

How to tell people ...

you have bladder cancer.

The news

Breaking the news that you've been diagnosed with bladder cancer can be just as difficult as first hearing that news from your doctor. You may feel concerned about upsetting your family and friends, or worried about how they will react. Even after you have shared the news, at times you may find it difficult to communicate openly.

Sometimes it's uncomfortable to ask for help, answer questions about how you're doing, or tell well-meaning relatives and friends that you need some time and space for yourself.

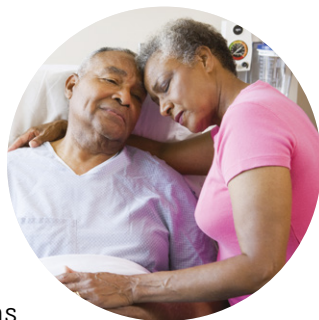
Being patients and carers ourselves, we understand that we are all different. Some of us find it easy to talk about cancer whilst others of us worry enormously.

After talking to many people about this subject, we have drawn up some tips for talking about bladder cancer with your family and friends. Naturally, the conversation is likely to change depending on whether you are talking with a close relative or acquaintance, an adult or a child. The most important thing to keep in mind is that you are the one who guides the conversation and decides how much information you wish to share. The content and the tone are entirely up to you.

Talking to your spouse or partner

If you are married or living together in a committed relationship, your spouse or partner is likely to feel the greatest impact from your diagnosis with bladder cancer.

It's natural for your partner to fear for your health and well-being, and to feel concerned about what will happen in the long term. Since the two of you run a household together, you've probably grown accustomed to certain roles and responsibilities. Your partner may wonder what will happen if you cannot handle your usual tasks, whether that means earning income, caring for children, paying bills, preparing meals or any other activities of day-to-day life.



Bladder cancer can intensify whatever patterns of communication existed in your relationship before. If you and your partner have always been able to talk through difficult issues, that ability will probably work well for you now. If open communication has been difficult, you might need to do some extra work to talk about cancer and what it means for your relationship and your family.

Although every relationship is unique, you may find it helpful to:

- **Involve your partner in medical appointments when possible.**

By coming with you to doctors' appointments, your partner will gain a first-hand understanding of your diagnosis, the treatment options and any side effects you might experience. Your partner will be better prepared for how you'll be feeling, you won't need to explain everything your doctor said after every appointment, and if your partner has a question, he or she can ask your doctor directly.

- **Be clear about your needs.**

Tell your partner exactly what you need. On some days, you might want to hand off certain household tasks that you typically handle. You might ask your partner to field phone calls from concerned friends, talk through treatment options with you or simply sit with you at the end of a long day. Try not to assume that your partner will be able to sense how you're feeling or what you need.

- **Ask your partner what he or she needs.**

As you, your family and friends focus on your treatment and recovery, it is easy for your partner to feel lost or overburdened. Talk to your partner about what he or she needs to do in order to get away and recharge. Encourage regular exercise, outings with friends or any other activities your partner enjoys.

- **Schedule time alone, just the two of you.**

This can be especially challenging if you have children, but it's important. Schedule regular times for you to get away from distractions so you can talk — not just about cancer, but about anything you have been thinking or feeling.



- **Accept the fact that you may have different coping styles.**

Each person responds to a cancer diagnosis differently. You may want to do lots of research, while your partner may prefer to rely solely on the doctor's guidance. One of you may be consistently upbeat and optimistic, while the other may need to ask all of the "What if?" questions. Talk about your differences and tell your partner what works best for you.

- **Figure out what adjustments will be needed in the household, and then ask for help together.**

While you're going through treatment, there are likely to be times when you cannot help with tasks such as household chores, shopping, errands, and caring for any children and pets you may have. You may have to cut back on work time, which could impact household income. Your partner might need outside support to keep the household running smoothly. Work together to figure out what kinds of help you need, and then approach family members, friends and neighbours for assistance.

- **Prepare for possible changes in your sexual relationship.**

Surgery, chemotherapy and other treatments for bladder cancer can affect you both physically and emotionally. Your body may feel and look different, and at times you may feel weak, nauseous or tired. Talk honestly and openly with your partner about these changes and ask for understanding while you are going through treatment.

- **Get professional help if you need it.**

A cancer diagnosis can place a great amount of stress on even the strongest relationships. A therapist, counsellor or social worker can help guide you and your partner through difficult conversations if you are having trouble communicating. If you're interested in finding a professional to talk to, ask your doctor for recommendations.

Talking to young children (age 3-9)

If you care for young children as a parent or grandparent, it may be tempting to shield them from the fact that you have bladder cancer. Experts agree that this is not a good idea. Even very young children can sense when family members seem stressed or anxious, or when usual routines are disrupted. They will notice changes in your appearance and your energy level, and they will know that you are spending time at the hospital.

