

Carers' A to Z guide

for all supporters of bladder cancer patients



**A GUIDE
FOR CARERS
BY CARERS,
PROFESSIONALS
& PATIENTS**

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This series of booklets has been prepared by a team of carers, patients and medical professionals working together to give clear, straightforward guidance.

The booklets have been produced in conjunction with the **British Association of Urological Nurses (BAUN)**, the professional organisation for specialist urology nurses in the UK, and are endorsed by the **British Uro-Oncology Group (BUG)**, the **British Association of Urological Surgeons (BAUS)** and **The Urology Foundation**.

WITH THANKS TO ALL THE CONTRIBUTORS

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Fight Bladder Cancer

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Settlement

MERCK

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This booklet is part of a series covering all aspects of the bladder cancer pathway.

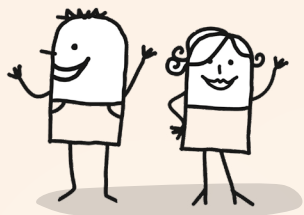
We also publish our regular *Fight* magazine, full of inspirational stories, research information and practical advice.

They are all available free in print and digital editions (see page 57).



This symbol is used throughout the booklet to highlight information that is most likely to be relevant to those with higher-grade cancers.

Our **carer tips** come from **real carers** around the world!



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 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.

Hello, carers

You have found yourself in a situation where you are caring for someone with bladder cancer. Perhaps your partner or loved one has just been diagnosed, or maybe they are a long way down their cancer pathway. Whatever your relationship with the cancer patient – spouse, partner, parent, child, sibling, relative or friend – this book will help you cope with this unexpected, unplanned and incredibly daunting role.

Bladder cancer affects every patient – and therefore every carer – in a different way.. We have tried to support all carers in this booklet, so inevitably only some topics will affect you. The information is organised so that you can dip into just those problems or challenges that affect you and gloss over anything that is not appropriate to your circumstances.

There are many entries that will be irrelevant to those who are caring for someone with non-muscle-invasive bladder cancer (NMIBC) but will prove useful for anyone supporting a patient who has been diagnosed with muscle-invasive bladder cancer (MIBC). We recommend you focus only on your unique situation.



To help you find the appropriate level of information, text marked with a star is for carers of people with MIBC and more advanced forms of bladder cancer.

First, take a deep breath. If you are anything like most people who have discovered themselves to be carers – sometimes shockingly suddenly – you will not only be feeling the same panic and fear that your loved one is feeling, but also trying to fathom out what your role will be in the difficult times that you know are ahead.

Along with rising panic, you may be feeling overwhelmed, frightened and probably angry. What will it involve? How will you manage? Are you the only one who experiences that fleeting thought that you are relieved it's not you (definitely not!)? You may also be wondering whether you have it in you to cope.

We are here for you every step of the way

**Let us reassure
you: you are not alone.**

There are thousands of others shouldering the same responsibilities as you, and there are people and resources to help you find the information you need so that you can make the best choices and get the best support.



Fight Bladder Cancer Forum Members

This booklet has been written for and by bladder cancer carers and family members, with support from the patients they care for and the professionals who care about them and for them. No matter what path your bladder cancer journey takes, know that there are others here who will share the journey with you.

Where Fight Bladder Cancer began

In the middle of the night, while her partner, Andrew Winterbottom, was in hospital awaiting surgery for muscle-invasive bladder cancer, Tracy Staskevich desperately searched the internet for sound UK-based information. She drew a complete blank. So at visiting time in the hospital the following day, they decided that something had to be done to address the shortfall – and Fight Bladder Cancer was born.

From the outset, it was clear that it was not only patients who needed good-quality information, support and resources, but also those who loved them – the partners, family members and friends who play such a huge role in any cancer journey. It is often the carers who are the ones on the internet in the middle of the night searching for information, the ones trying to keep life together during hospital trips and treatments, and whose difficult role is to sit on the side-lines and endure the worry and uncertainty that loving someone with a bladder cancer diagnosis brings.

Therefore Fight Bladder Cancer has always had, and will always have, carers alongside patients at its heart and why we at FBC will always offer support and information to ALL those affected by the disease.

Your role as a carer

When someone you love is diagnosed with cancer, it is like being run over by a truck. Your first reaction is likely to be that you feel completely powerless. Stop. Breathe and take stock. Take the time to absorb the diagnosis and find out what you are dealing with in your specific case. There is a huge range of possibilities and no two cases are the same.

It may be that your partner has a low grade of bladder cancer and can be successfully treated in a relatively short space of time, with subsequent regular follow-ups – just like an MOT. You will need to know about the tests and procedures involved, and the best places to find out more information. You will be introduced to your clinical nurse specialist (CNS), who will be able to order for you the appropriate booklets in this series by Fight Bladder Cancer to help you understand what is likely to happen and give you practical tips on navigating your way through.

★ Alternatively, your partner may have been diagnosed with a higher grade of bladder cancer. Suddenly becoming their carer and watching someone you love face cancer, from diagnosis through treatment and beyond, could be one of the hardest things you will have to cope with in life. It can involve uncertainty, waiting, impossible decisions and many hours of worry. It could change your life.

Whatever you have ahead of you, you may feel that you are not suited to the role and you won't be any good at it. You may be a massive control freak and hate having to stand by and watch uncomfortable or distressing things happen to someone you love that you can do nothing about. You may make an exceptionally poor nurse (or think you will), running low on both sympathy and patience in equal measure. We all have our shortcomings and no one can be prepared in advance for a caring role that we didn't ask for. But at Fight Bladder Cancer, we believe in our strengths and not our perceived shortcomings, and we will help you find your strengths.



Malcolm and Jeff

Tracy's magic hour

In the many years of Andrew's appointments, mad dashes to A&E, operations, results, clinics and the like, Tracy realised the impact of the first 60 minutes of receiving the latest news about Andrew and she called it the magic hour. This was the first hour she was alone with the update on the cancer's progress. It was a time she never let him see. In front of him, she was his rock – steadfast, strong and encouraging, cartwheeling hope and positive mental attitude.

★ The first magic hour was when the consultant broke the news that Andrew had a large tumour that had grown beyond the bladder wall and that they had been unable to remove it all with the first procedure a transurethral resection of bladder tumour, or TURBT (see page 14). The chart on the wall ominously labelled it 'Stage 4' (there was no Stage 5). Tracy and Andrew huddled together on his hospital bed and discussed what they would do in the next six weeks until his operation. They joked about the size of the parties they'd have and how much they'd drink, and they decided to get engaged. Then Tracy waved her way down the corridor and, somehow, got back to the car park. Tracy remembers:

'As I unlocked the car door, my legs crumpled beneath me and I wailed. Sobbing into the steering wheel, I pounded my fist on the dashboard and screamed at the sky at the utter unfairness of it all before disintegrating into a pile of salty tears and snotty gulps. It took me 56 minutes to compose myself that day.'

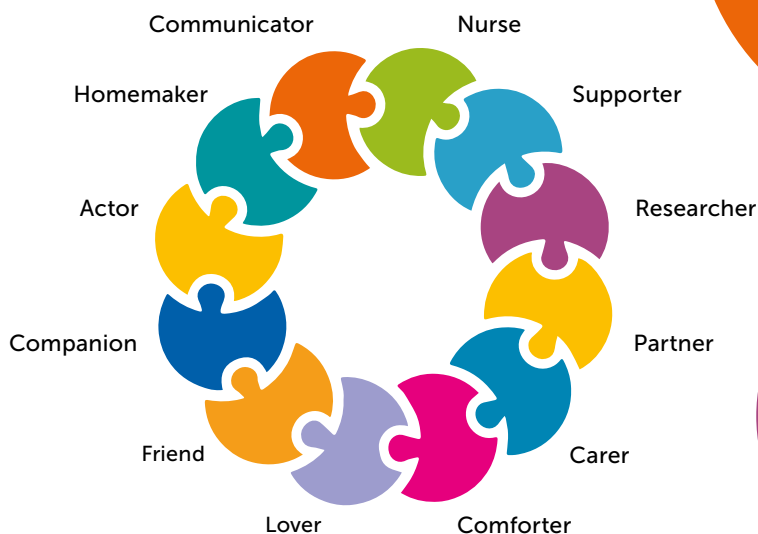
Once the magic hour is over, it is time to enter the other default setting as a carer ... war mode. Summon your strength and get ready for battle as it could be the best route to staying sane in a situation over which you have little control. For a partner, a cancer diagnosis is emotionally as tough a journey as being the patient ... in fact, sometimes it's harder.



