Treatment approaches for non-invasive bladder cancer are typically a combination of the following:

- **Transurethral resection (TUR).** A small electrified wire loop is passed through a cystoscope into the bladder and is used to remove the tumor.

- **Partial cystectomy.** The portion of the bladder that contains cancer cells is removed.
- **Bacille Calmette-Guerin (BCG).** BCG is an intravesical (delivered into the bladder) therapy that causes an immune reaction against cancer cells within the bladder. In April 2024, the U.S. Food and Drug Administration (FDA) approved the immunotherapy-boosting drug N-803 (Anktiva) in combination with BCG for the treatment of non-muscle invasive bladder cancer that is resistant to treatment with BCG alone.
- **Chemotherapy.** Chemotherapy drugs are sometimes used as an intravesical treatment (directly inside the bladder); they include mitomycin C, thiotepa, doxorubicin, gemcitabine and valrubicin. Some multi-agent (more than one drug) chemotherapies are given sequentially such as gemcitabine and docetaxel (Gem/Doce).
- **Novel therapies.** For non-muscle invasive bladder cancers that do not respond to initial therapy, there have been recent FDA approvals for the immunotherapies pembrolizumab (Keytruda) and nogapendekin alfa inbakicept (Anktiva), and the gene therapy nadofaragene firadenovec-vncg (Adstiladrin).

In cases where there has been a recurrence (return) of non-invasive bladder cancer after treatment, a radical cystectomy is often performed. In this surgical procedure, the entire bladder and surrounding lymph nodes are removed. This surgery also includes the removal of the prostate in men and the uterus, ovaries and part of the vagina in women.

Muscle-invasive bladder cancer

Surgery

If the cancer has invaded the muscle layer of the bladder wall or beyond, a radical cystectomy (as described in the previous

section) is often performed. With the removal of the bladder, the surgeon will also create new ways for urine to be expelled from the body. Several options exist; the chosen option depends on the person's individual circumstances and their personal preferences.

Chemotherapy

Systemic (whole body) chemotherapy, often used in conjunction with a radical cystectomy, is designed to destroy cancer cells that may have spread beyond the bladder. Common drug combinations include MVAC (a mix of methotrexate, vinblastine, doxorubicin and cisplatin) and GC (gemcitabine plus cisplatin). Systemic chemotherapy is most often administered prior to surgery (neoadjuvant), but is sometimes given after surgery (adjuvant). When given prior to surgery, chemotherapy can shrink tumors, making surgery an easier process and increasing its change of success.

Systemic chemotherapy is also the primary treatment for bladder cancer that is not treatable with surgery or is metastatic (has spread from the bladder to other organs).

Radiation Therapy

In certain situations, people with muscle-invasive bladder cancer are given the option of radiation therapy as an alternative to radical cystectomy. This treatment works better in smaller and less invasive tumors. Radiation therapy is most commonly given in combination with low-dose systemic chemotherapy. The chemotherapy makes the tumors more sensitive to the radiation treatment.

Targeted Therapy

Targeted therapy focuses on specific molecules and cell mechanisms thought to be important for cancer cell survival and growth, taking advantage of what researchers have learned in recent years about how cancer cells grow.

In January 2024 the FDA approved erdafitinib (Balversa) for the treatment of locally advanced or metastatic bladder cancer that has an FGFR3 genetic alteration and that has progressed after prior systemic therapy.

Immunotherapy

Many cancer cells carry "checkpoint" proteins that prevent the immune system from effectively attacking tumors. Certain immunotherapies, known as "checkpoint inhibitors," allow the immune system to bypass these blocks.

There are four checkpoint inhibitors currently approved by the U.S. Food and Drug Administration (FDA) for the treatment of people with urothelial carcinoma that is locally advanced or metastatic: atezolizumab (Tecentriq), nivolumab (Opdivo), pembrolizumab (Keytruda) and avelumab (Bavencio). These drugs can be used as an initial treatment, when the bladder cancer did not respond to chemotherapy, or to retain the benefits of prior therapy.

Antibody-drug conjugate

Antibody-drug conjugates work by combining a chemotherapy with an antibody that seeks out cancer cells.

- In December 2019 the FDA approved enfortumab vedotin-ejfv (Padcev) for the treatment of urothelial carcinoma that has progressed after chemotherapy and immunotherapy. In July 2021, the approval was expanded to include treatment of urothelial carcinoma that has progressed after at least one treatment regimen. In December 2023, enfortumab vedotin-ejfv was approved, in combination with the immunotherapy pembrolizumab, for the treatment of bladder cancer spread to other parts of the body or cannot be removed surgically.

- In April 2021 the FDA approved sacituzumab govitecan-hziy (Trodelvy) for the treatment of locally advanced or metastatic urothelial cancer that was previously treated with chemotherapy and immunotherapy.

Treatment Side Effects

All cancer treatments can cause side effects. It's important that side effects are reported right away so that your loved one's health care team can help manage them. It's important to remember that not all people being treated for bladder cancer experience all of these side effects, and people may experience side effects not listed here.