Although young children do not need detailed information, they do need honesty and reassurance. Without any direct explanation from you, children may imagine a situation that is actually much worse than reality. Being honest with them builds a sense of trust that will be helpful in facing not only this situation, but also other challenges that life inevitably brings.



Young children need reassurance & honesty.

- **Plan out the conversation in advance**

Decide what you are going to say and how you are going to say it. This will give you a framework for the conversation. Involve your partner or another adult the children trust if you think their presence will be helpful.

- **Use direct, simple language to define what cancer is, where it is in your body and how it will be treated.**

Experts agree that naming the illness is important — “cancer” should not be a forbidden word. Even very young children can grasp simple explanations of what cells are and how they sometimes don’t “follow the rules” and grow as they should. You might also explain that the doctor has to remove all or part of your bladder where the cancer is, and then use special strong medicines to make sure the cancer is all gone from your body. A doll or stuffed animal could be a useful visual aid.

- **Make sure children know that the cancer isn't their fault and that they cannot "catch" it.**

Young children often see themselves as the centre of their worlds. They may worry that the situation is their fault or that they did something to cause the cancer. Also, children tend to associate sickness with catching colds or sharing germs. Explain that no one can catch cancer from someone else.

- **Tell children how treatment for cancer will affect you.**

Prepare them for the physical side effects of treatment, such as feeling sick or tired at times. You might explain that medicines for cancer are powerful, and that the side effects show that the medicines are hard at work inside your body.

Tell children that you might feel sad, angry or tired, but that these feelings are not their fault. Always let children know when you will need to be away from home in the hospital or at the doctor's surgery.

- **Reassure children that their needs will be met.**

Experts agree that young children need reassurance and consistent routines in times of crisis. Let your children know that you may not always be available to take them to school and special activities, play with them or prepare their meals.

Hugging, lifting and bathing them may be off limits for a while, too. Tell them about the trusted friends, relatives or other care providers who will be helping out until you feel strong again.



- **Keep usual limits in place.**

When there is an air of uncertainty around the house, it can be tempting to let children have more treats, watch more TV, play more computer games or buy more toys. However, maintaining the same sense of structure you *always* have is likely to reassure your children more than giving them special treats. Keep their usual routines as consistent as possible.

- **Invite children to ask questions and learn more.**

Let children know that you will answer any questions they may have. If your children are old enough, you might consider bringing them to one of your doctor's appointments or allowing a visit during treatment. This can help to take away some of the mystery surrounding cancer and its treatment.

- **Let children know you will still make time for them.**

Carve out a special time in the day just for them. Simple activities like reading a book or watching a movie can let them know that you are still there for them, even when you're tired or not feeling well.

- **Set a positive, optimistic tone without making promises.**

Even if you are sad or frightened, try to project a positive tone during your conversations with young children. Children may feel overwhelmed if you seem overly anxious or emotional. Make sure they know that your doctors and nurses are doing all they can for you, and that most people with bladder cancer do get better. Reassure them without making definite promises about the future.

- **Let teachers and other caregivers know what is going on.**

Other trusted adults who spend time with your child need to know about the diagnosis. Changes at home often cause changes in children's behavior in other settings. These adults can help you know how your child is doing, and they can become a source of additional care and support.

Talking to older children & teens

Although much of the advice for talking to children given on the previous pages also applies with older children (ages 10 to 18), older children have additional needs.

Given how often cancer gets talked about in the news and on television, older children are likely to be aware of the seriousness of the disease. In addition to your honesty and reassurance, they may crave more information than younger children do.

- **Be truthful about your diagnosis and course of treatment.**

Shielding children from the hard facts can harm their sense of trust in you. Even though you do not want to worry them, you do need to let them know what is happening to you.



Older children may need more information.

- **Schedule regular family meetings or other discussion times.**

Involve older children in talks about how family activities and responsibilities will change while you undergo treatment. You may need to ask them to handle more household tasks than they normally do. A family meeting gives everyone a chance to have a voice in the changes that are taking place.

- **Anticipate children's questions about the future.**

Older children are likely to have heard that people can die of cancer. It is natural for them to be afraid that you could die and to wonder what will happen to them. Make sure your children know that most people with bladder cancer do get better and live long, healthy lives. Even if the cancer is advanced, treatments can often keep it under control for some time. Reassure them that, no matter what happens, their needs will be met by you, your spouse or partner, or other caring adults in their lives.



- **Anticipate children's questions about their own health.**

Your children may fear that, since you have cancer, they may get it one day, too. Reassure them that this is very unlikely but that, together, you will find out all you can about bladder cancer to make sure that the whole family knows what to do to help prevent them getting it later in life.

- **Give older children permission to keep up with school and social activities.**

Even though older children and teens can take on more responsibility at home, they are still children. Let them know that they should continue focusing on their schoolwork, other activities and time with friends. Children need to maintain that sense of normalcy, but they might only do so if you let them know it's what you want.