Tracy and Andrew

What will I have to do?

Every caring role will be as individual as you are. There are no hard and fast rules but, for sure, you will be fulfilling plenty of equally important roles while you are a carer.



! This booklet is designed for all carers – spouses, partners, parents, children, relatives – so no single word describes the person you are caring for. We decided to call them *patient* or *partner*.

'My late husband would have verbally wiped the floor with anyone who described me as his "carer" – we preferred "supporter".'

Learning to juggle whichever roles come with your brief without losing yourself, is at the heart of being a carer and this booklet will give you the ideas and support you need to find the way that is right for you.

Do remember, though, that your journey is your own. Others may have an easier or a tougher path than you.



Mike and Alison

What is cancer?

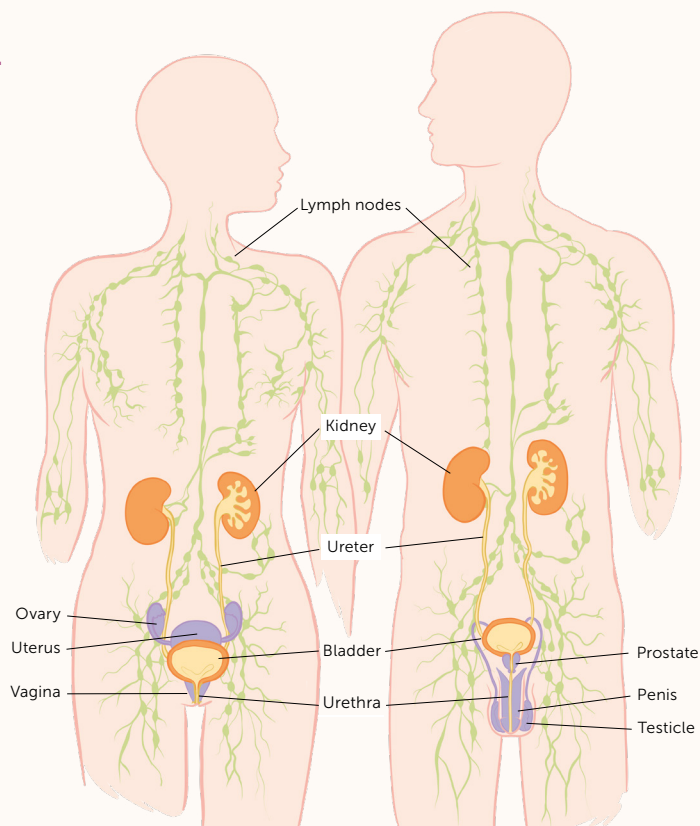
Firstly, knowing something about the disease you are dealing with will help you understand what is going on and allow you to support your partner through appointments, consultations and treatment.

Cancer is a genetic disease, the name given to a collection of related diseases that can start almost anywhere in the human body, which is made up of trillions of cells. Cells are the components from which our bodies are built. They divide and grow while they are needed, then stop growing and die when they are not. If something goes wrong in a cell, it continues to divide, making more abnormal cells which eventually form a lump, or tumour. A benign tumour will not spread beyond where it originally formed but a malignant tumour can grow into nearby tissue, and can travel around the body via the blood or the lymphatic system.

The lymphatic system is a network of organs and tissues that help the body to get rid of toxins, waste and other unwanted materials by circulating lymph, a fluid containing infection-fighting white blood cells.

The urinary system

Urine is formed in the kidneys, which filter the blood, removing waste products and water. Urine then travels to the bladder from the kidneys, via tubes called the ureters, leaving the body through another tube called the urethra. A tumour in the bladder, or anywhere in the urological system, can disrupt the rest of the urinary system.



You need the right knowledge

To add to the emotional storm whirling around you as you begin your cancer journey is the fact that you need to take on board a whole raft of new information about your partner's condition. To support the informed decisions that will be necessary, it will be helpful if you can understand what the diagnosis means and what treatment options are available.

Cancer has one name but a vast number of subcategories. Bladder cancer alone subdivides into muscle-invasive and non-muscle-invasive, and different stages, grades and types. There are considerable differences between muscle-invasive and non-muscle-invasive bladder cancer as far as the treatments and prognosis are concerned, so remember, while it helps to do some research into the disease, this is personal. Every case is different.



Doing extensive research before you understand the diagnosis may not only leave you with information overload but could also cause unnecessary worry.

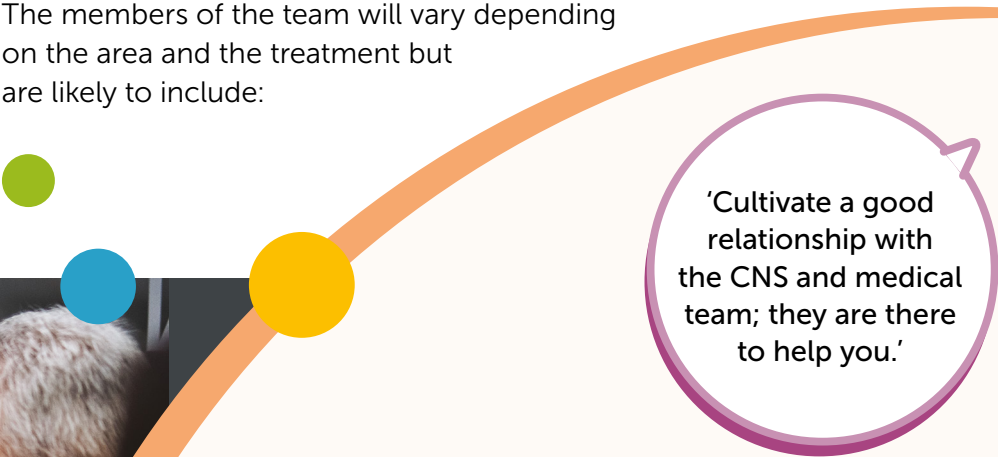


While your medical team will explain things to you, most people need time to reflect on all this new information and look for more guidance from other sources. That can be very valuable, but do remember firstly that a bladder cancer diagnosis is unique to your case, and secondly that you should only look for information from reliable sources, such as a nationally respected research institute or organisation like Fight Bladder Cancer, Macmillan or Cancer Research UK, and discuss what you have found with your clinical nurse specialist (CNS) or medical team.


You are part of a team

People with bladder cancer are cared for by a multi-disciplinary team (MDT) of medical professionals, each with their own expertise.

The members of the team will vary depending on the area and the treatment but are likely to include:



'Cultivate a good relationship with the CNS and medical team; they are there to help you.'

- 
- **GP:** your family doctor
 - **clinical nurse specialist (CNS):** your first point of contact, sometimes called a urology nurse specialist
 - **urologist:** a doctor who specialises in treating conditions that affect the urinary tract
 - **clinical and/or medical oncologist:** a specialist in non-surgical treatment of cancer
 - **pathologist:** a specialist in interpreting biopsies and removed tissue
 - **radiologist:** a specialist in interpreting x-rays and scans

The team may also include professionals such as a research nurse, a stoma nurse, a physiotherapist, a district nurse, a counsellor or an occupational therapist.

