CANCER RESEARCH UK

Living with Bladder Cancer

A Quick Guide

Contents

This is a brief summary on 'Living with bladder cancer' from our website. You will find more detailed information on there. In this information there are sections on

- Coping with bladder cancer
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- Bladder cancer organisations

You can view this information in a larger print on our website.

Coping with bladder cancer

It can be very difficult coping with a diagnosis of cancer, both practically and emotionally. You are likely to be feeling very confused and upset at first. As well as coping with the fear and anxiety that a diagnosis of cancer brings, you have to work out how to manage practically.

Our coping with cancer section contains lots of information you may find helpful. There are sections on:

- Your feelings
- Talking to people: who and what to tell
- Talking to children
- How you can help yourself
- Who else can help you
- Financial support including Government benefits and charity grants

Life after bladder surgery

Living with a urostomy

After some operations to remove the bladder you have a small hole like a spout called a stoma (urostomy) on your abdomen. The urine comes out through the stoma. It may take some time to get used to this but you will have a stoma nurse to help you. There are practical things to learn such as changing your urostomy bags or self catheterising and irrigating your stoma. But there is also the change in your body to come to terms with. If you find this difficult, you could contact one of the bladder cancer organisations.

Job, sports and social life

Unless you do heavy manual work, your surgery should not make any difference to your job. Ask your stoma nurse if you are unsure. Your urostomy will not stop you enjoying your favourite pastimes. Exercise and swimming are possible. Your stoma nurse can give you advice. To avoid having to get up in the night to empty your stoma bag, don't drink large amounts of fluids late in the evening. You can also attach a night drainage bag to your day one so it can hold more urine.

Your relationships

It is very likely that you will feel worried about how the stoma will affect your relationships. These can be practical worries about the bag being noticed or leaking. Or you may have emotional worries about how your friends or partner will react. If you are able to talk openly with close friends and family about your surgery, you will probably find that these worries may lessen or disappear.

Living with bladder reconstruction

There are really very few things you can't do. If you lift something really heavy, you may find that your bladder leaks. You will find out by trial and error which activities cause problems.

Changing your urostomy bag

There are different types of urostomy bag, so we can't give you detailed information about how to change it here. Your stoma nurse will show you how to change your bag. It is helpful to keep everything you need in a bag or in one place. That way, you won't discover that something is missing half way through. Your nurse will make sure you are confident about changing your bag before you leave hospital. Remember it takes time to learn how to do new things. If you are having any problems contact your stoma nurse.

You don't have to keep anything sterile (completely free from all germs) for a bag change. But it's important to be hygienic so do wash your hands before and after. It's also important to look after your stoma and the skin round it. As part of each bag change, you'll need to wash and dry the skin thoroughly.

Emptying and washing out your continent urinary diversion

If you have had your bladder removed and an internal pouch created to hold the urine this is called a continent urinary diversion. You will need to learn how to empty urine from the pouch and wash it out. On your abdominal wall you will have a small spout like hole called a stoma for the urine to come out. The stoma acts as a valve to stop the urine coming out.

Emptying the pouch

You empty urine from the pouch by putting a tube called a catheter into the stoma. This is called self catheterisation. You start doing this once the stoma and pouch has healed. This is normally 2 to 3 weeks after your operation. Your stoma nurse will show you how to do it.

You don't have to keep everything sterile when you drain your urine. But it's important to be as clean as possible to avoid getting an infection. To start with, you will need to empty the pouch every 2 hours or so. As the pouch stretches, you will be able to cut this down to every 4 to 6 hours during the day.

Washing out the pouch

Mucus can build up in the pouch and so you will need to wash this out. Your stoma nurse will advise on how often to do this, as it can vary.Washing out the pouch is called irrigating it. You put a catheter into the pouch and then put water or salt water through this into the pouch using a syringe. Then you draw the liquid out with the syringe. You repeat this until the liquid is clear.

Your sex life and bladder cancer

For men

If you have your bladder removed, your prostate will If you have your bladder removed, your prostate will be removed as well. During this operation the nerves that control erection can be damaged. This means you may not be able to get an erection after your operation. Having your prostate removed also means you cannot ejaculate, so your orgasms will be dry. Radiotherapy to the bladder area can also cause erection problems for some men.

There are several options to help you get an erection. These include drugs such as sildenafil (Viagra) or other similar drugs. There are also injections or pellets that go into the penis itself. Another alternative is a vacuum pump that draws blood into the penis to stiffen it. Talk to your doctor or specialist nurse if you would like to try any of these.

For women

Often the operation to remove your bladder and urethra can shorten or narrow your vagina. You may need to use small cone shaped dilators to stretch the vagina. Talk to your surgeon or specialist nurse beforehand if this is a concern for you. Radiotherapy can sometimes cause vaginal dryness and vaginal shrinking. Gels and creams are available to help reduce vaginal dryness. And dilators can help to stretch the vagina. Your specialist nurse can advise you about this.

What to ask your doctor about living with bladder cancer

- Who can answer my questions about coping after bladder surgery?
- How do I get the equipment I need to manage my urostomy or continent urinary diversion?
- Do I have to pay for any of the equipment?
- When can I go back to work?
- Can I start my usual sports, hobbies and activities again?
- Is there anyone I can talk to about how treatment has affected my sex life?
- Can my partner come too?
- Who can help me manage symptoms or treatment side effects?
- Is there a specialist nurse I can see?
- Where can I get help dealing with my feelings?
- Do I have to pay for counselling?
- What practical help is available?
  Is there anyone who can help me with money matters, including claiming benefits?

Bladder cancer organisations

Cancer Research UK

Website: http://www.cancerresearchuk.org/cancer-help/
Cancer Information Nurses phone: 0808 800 4040

The Urostomy Association

Phone: 01889 563191
Email: secretary.ua@classmail.co.uk
Website: www.uagbi.org

Bladder & Bowel Foundation

Phone: 01536 533255
Email: info@bladderandbowelfoundation.org
Website: www.bladderandbowelfoundation.org

Notes

For more information, visit our website http://www.cruk.org/cancerhelp

You will find a wide range of detailed, up to date information for people affected by cancer, including a clinical trials database that you can search for trials in the UK. Our information is based on the best current scientific evidence and reviewed regularly by leading clinicians and experts in health and social care.

For answers to your questions about cancer call our Cancer Information Nurses on 0808 800 4040 9am till 5pm Monday to Friday.