- **Realise that older children may express feelings that seem inappropriate, such as embarrassment or anger.**

Preteens and teens may express emotions that seem unkind or even completely out of line. They may be embarrassed by changes in your appearance, such as hair loss or weight loss, and avoid going out with you or bringing friends home. They may be angry about the ways that your illness limits them and their activities. Although their reactions may upset you, remember that teens are at a time in their lives when they value appearances and their growing sense of independence.

- **Connect them with books and other resources.**

Talking about cancer can be hard, even in families where communication is strong. You may want to look for books or other publications written especially for young people who have parents with cancer. Your child may also find it helpful to confide in an adult outside the immediate family, such as another relative, close friend or even a professional counsellor. Reach out to your relatives and friends and ask them if they can be available.

Talking to other relatives & friends

Like most people, you probably have close relatives and friends you see and talk to regularly, as well as a wider circle of contacts you may only keep in touch with occasionally. You get to decide whom you want to tell about your diagnosis and how you wish to reveal the information. At the very least, it is important to tell the people who are closest to you, because they are most likely to be a source of emotional and practical support.

- **Decide on whom you want to tell yourself, and plan out the conversation in advance.**

There are likely to be certain people in your life — parents, siblings and close friends, for example — with whom you will want to share information directly. Determine whether you want to share the news in person (if it's practical) or over the phone. Spend some time scripting out the conversation in advance.

Some relatives and friends might react with shock, surprise and even dismay. Keeping the focus on the facts as you know them and the treatment plan going forward may be helpful for each of you. Think about how you want to put it and what you want to say.

- **Be prepared to accept and ask for help.**

Friends and family often respond to a cancer diagnosis by asking, "Is there anything I can do to help?" Be ready for that question with some specific suggestions. You might ask them for a few hours of childcare, help with running errands, a frozen homecooked meal or two (always in a disposable container so you don't have to worry about returning dishes) or some other favor. Anticipate what you might need and keep a list of "assignments" you can make.

**Don't be
afraid to ask
your friends
for help!**



- **Tell loved ones what the plan will be for sharing updates about your condition.**

You may not want to take on the task of calling family and friends yourself or having to field their phone calls while in the midst of treatment. Consider assigning a “point person” or two to keep others up to date. You may wish to use e-mail or the web to post regular updates if you have an especially large or far-flung circle of contacts.

- **Set limits on communication if you need to.**

You may find yourself overwhelmed with calls and visits from family and friends who want to check in on you. If this happens, consider screening your calls and then returning them all at the end of the week, or getting a trusted family member to return them. You also might limit visits to 1 or 2 days or evenings per week. You could ask one friend or relative to organize the network of people who want to help out.

- **Understand that family and friends may not respond the way you want them to.**

Be prepared for the fact that some people might say or do the wrong thing, not because they are unkind, but simply because they do not know how to respond. They might look for reasons why you got bladder cancer, such as smoking, diet, exercise or lifestyle factors. They might offer up clichés such as “Be strong,” “Stay positive” or “If anyone can handle this, it’s you.” They may want to tell you stories about other people they know who have had cancer. They might start avoiding you entirely because they don’t know what to say or do. Try not to take any of this personally. Instead, focus on family and friends who can give you the kind of support you need.

- **Remember that you have control over how far you want to spread the word.**

While it is important to tell your closest relatives, friends and people who will be affected directly, you can decide whether or not you wish to inform anyone else. Some people find it helpful to keep certain spaces in their lives “cancer-free,” so that they don’t always have to contend with questions about how they’re doing or feeling.





Finding someone else to talk to

It's important to find a trusted confidant with whom you can discuss your most intense fears and concerns as well as your hopes.

You may find that your spouse, life partner, or other relative or friend can play this role. If they cannot, consider going outside your usual circle of family and friends to find someone you can talk to. This person might be a doctor or nurse, or another person with bladder cancer

It does not matter who this support person is; what is important is that you have someone who allows you to speak openly. Don't forget that you can always talk to someone on our [Confidential Forum](#) or use our [Bladder Buddy Service](#).



**bladder
CANCER**

Reg. charity 1157763

ABOUT FIGHT BLADDER CANCER

Fight Bladder Cancer is a patient-led charity in the UK that exists to:

- **support anyone affected by bladder cancer**
- **raise awareness** of the disease in order to improve early diagnosis
- **campaign for and support research** into this disease
- **affect policy** at the highest level to bring about change

Fight Bladder Cancer has a worldwide reputation and is supported by top international healthcare professionals.

At Fight Bladder Cancer, we take great care to provide up-to-date, unbiased and accurate facts about bladder cancer.

We have a very supportive medical advice panel made up of some of the best professionals working with bladder cancer, and hope that our information will add to the medical advice you have had and help you to make decisions.

REMEMBER, YOU CAN CONTACT US AT ANY TIME FOR SUPPORT

or to engage with us in fighting bladder cancer

via our website at

fightbladdercancer.co.uk

via our online forum at

facebook.com/groups/bladdercanceruk/

by email at info@fightbladdercancer.co.uk

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