All about the types of bladder cancer

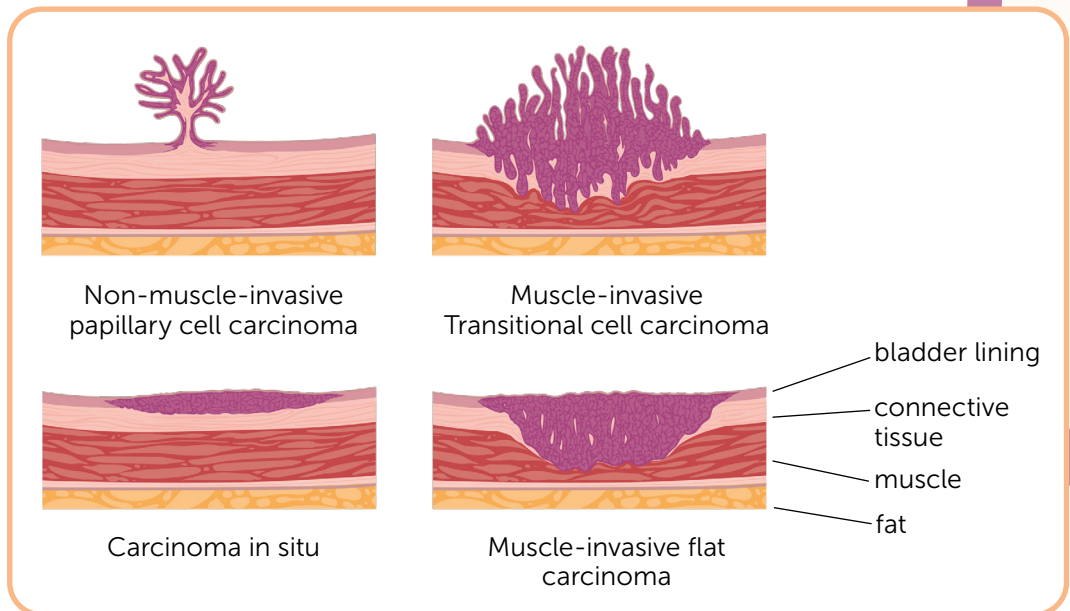
When a cancer is diagnosed, it will be described by type, stage and grade. This will define whether the cancer is low, intermediate or high risk and determine the type of treatment that will be offered. It is important to discuss the situation with your medical team and make sure you understand both the diagnosis and the proposed treatment.

TYPE

The most common form of bladder cancer is transitional cell carcinoma (TCC) or urothelial cancer. TCC begins in the cells of the bladder lining. If it has only been found on the bladder lining, it is known as non-muscle-invasive, superficial or early-stage bladder cancer. If it has spread into or beyond the muscle wall, it is known as muscle-invasive. Carcinoma in situ (CIS) is a wide, flat tumour.



If you have any questions, ask. And ask again if you don't understand.



Less common types of bladder cancer include *squamous cell cancer*, *adenocarcinoma*, *urachal* and *small cell bladder cancer*. These are usually muscle-invasive forms of cancer.¹

STAGES

A system called the TNM system is used to define the stage of the cancer, which means how far it has spread from the bladder lining.

- 1 T** (tumour) – how far the tumour has grown into the bladder
- 2 N** (nodes) – whether the cancer has spread into nearby lymph nodes
- 3 M** (metastasis) – whether the cancer has spread into another part of the body, such as the lungs

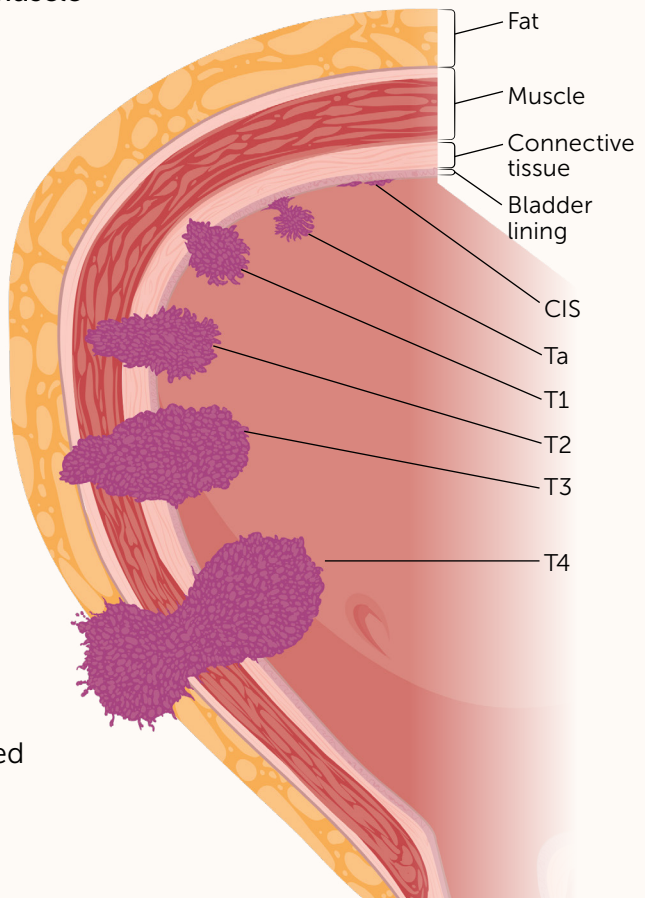
1 The T stages

The T stages define how far the tumour has grown into the bladder.

These are the T stages of non-muscle-invasive bladder cancer.

- **T0:** no tumour
- **TIS (CIS):** carcinoma in situ, a flat, fast-growing tumour that spreads across the inner layer of the bladder
- **Ta:** papillary, mushroom-shaped, tumour that is only on the innermost layer of the bladder
- **T1:** tumour has started to grow into the connective tissue

Although CIS is a type of non-muscle-invasive cancer, it is an aggressive form which may spread more quickly than other types, so it is always classed and treated as high grade.



If the tumour grows further than this, it's usually called muscle-invasive bladder cancer.

These are the T stages of muscle-invasive bladder cancer.

- **T2:** tumour has grown through the connective tissue into the bladder muscle
- **T3:** tumour has grown through the layer of muscles into the surrounding fat layer

If the tumour grows further than the T3 stage, it's considered to be advanced bladder cancer.

The final T stage is defined as advanced bladder cancer.

- **T4:** tumour has spread outside the bladder into other organs (such as the prostate or uterus)

2 The N stages

The N stages define the cancer in relation to its spread to the lymph nodes:

- **N0:** there are no visible cancerous cells in any of the lymph nodes
- **N1:** there are cancerous cells in one of the lymph nodes in the pelvis
- **N2:** there are cancerous cells in two or more of the lymph nodes in the pelvis
- **N3:** there are cancerous cells in one or more of the lymph nodes (known as common iliac nodes) deep in the pelvis

3 The M stages

The M stages define whether the cancer has spread into another part of the body

- **M0:** there is no sign of cancer spread to another part of the body
- **M1:** the cancer has spread to another part of the body, such as the bones, lungs or liver



GRADE

The grade refers to what the cancer cells look like under the microscope compared to healthy tissue and indicates how aggressive the cancer is and how likely it is to spread. The number of tumours will also affect the grading.

To classify bladder cancers, the World Health Organisation established a system in 1973, and then established a slightly different system in 2004.

In the 1973 grading system, grades are expressed as a number; the higher the number, the less the tumour resembles a normal cell and therefore the more aggressive it is. Alternatively, the doctor may simply refer to the grade of the tumour as low, intermediate or high.

- **G1 / low grade**
- **G2 / intermediate grade**
- **G3 / high grade**

In the 2004 system, the categories are:

- **PUNLMP** (Papillary Urothelial Neoplasm of Low Malignant Potential)
- **low grade**
- **high grade**

You can see from the diagram below that the boundaries of the three sections are not the same. It is like comparing UK and European shoe sizes; a size 7 can be converted to a 40 or a 41.

PUNLMP	Low grade	High grade	2004 WHO
Grade 1	Grade 2	Grade 3	
			1973 WHO

Stratification of tumours according to grade in the WHO 1973 and 2004 classifications

Understanding treatment options

There are many different treatment routes that your partner's cancer may require. This is an overview of possible treatments – your partner's medical team will explain those that are relevant and you will find the details of the treatment in the most appropriate FBC booklet, which your CNS can order for you, or you can download direct (see page 57).

Everyone is different. Some people want to know every minute detail of what is likely to happen; others prefer just to stick to the basics. Try to tune into your partner's wishes and act accordingly. But remember that the doctor cannot read their mind and you need to communicate with them so they know how much detail is required. Encourage your partner to ask questions and ask your own, so you understand the options and, between you, find out everything you need to know.

Urine tests

Various urine tests are done by the GP to ascertain the initial problem and the patient will have many more during their treatment.

Flexible cystoscopy

Known as a 'flexi', this will become a familiar procedure. It is usually done under a local anaesthetic. A camera attached to a flexible tube is inserted into the bladder to investigate and diagnose the problem.

TURBT

Similar in principle to a flexi, a Transurethral Resection of Bladder Tumour is carried out with a rigid rather than a flexible instrument so is done under general or spinal anaesthetic. The doctor can examine the tumour more effectively and may also be able to remove some or all of the tumour at the same time. A sample, or biopsy, is sent to a pathologist for examination.