General side effects of bladder cancer treatment can include digestive tract symptoms (nausea, vomiting, diarrhea, loss of appetite) and fatigue. Your loved one's health care team can suggest ways to manage these side effects should they occur.

Side Effects of Chemotherapy

With intravesical chemotherapy (delivered directly into the bladder), the most common side effects are bladder irritation and painful urination. Since very little of the medicine is absorbed into the bloodstream, other more general side effects are uncommon.

The side effects of systemic chemotherapy depend on the type and dose of the therapy given and the length of time it is used, and can include:

- Fatigue
- Nausea or vomiting
- Hair loss

- Increased risk of infection (from having too few white blood cells)
- Easy bruising or bleeding
- Peripheral neuropathy (numbness or tingling in hands and feet)

Side Effects of Immunotherapy

Immunotherapy drugs travel through the body, helping to enhance an immune response. Sometimes the immune system may attack healthy cells as well as cancer cells, and certain side effects may be experienced, including fatigue, decreased appetite, skin rash and digestive tract symptoms.

Side Effects of Radiation Therapy

Changes to the skin are the most common side effects of radiation therapy. Those changes can include dryness, swelling, peeling, redness and blistering. If a reaction occurs, your loved one should contact a member of their health care team so the appropriate treatment can be prescribed. It's especially important to contact the health care team if there is any open skin or painful area, as this could be sign of an infection. Infections can be treated with an oral antibiotic or topical antibiotic cream. Radiation therapy can also lead to bladder irritation and diarrhea. Rarely, it can lead to incontinence and damage to the lining of the bladder.

The Importance of Clinical Trials

Clinical trials are the standard by which we measure the worth of new treatments and the quality of life of patients as they receive those treatments. For this reason, doctors and researchers urge people with cancer to take part in clinical trials.

Here are a few things, as a caregiver to a person with bladder cancer, that you should know:

- A member of their medical team can provide guidance as to whether a clinical trial is right for their specific circumstances.
- Often, people who take part in clinical trials gain access to and benefit from new treatments.
- Before they participate in a clinical trial, they will be fully informed as to the risks and benefits of the trial, including any possible side effects.
- Most clinical trials are designed to test a new treatment against a standard treatment to find out whether the new treatment has any added benefit.
- Participation in a clinical trial is voluntary. Your loved one can stop taking part in a clinical trial at any time for any reason.

CancerCare's Free Support Services and Programs

Being a caregiver to a person living with bladder cancer can be very difficult, and adjusting to the necessary changes in your life can be challenging.

Cancer*Care* can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our licensed oncology social workers can provide support and education, help in navigating the complicated health care system and offer information on support groups and other resources.

To learn more about how Cancer*Care* can help, call us at 800-813-HOPE (4673) or visit www.cancercare.org.

Frequently Asked Questions

Q: My brother has bladder cancer. I want to help with caregiving, but I live far away. What can I do?

A: Even from a distance, you can provide ongoing emotional support to your brother and to his primary caregiver. It is sometimes easier for people to talk about difficult topics over the phone than in person, so be willing to have in-depth and serious conversations. You can also help coordinate medical appointments (and send reminders to your brother and his caregiver about those appointments), provide verbal updates to other family members, and share information on how your brother is feeling (if he agrees) in an on-line journal such as CaringBridge.

Q: How does HIPAA affect my ability to talk to my loved one's health care team?

A: The Health Insurance Portability and Accountability Act (HIPAA), enacted in 1996, gives people greater access to their own medical records and more control over how their health information is used. Information about your loved one's health care condition or treatment can be shared with you in their presence. Your loved one can also sign a consent form allowing information to be shared with you without them being present.

Q: What can my loved one expect after treatment?

A: After treatment, your loved one will be closely monitored by their health care team, who will check to make sure the cancer has not returned. The specifics of the monitoring depend on the treatment they were given and often include physical examinations, imaging tests and routine blood and urine tests. If their bladder has not been removed, a cystoscopy (a minimally invasive procedure that allows the doctor to see the inside of the bladder with a small camera) may also be performed.

For people with a urinary "diversion" created after the removal of the bladder, follow-up care may include urine tests to check for infection, assessing and fixing any problems with urination control and checking for changes in kidney function through blood tests and imaging tests.

Resources

Cancer*Care*®
800-813-HOPE (800-813-4673)
www.cancercare.org

American Cancer Society
800-227-2345
www.cancer.org

Cancer.Net
Patient information from the American Society of Clinical Oncology
888-651-3038
www.cancer.net

Bladder Cancer Advocacy Network
888-901-BCAN (888-901-2226)
www.bcan.org

Medicine Assistance Tool
888-477-2669
www.medicineassistancetool.org

CAREGIVER RESOURCES

Family Caregiver Alliance
888-445-8106
www.caregiver.org

National Alliance for Caregiving
202-918-1013
www.caregiving.org

My Cancer Circle
https://mycancercircle.net

Well Spouse Association
800-838-0879
www.wellspouse.org

CLINICAL TRIALS WEBSITES

ClinicalTrials.gov
www.clinicaltrials.gov

EmergingMed
www.emergingmed.com

National Cancer Institute
www.cancer.gov

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