Chemotherapy bladder wash

After a TURBT, the bladder is often filled with a chemotherapy solution which is then drained off after an hour. This can reduce the chance of the cancer recurring.

X-rays, CT and MRI scans

All of these are diagnostic tools rather than treatments, designed to help the medical team understand the type, stage and grade of the cancer and determine the best treatment.

BCG

Bacillus Calmette-Guérin treatment involves a solution full of bacteria being introduced into the bladder and remaining there for a couple of hours before being drained off. The objective is to activate the immune system to kill the cancer cells and reduce the chance of the cancer coming back in the future. This is repeated in a series of treatments.

Radical cystectomy

Surgery usually involves a radical cystectomy (RC), during which the bladder, part of the urethra and the surrounding lymph nodes are removed as well as the prostate (in men) and the cervix and uterus and upper third of the vagina (in women).

If the bladder is removed, the patient needs another way to wee. They may be given a stoma: an opening near the belly button connected to the urinary system to which the patient attaches a bag to collect their wee; or they may have a neobladder fashioned out of a piece of bowel. Other methods are less common in the UK.

Radiotherapy

This uses carefully measured doses of radiation to destroy cancerous cells. Curative radiotherapy is usually given daily for five days a week over four to seven weeks. Palliative radiotherapy can be given in a single dose, three doses or six doses in six weeks, depending on the patient.

Chemotherapy

This involves injecting drugs into the bloodstream with the aim of destroying the cancer. Neoadjuvant chemotherapy is given before surgery or radiotherapy to shrink the tumour before the main treatment. Adjuvant chemotherapy is given after surgery or radiotherapy, to lessen the chance of the cancer coming back. Concurrent chemotherapy is given alongside radiotherapy. Palliative chemotherapy aims to improve symptoms and extend life, hopefully of a better quality; it does not mean that the patient is terminal.



Immunotherapy

The role of our natural immune system is to fight off foreign, unwanted things in the body that can cause damage.

Immunotherapy takes advantage of this to teach the body's immune system to target the distinguishing characteristics of specific cancers and destroy the malignant cells. These treatments are given as intravenous infusions. The administration of treatment can be an all-day event for some patients. Significant successes have been achieved in clinical trials.

'My husband was on immunotherapy for 18 months. He did well with it. There were not many side-effects at all and he remained working the whole time.'

Targeted therapies

Currently in clinical trials for people with advanced cancer and showing promising results, the use of these drug therapies is likely to become more common. Unlike immunotherapy treatments, which focus on helping the immune system to destroy the cancer, targeted therapies look at a specific protein in the DNA of individual cancers and tries to isolate what is unique about them. When that can be defined, researchers can identify the cancer's 'Achilles' heel' and find ways to destroy it.

You will find detailed explanations of all these treatments in other booklets in this series (see page 57).

Your A to Z guide

As a carer, you are likely to fulfil many roles and experience many emotions. These guidelines – developed by carers across the world – are designed to inform, support and reassure you that you are not alone.

★ This indicates entries that are most useful for carers of patients with MIBC.

A is for anger

Many carers are surprised by the extent of the rage they feel on hearing their partner's diagnosis. It is common for partners to feel outraged that this could happen to them, that cancer has stomped its way into their lovely life, broken everything and then walked away. When your partner is diagnosed, it's normal to feel as though you have been cheated of your future and to strike out at those you are closest to, often the person who has been given the cancer diagnosis themselves.

'Have patience but also to remember it's ok to be frustrated or angry. We are human and it is unreasonable for us to be positive all the time.'



'The realisation that our lives had changed forever was the next hurdle to cross.'

Let yourself feel this way and acknowledge the change in your lives rather than trying to cover it up and hope it will go away. (It won't.) Talk openly about it. Then try and use the emotion to make positive differences in your life, focusing on the things you have both always wanted to do. Often cancer can be the impetus you need to make significant changes in your outlook on life ... for the better.

A is also for ...

alone

You are lucky if you have an extensive support network both for yourself and the patient. Don't refuse offers of help – accept them with thanks. Tell people what would be most helpful and let them share the load.

alternative therapies

There is no scientific evidence that alternative treatments – using diet, herbs or homeopathic remedies – can be successful in combatting cancer. If you are considering including any such remedies in your treatment programme, do discuss it with your GP or consultant before taking any action as there is the possibility that they will interfere with existing treatment. Complementary therapies (see page 21), exercise and a healthy diet and lifestyle, however, can help to promote physical and mental wellbeing.

'Your friends may suggest the whackiest of "treatment" ideas but it's okay to say, "no thanks".'



anxiety

'You have that constant sick feeling about what the future holds, the hours lying in the dark when you can't sleep, the fear of the next phone call or the nervousness of opening the hospital letter that drops on your mat. And all the time, you are trying to keep up the positivity.'

Anxiety is defined as a feeling of worry, nervousness or unease about something with an uncertain outcome. It is the result of that constant drip-drip-drip of the cancer symptoms, appointments, waiting for results, poor sleep ... never being able to get away from its all-consuming nature. Try some of our tips to help you sleep, then try to prioritise those things you can alter. Anti-anxiety medications have helped some people – discuss with your GP to see if they are right for you.



appropriate

Local authorities must make sure that young carers (see page 51) are not doing jobs that are inappropriate to their age and their relationship with the patient. Ask your GP or Carers UK² about the appropriate local services.

B is for build

Build a support network – as big as you can and as fast as you can. Remember, this network is for YOU, not the patient. You both need one. Many carers try to do everything themselves, assuming they must take on the mantle of some kind of caring superhero. The only possible result of that is exhaustion. And you are no good to your partner if you are in a state of collapse.



Build that network and take every scrap of help offered to you. Let someone come and do your housework or take a few loads of washing from you. Welcome friends who offer to cook you dinners or drop in something for the freezer. It's good for you and it actually also helps them, as they feel they are actively doing something useful. So, next time someone utters that immortal line, 'Well, if there's anything I can do ...' make sure you take them up on it.

B is also for ...

brave

Most carers say they are not brave at all – they just do what they have to do to support their partner but it does take courage and strength to hold it all together and keep life moving forward on a day-to-day basis. It may not make headlines but it is courage nonetheless.

breathe

When you begin to feel rising panic, when your head is spinning with knowledge you would rather not have, when you can't get to sleep at night, don't forget to breathe. Stand up with your arms raised, or just lie still, and breathe deeply in through your nose, then out through your mouth.

'As a carer you need to be brave and try not to show your concerns at times.'

'To help you relax, there are some great apps you can download on your phone that help you practise your breathing any time you need.'

C is for cry

The emotions you will feel will change, strengthen and weaken as you share your partner's cancer journey. There will be sadness and joy, regret and positivity, anger and love. Whatever emotions you are experiencing, you cannot keep them locked inside. It's much too big. Wail, shout, curse the gods and let it out. Scientists still don't know why crying makes us feel better; there are all kinds of theories about tears containing excess stress hormones which are washed away when we cry. Whatever the science behind them, tears do help, so grab a box of tissues, wrap yourself in a duvet and as Elsa in Frozen so wisely advises, 'Let it go.'

C is also for ...

calm


Try not to lose it at critical moments when your partner most needs to be supported.

children

Especially if your partner is very ill during treatment, it may fall to you to continue to ensure that your children's routines are disrupted as little as possible. Try to explain to them what is happening with

a level of detail appropriate to their understanding, because it is better to have correct information from you than to imagine what is going on and get it wrong. Answer their questions as accurately as you can. Try to make time for them and to maintain their social and educational patterns as much as possible as that will give them reassurance and confidence.

The school will have a pastoral care system so do contact their teacher or the head to explain what is going on in the family. They will then be able to look out for early signals if the child is finding it difficult, and may well be able to offer you additional support.



'You have to remain calm when you want to just scream or cry.'



clinical trials

Every clinical trial has a specific goal in mind and a rigid set of criteria for entry. Ask your partner's consultant if there are any trials available for which they could apply, or look out FBC's complete list of the clinical trials that are currently recruiting bladder cancer patients in the UK at fightbladdercancer.co.uk/research

'My husband has now had nine sessions of immunotherapy and is doing really well with few side-effects. The first scan after five sessions showed a reduction in the size of the tumours. We got the results of the second scan yesterday and things are "stable". He is feeling very well and back cycling.'

communication

Not everyone will agree on the best way to communicate but it is essential to find a way to express your thoughts and feelings to each other. If you don't tell your partner how you are feeling, you cannot expect them to guess. Especially if you are someone who likes to share all, while your partner tends to keep things bottled up, a middle way will need to be found. Sometimes, a patient may not wish to discuss things with you as a way of protecting you, and may find it easier to share their fears and feelings with their CNS. As long as you both have an outlet for your concerns, perhaps gentle encouragement can help you communicate directly. Ask your CNS to help you.

'Find the right way to communicate that suits both of you.'

'Handling difficult conversations with family and friends takes courage, patience and bags of tact.'

'Mindfulness and meditation help me feel calmer.'

complementary therapies

Many complementary therapies – such as yoga, meditation, acupuncture, aromatherapy, reflexology, mindfulness and massage – can help both you and your partner to combat stress and help you feel more relaxed and able to cope with your ongoing fight against bladder cancer.

The NHS allows the use of medicinal cannabis products for nausea and vomiting due to chemotherapy. It can only be prescribed by private doctors on the General Medical Council specialist register. Cannabis does not cure cancer.

D is for distance

If you are trying to care for someone at a distance, you will have a different set of problems from on-the-spot carers, but it is possible.

You will be pulled both ways – wanting to be there to help the person who is unwell but tied by personal, work and family responsibilities. You might feel you are not doing either job well, but remember you can't do everything, you can only do your best. Delegate as many responsibilities as you can so you are not making unreasonable expectations of yourself.

- **Look after yourself:** The additional responsibilities may have physical and mental impacts – tiredness, stress, lack of concentration, sleeplessness and anxiety. Be good to yourself, too.
- **Changes:** Be prepared to notice alterations in your loved one when you do see them – they will be more marked than if you witnessed them gradually. Visit as often as you can.
- **Getting help:** Enlist the help that you will need, both from family and friends but also from professional carers.
- **Get organised:** There are many ways to make your life easier and technology can be a real boon – use it! From individual or group video meetings to accessible calendars and support rotas. Ask for help if you are not familiar with the technology.
- **Emergencies:** Have a plan for if you are called upon urgently.
- **Communication:** This is always the key and, again, technology is your servant. Texting, Skype, Zoom, Facebook, WhatsApp or just an old-fashioned phone call can all help you feel less distant and allow you to monitor what is happening and what needs doing. Remember to let the on-the-spot team know they are appreciated
- **Don't let guilt get you down:** Accept that there are things you can do and things you can't and ignore the internal and external factors that press your 'guilt' buttons. Loyalty is stronger than geographical distance and you can make it work.
- **Support:** You are just as entitled to support as someone on the spot. Enlist the help of friends, go on the FBC forum, visit your local Maggie's cancer support centre¹ or the Carers UK² website or Macmillan Cancer Support³, ask for an FBC Bladder Buddy – the support is there for you.

D is also for ...

decisions


It can be really hard to stand back and let your partner make life-changing decisions but they are their decisions to make and while you can share in researching the information and considering the options, you have to let the patient set the agenda.

down and depression

There is a vast difference between having a bad day and slipping into a constant state of darkness from which there seems no escape. When you are feeling down, you need to cut yourself some slack. Simple remedies like a hot, fragrant bath, a bar of chocolate, a favourite comedy film or a walk in the park can be enough to pull you back. Don't be afraid to admit that you are having a bad day – either to your partner or your support network. Perhaps you could both snuggle up under the duvet, watch daytime TV and get a take-away. So the house hasn't been tidied – who cares?

However, when you are a carer it's easy to ignore the warning signs that accompany a more serious bout of depression until you are sucked beneath its suffocating hold. You are busy concentrating on existing, surviving one day at a time. This is when you must see your doctor straight away.

There is so much your GP can do to help and often talking about these feelings is enough to start loosening their grip. Most GPs would suggest calling them if you have been feeling down for a couple of weeks. In an emergency, call the Samaritans on **116 123**.



'I was devastated when my husband chose to have a radical cystectomy. I totally supported him but I was shocked and found it incredibly daunting – but it was his choice to make, not mine.'

'We all worry about the future at times. Don't let things get out of hand. Never be afraid to ask your GP for help with depression.'



If you feel constantly overwhelmed, are unable to cope, aren't sleeping, or feel you no longer find joy in things you used to, or you sleep more during the day, then please go to see your GP straight away.

E is for educate

What did you know about bladder cancer before it came into your life? For most people the answer is 'nothing', and one of the key problems with the disease is that no one really talks about it. If we are ever to improve outcomes and treatments, we must make a significant change. Some people don't want their diagnosis and treatment to be broadcast to all and sundry, and that should be respected, but many patients and carers do feel able to raise awareness by talking about the diagnosis and treatment. It might feel weird at first but you'd be surprised by the number of people who have also had the disease affect someone in their life. Remember, bladder cancer is the fifth most common cancer in the UK.

If we all started talking more about bladder cancer, it would raise awareness, not only with individuals but also primary care staff like GPs, which in turn could make a big difference to early diagnosis. By educating yourself about bladder cancer, you will also feel better prepared for what the disease may throw at you both in the future. Knowledge is power.

'Start a book, write down every appointment, result, phone call – you will be surprised how thick and fast they come in the early days and if you are referred to different hospitals you will have all the information to hand.'

E is also for ...

exercise

It may be difficult to maintain an exercise routine but try at least to get some exercise, in the fresh air if possible, even if you can only manage a walk round the garden or a bit of energetic hoovering.

!
Don't overdo it, and don't feel guilty if you are too tired.



Mali and Deborah

F is for friends and family

A cancer diagnosis can really clarify relationships with friends and family. Friends you have been close to for years can suddenly disappear from your lives with the appearance of the C word. Many people are unable to cope with the reality of a friend's mortality and find it difficult to accept any change to the status quo. On the upside, you may find many friends step up in unexpected ways, becoming stalwarts in your battle. Take strength from their support, laugh with them, cry with them and celebrate all the little steps to recovery along the way.

Small, practical gestures can be disproportionately comforting. Someone might show up to trim your partner's hair, rub their back or just hold their hand. You will need these people to be your rocks. Be prepared for this kind of substantial friendship shake-up and be honest with your family and friends. It can be incredibly upsetting to lose people over something you cannot control, but you may find by talking to them about what's happening you can get things back on track. FBC has a great downloadable booklet that tells you more about talking to family and friends about bladder cancer.



Amanda and friends

'Help in any way you can – sometimes the small gestures mean more than you think.'

'Friends, and family sometimes, just seem to drift away, cross the street, not know what to say, so say nothing. But on the FBC forum there is always someone to talk to, get advice from or just listen.'

'Our dad's bladder cancer has taken over our whole life – even when we pretend things are normal, the next scan, the next treatment, fear of the future never go away. Supporting my dad leaves me little time or energy for much else!'

G is for guilt

It is a human instinct to always feel we could do better – that we should always be able to find a solution to every problem. Cancer is not something you can control. You need to accept that there are things you can do and things you can't and ignore the internal and external factors that press your 'guilt' buttons. You are doing your best – that is all you, or anyone else, can expect.

'Tackle any guilt you feel head on. This is not your fault.'

'I tried to support her through treatment but I let her get on with everyday life, including cooking, cleaning, looking after the boys and pets when, with hindsight, I should have helped more.'

G is also for ...

gender stereotypes

There is no reason why a woman should make a better carer than a man, and certainly the pressures are no different. However, academic literature focusing on the care experience does so from a largely female perspective and highlights the support networks that women tend to have easier access to. Research⁴ is beginning to show that:

- men and women have a different experience of the carer's role
- men are more likely to continue full time work, whereas women are more likely to be expected to give up work commitments
- men often experience a greater bond with the individual they are caring for
- men are proud of their role and of doing it well whereas women are more prone to feel they should always do more
- men have less access to or knowledge about support and find it difficult to ask for help
- men find it easier to make a little time for their own interests to reduce stress

This is not to say that these are the shared experiences of every male carer, nor that female carers do not share these experiences.



Corrina and Robin

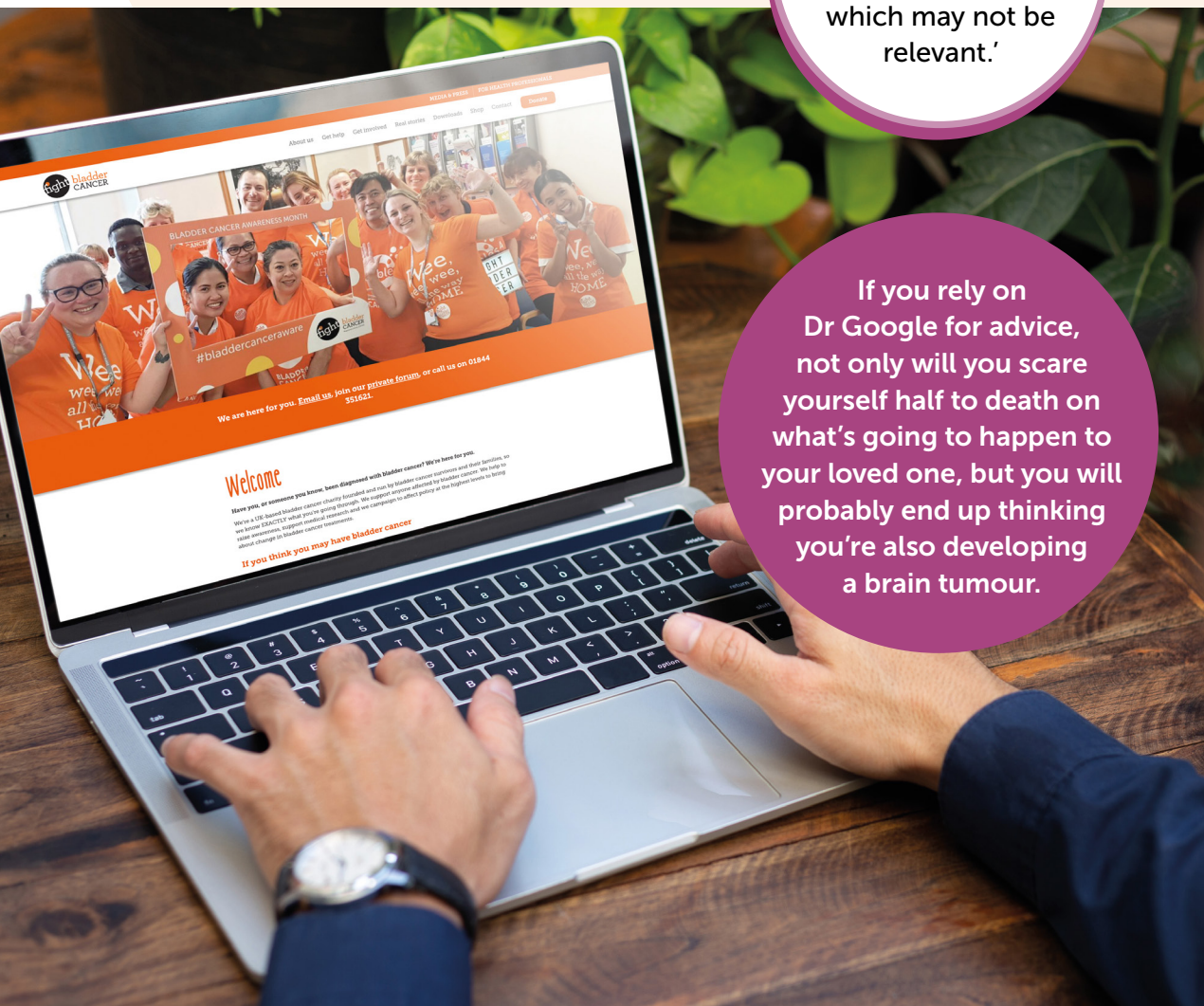
Google

Please don't sit alone with your phone or laptop in the evening searching for everything you can about bladder cancer on Google, especially not if you've had a glass or two of wine.

Only use reputable sites like fightbladdercancer.co.uk, cancerresearch.org, nhs.uk or macmillan.org.uk to get good information on every aspect of bladder cancer and don't forget to talk to your medical team. They are there to help you both.

'Be very wary of 'Dr Google' – he can easily lead you to worst case scenarios which may not be relevant.'

If you rely on Dr Google for advice, not only will you scare yourself half to death on what's going to happen to your loved one, but you will probably end up thinking you're also developing a brain tumour.



H is for hospitals

Many people dislike hospitals – the smell or the echoing corridors are enough to send some carers scurrying for the exit. Depending on your partner's diagnosis, however, it is possible that you may be spending quite a bit of time there, so you need to get over it. Grit your teeth and, within a few months, the hospital can feel like your second home. You'll know the staff, the shift patterns, where the best loos are and how to get a decent cup of coffee.



'I keep ALL the letters from the hospital and have a file with them in date order – it's really useful.'

'Take snacks and drinks with you and a book to read – the patient may like you to be there but sleep a lot.'

★
'Try to be at the hospital when the stoma nurse is present so you can learn the procedure.'

'If you have to drop off and pick up, do something relaxing like doing a crossword or taking a walk, instead of sitting in the car worrying.'

An important thing to remember about hospitals is that they are generally full of people who care. Your medical teams and support staff are the front line in any cancer journey and they will have your back. Remember, too, that you are all on the same side, so if things aren't going to plan or you feel concerned in any way about treatments or medical care, talk to them at once.

If you don't clarify things you haven't properly understood, it can lead to misunderstandings and stress. Talking things through, on the other hand, generally deals with any negative feelings and leads to a better outcome. Try not to express any anger you may feel at the person delivering the treatment rather than at the disease that has put you in this position. If you really feel things have been mishandled, ask for a second opinion.

H is also for ...

hobbies

Don't laugh! We know that when time is so precious, it seems totally impossible that you will be able to find any time available for the hobbies or pastimes you used to enjoy. But it is important that you try to carve out a little time for yourself so if there is something you really love to do, forcing yourself to make some room for it in your life will be a huge help in keeping you sane.

Think about what you would be able to fit into your timetables which would do you good and not stress you out further. The time will not magically appear – you will have to find it. Match your project to the time you have so you don't try anything too strenuous, mentally or physically. Perhaps you could do a quick crossword instead of a cryptic one, some plain knitting or crochet rather than a complex, fine pattern, a quick sudoku rather than a challenge.

'You have to remain patient but try to find just the tiniest bit of time for your very own.'



Malcom and Jean

'Find something you love doing and carve out time to do it.'



'I saved up my worries during the bad times and used a journal to express myself.'

hope

For many people with bladder cancer, they will need some form of intervention and treatment and then will be monitored to make sure the cancer does not return. They will be able to go back to their normal lives. Many, however, will need additional investigations and treatments. Throughout that difficult time, try to remain positive. There is always hope for the best outcome, and the more positive you can be in your outlook, the better you are likely to cope. In addition, advances in new treatments have been well reported from recent clinical trials so new possibilities come onstream all the time.

I is for inner strength

We will all access our inner strength in our own ways but most people do discover that they can cope with more than they thought possible. Whether that strength comes from a belief in a specific god or universal power, a spiritual awareness or simply inner resilience does not matter. Whatever it is that gets you through a tough patch, you need to rely on it now. Remember to focus on other times in your life when you have overcome difficulties and faced problems. Remind yourself that you are bigger than what is happening to you and that you will get back to your real self soon. Be mindful and trust that you can and will move forward.



PATIENT TIP:

'As the patient, we understand that you, our support partner, want to be there for us every minute of the day but we know to be strong takes a lot of inner strength. We also know you need time out and we want you to have time away from the eye of the storm.'

J is for journey

Each carer will go on their own personal journey. For some, their worries and concerns may be short-lived.



For those caring for someone with MIBC, however, there is no getting away from the fact that things are likely to be tough. Being a carer can test your relationship with the patient in ways you haven't imagined, and with it your own resilience. But it is a journey. At the start of it, things may feel insurmountable and you might not be able to imagine ever reaching the end. But you can ... and you will. Day by day you will learn more, grow more, gather more support and be a little further ahead. Slow and steady in this instance definitely wins the race. Just take one step at a time. And at every step, FBC will be beside you.

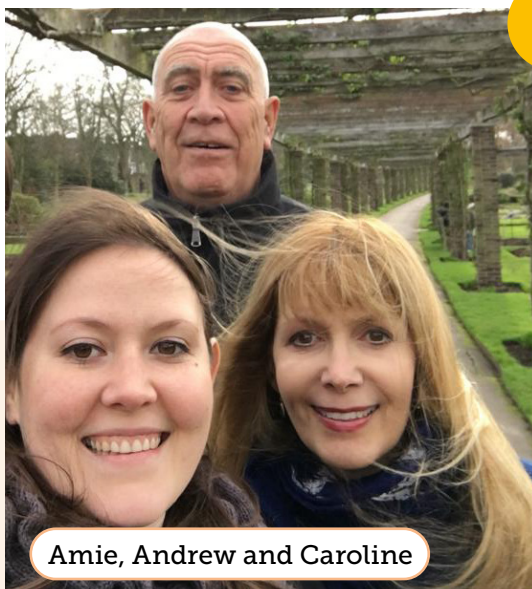
'We who care for our loved ones all tread a similar path – the search for answers to questions, the desire to support and assist, the need for a bit of space to allow us to be the best carer we can be.'

K is for kindness

Be kind to yourself. You do not have to be the living reincarnation of Florence Nightingale to be a good carer (so step away from the lantern, okay?). Set yourself realistic goals and do what you can. Luckily there are no carer police so you will not be arrested on the days you cannot bring yourself to be nice or look after anyone (not even the cat). Some days are just like that. Tomorrow is another day and it will be better.



Tracy and Mark



Amie, Andrew and Caroline

'Value your friends. I remember returning home after a very challenging day and collapsing in the chair, then hearing the doorbell ring only to be presented with a plate of delicious Sunday roast from a stalwart friend. Wonderful!'

'It wasn't until several months later that I persuaded him to tell his friends, and once that hurdle was crossed it was a big step forward. I have a good friend who I confided in who was a great support.'

L is for laughter and living

Just because cancer has come into your life doesn't mean you can't have fun any more. And what did your nan say? Laughter is the best medicine. It is okay to still live life, go out with friends, get a little tipsy and laugh. In fact, it's probably more important now than ever.

In the midst of treatments, medication and surgeries, it's easy to forget that there is life outside of the cancer bubble you are living in. Try and schedule some time for activities and things you both like that are fun. Even staying in and watching a good comedy movie can be therapeutic. Have you jumped in a puddle lately? Kicked leaves around? Gone outside after dark and gazed at the stars?

If you don't keep an eye on it, cancer can consume your life and you become just a carer, forgetting who you are in the process. Even through treatment and recovery, it's important that both you and your loved one do normal things, as it's these moments that give your life balance. Give yourself a break from thinking about the future and just live for the day.

'Try to laugh every day.'

'The big C becomes the predominant thing in any relationship. But it should not stop you living your lives as individuals. We all have wants and needs. Life is short, LIVE IT.'



Snettie and Alan




Paul, Brenda and Alex

L is also for ...

legal advice

If you need legal advice with regard to managing someone's affairs, visit the government website to find out about different types of power of attorney.⁵ There is one for health and welfare and one for finances. The forms are straightforward so it is not essential to pay for a solicitor. You will then only need to pay the registration fee.⁷ You can put the powers of attorney in place even if you have no intention of using them; they will then be ready if a turn of events means that they are required.



'Family members can sort out bill or paperwork, contact Macmillan⁶ for budget advice, apply for benefits, blue badges, etc.'

M is for money

Depending on your job situations, cancer can put a huge strain on the household finances. The best advice here is to act sooner rather than later. Don't bury your head in the sand and hope for the best. Taking an active role in planning your finances through tests, treatment and beyond will put you back in the driving seat and eliminate an area of stress for both of you.

If you are still working, then any longer-term treatment might interfere with your attendance at work and have implications for your sick leave. Find out your entitlements and what support is available. Both Macmillan⁷ and the Citizens Advice Bureau⁸ have dedicated financial helplines with advice for carers and cancer patients.

There is also a range of financial support available to carers, in terms of benefits, help with Council Tax, fuel costs and NHS costs. There is advice on the Carers UK website² as well as a benefits calculator, guidance on who is eligible, and how Carer's Credit works.

You might be eligible for non-emergency patient transport services, or you may be able to claim a refund for the costs of your transport to hospital through the Healthcare Travel Costs Scheme. Speak to your healthcare team for more information or visit the NHS website page on the travel costs scheme.⁹

It might be a good idea to change a bank account into joint names to make it easier to have access for everyday expenses.

Carers UK has a new contingency planning tool to help you prepare for the unexpected.¹⁰

M is also for ...

medication

To make sure you keep medication organised and know what should be taken when, buy a dosette box with a compartment for each day so you can sort it all out once a week. If you do find you and your partner are getting confused with medication, speak to the pharmacist and they should be able to sort out a dosette box for you.

'If your partner is having chemo, one of the side-effects can be confusion, so it might be worth taking over organising their medication to make sure they are taking the right pills at the right time.'



Have a list
of medications
with you at
all times!

meditation

A deeper state than simple relaxation, try a meditation tape to get yourself out of the hurly-burly of being a cancer carer. You can begin with progressive muscle relaxation (see relaxation), then visualise yourself moving slowly down a long staircase until you reach the bottom, going deeper and deeper into a relaxed state. Rest there for as long as is comfortable, then walk back up the stairs until you are ready to rejoin the world. There are a wealth of options on the internet, including Headspace.com.¹¹ They are a great choice for carers and patients.



Darren




N is for news

One of the roles for a carer that can be inordinately time-consuming is that of news gatherer. It seems there are so many people you need to keep updated with what's happening that it can be completely exhausting. Then there is the emotional drain of repeating the same information over and over on the phone while listening to people repeat how sorry they are.

Take control of this to make it easier for you to keep everyone up to date. A closed Facebook, WhatsApp or email contact group can be a brilliant way of getting the current status out there with minimal effort, and allows friends to send sympathy or make practical offers of help.

You may want to make more than one group if you are likely to go into more detail with closer family members and friends than with neighbours or acquaintances. Make the group names clearly different so you don't send messages to the wrong group. If you are using a mailing list, remember to check the settings to make sure that only the recipient's email appears on their copy, not the whole list; use the bcc option on general emails.



'Keep a list of contact numbers for medical teams and also family and friends so you can ring or text with updates.'

N is also for ...

normal

There is no such thing as a standard 'normal'. Your new routines will be normal for you – that's all that matters.

Dylan



'Try to maintain some normalcy. Go out to dinner, have friends over, go on a hike. Talk about something other than cancer.'

'I try to keep life at home as normal as possible. I see my role as taking the day-to-day problems on my shoulders so my husband can concentrate on getting better.'



'This is scary stuff, and my partner was nervous every time she went to the doc, and she didn't always hear everything that was said or remember it.'

notes

There is a lot to take in when you go to a consultation and you will almost certainly forget something. Your partner is even more likely to do so. Have a notebook with you (a hardback is best in case you have to write on your lap) and write down the salient points as you go along. It might also be worth stopping for a coffee after your appointment to go through your notes and add any details while they are fresh in your mind.

'I recommend keeping everything medical in a file, marked out with different dividers for different consultants.'

If making notes is a problem for any reason, you might also want to consider recording meetings on your phone, then you can go back over what has been said in the comfort of your own home, discuss things without any loss of detail, or you can share them with family members and friends if you want to. Do make sure you ask permission of those present, though, as some people find this intrusive and will not consent. You can also download an app, such as Otter, that will transcribe recorded meetings.

'My husband's medical file is now two volumes and very thick. Having watched doctors trying to find info, we now have a summary of key treatments and the dates, that gets taken to any medical appointments. After a year or two, it's easy to forget some of the detail.'

If anything is not clear after you have gone through your notes, ask for further explanation. You can usually do this by email.

'I repeat back to the consultant what he has said, to make sure I understand or, with permission, tape it.'

O is for operations

Most bladder cancer patients will have at least one Transurethral Resection of Bladder Tumour (TURBT). This is an operation performed under general or spinal anaesthetic for which the patient may be seen as a day case or kept in hospital for 24 hours. This may be the only operation you encounter.

For those whose partners undergo major surgery, it can be more daunting. If anything is likely to derail you, it will be the sight of your beloved fresh out of theatre hooked up to a huge pile of cables, machines, drains and devices, all the while emitting a cacophony of beeps. Utterly terrifying. So be prepared when it comes to operations and post-op recovery.

There is no law that requires you to sit at the hospital waiting for news while the patient is in surgery. In fact, many carers recommend you don't. Instead gather someone from your support network and be busy. Go shopping, go to the movies, try a new dance class. Do anything you can to take your mind off what's happening.

Otherwise the time will drag in a way you didn't think was possible.

Oh, and don't freak out if it takes longer than you think. This is why we recommend you keep busy. It's highly likely there's been a delay in getting the patient to theatre or the op start time, which knocks on to recovery. Maybe there just isn't a porter free to take them back to the ward. Try and relax if you are several hours past time and you haven't heard. This is generally an instance of no news is good news.

Lastly, when you do go and visit, remember that the patient is not going to be looking their best. They are probably awake at this point but may well be giving you the run down on past girlfriends or asking for a chicken curry. Take it easy on them, they've just had some class A drug equivalents so are riding 'high'.

'The patient may be worried, tired, uncomfortable. After an RC most can be in a bad way for the first few days and look dreadful.'

'After a radical cystectomy, try to get them moved to a regular hospital ward as soon as possible if they are experiencing confusion. It seems to help orient them.'

P is for planning

Like all good battles, you are going to need a plan. You need to know who is on your side (see B is for build) and you need to know exactly *what* you are fighting against.

Your Cancer Nurse Specialist (CNS) is your first point of contact with your medical team, and they are the best sources of information on your particular circumstances, the likely road ahead and the tests and procedures that come with it. The medical team is unlikely to speak with a carer without the patient, so make sure they have the patient's express permission to do so.




Jane, Cancer Nurse Specialist

Once you have accurate details of the specific diagnosis, then do your research.

Go back to the reputable websites and read as much as you can about what's going to happen. Ask your CNS about Fight Bladder Cancer's series of Patient Information Booklets so the most appropriate titles can be ordered for you. Keep a note of your questions and raise them at appointments.

If there are any questions you don't want to ask of your medical team, you can always head to the FBC private forum where you can ask anything. Then plan in where you will need support and start asking for help: someone to do an extra visit to hospital when you need a night off, or to drive you to a results appointment. These little things can really make a difference when you are in the thick of it. Getting a plan puts you in control.

'Join the FBC forum where you can feel supported and support others as you tackle these life-changing circumstances.'



'But the most important advice of all was to try and focus on the positives – on the hope, on the next milestone, on the next day, to keep on moving forward, one step after another'

Rob and Rebecca

P is also for ...

positive

Staying positive is hard work but it will pay dividends. Try to keep a positive, forward-thinking attitude and that will really help to keep things on a good forward trajectory. But don't forget that it is exhausting, so take yourself out of the spotlight when you can and let off steam.

practicalities

Keep a notebook with practical ideas to help make things easier. Look out for tips on the forum and in FBC booklets or in *Fight* magazine – you never know when they will come in handy.



'Don't hog the bathroom; they often need the loo at short notice.'

'Make sure the patient has a phone and charger to keep in touch.'

'Buy extra bedding and pyjamas so they can always have one on, one in the wash and a spare.'

Q is for questions

It is a good idea to go with your partner to consultations. You can give them both moral and practical support. It is very hard to remember everything that is said at a consultation and a second person can make some notes or may remember some useful details that your partner had not grasped. You can talk beforehand about any questions you want to ask (see also **Notes**).

Depending on your unique situation, you will have a different set of queries, so look at the Patient Information Booklet supplied to your partner to get a list of the most commonly asked questions.

Remember, there are no silly questions. If you need an answer to something in the wee small hours, don't forget you can always head to the Fight Bladder Cancer private forum where someone is bound to come back with help and support.

'Never assume anything, always ask, however trivial the matter in question.'



Make a list of all the questions you have. It doesn't matter if they sound silly; if the question has popped into your mind, then it needs an answer, so do not be embarrassed to ask it.

'The FBC forum is the place to ask questions. You can never ask too many questions.'



Q is also for ...

quack

We all wish there was a magic pill you could give to your loved one to make cancer disappear. We'd also like to believe there's another type that'll get rid of fat the way that sun melts butter, but we all know that that's about as real as the tooth fairy.

When you are reeling from an initial diagnosis, it's natural to search around for *anything* that could make a difference. You are desperate for a cure and consider them all, and there are hundreds of unscrupulous companies and individuals out there who will take advantage.

Listen to our hard-hitting tip from FBC's co-founder, Tracy:

'We can tell you what is true ... there is no conspiracy over this ... Cancer is not caused by sugar and the pharmaceutical companies are not in a grand plot to deny us cures. The truth is while some research is being undertaken to see if certain diets, lifestyles or substances mean you have a reduced risk of developing cancer, there is currently no scientific evidence to support any of these other claims. Being blunt, I have seen a handful of people over the years turn their back on traditional medicine and treatments to pursue regimes sold to them by quacks and charlatans. Everything from clean water to cannabis oil. Want to ask them how that worked out for them? Well, unfortunately we can't because they are all dead. Evidence enough? Talk with your CNS and your healthcare team for more advice.'

R is for results

If there is anything guaranteed to make your mind turn immediately to **mush** it is **results day**. Bad enough for us carers but worse still for the **patient**. They can emerge from a half-hour consultation remembering nothing but 'we've found something'.

This kind of results amnesia is very common and the best way round it is a two-pronged approach. Firstly make a list of all the questions you want to ask before you go in and take notes during the consultation (see also **Notes**). Ask as many questions as you need to in order to understand what the options are and what lies ahead (see also **Questions**).





Tim, Sherlock and Anita

R is also for ... relationships

Don't ignore the fact that relationship dynamics can take a subtle or a drastic shift when one partner is ill. In the middle of all the practical details, the appointments and generally keeping life ticking over, try to take time out to nurture your relationship and keep it fresh by spending time together, enjoying each other's company, focusing on what brought you together in the first place.

'There's nothing wrong with allowing ourselves to be real about our feelings.'

'I found that if I was feeling anxious I found it impossible to feel connected to my partner. Counselling really helped me get through it.'




Paul and Deborah

Everyone will have both good and bad days when coping with cancer. For the most part, talking about how you feel, indulging in something you enjoy, having a massage or a treat can help to get you both back on an even keel.

relaxation

Progressive muscle relaxation is a well-known technique for calming the body and stilling the mind. It is especially good for those who find it difficult to switch off. Starting at your feet, then working up your body one muscle group at a time, tense your muscles, hold for a count of five, then release and relax.




'Learning different ways to manage my emotions and reducing my stress also help to improve my sleep quality and patterns.'

risk assessment

You will be supporting your partner in many decisions and may have some difficult choices to make. When you do, your role is to try to be objective. Collect all the data, weigh up the advantages against the impact of the treatment and try to stand back and let the patient make their decision when they have considered:

- the length of the treatment
- the logistics involved
- the likely outcome
- the quality-of-life improvement the procedure offers
- potential side-effects



'You may have to advocate for them, ask questions at appointments and demand attention from professionals when you know something is wrong.'

'Listen, take notes, remain calm and focus on what is being said.'

S is for sex

If it's your partner who has cancer, it is going to affect your relationship, especially intimacy. And realistically, you will both have to work hard to make sure that cancer doesn't come between you in that way. Obviously, operations and treatments can have a very real physical impact on the patient. They may be tired, suffering from side-effects or feel very weak. What is important during these times is not to become isolated from each other.

There is a full discussion of the impact of cancer on your sex life and ways of coping in other booklets in this series.

You may also have concerns about what you can and can't do sexually during or after treatments. Your clinical nurse specialist (CNS) is the best person to ask about this. You have no need to feel embarrassed as they'll be able to provide you with the information you need to make sure both you and your partner are safe when you are intimate. Perhaps treatments have led to difficulties with the physicality of having sex? Don't let this become a barrier in your relationship.

Urology teams always have a sexual health expert who can help with specific problems such as erectile dysfunction and other issues, or you may like to seek outside counselling. Again, they see these problems every day and have a variety of treatments designed to get you up and running again! Try to continue to be tactile, hold hands, give a gentle massage, a tender hug, or lean in for a soft kiss.

'Yes, things have changed. But our first solution was more cuddles and holding hands.'

'Don't be put off by any of the treatments offered. Try them all until you find the one that is right for you.'

'Our first step after treatment was being intimate with each other – after that everything fell into place.'

!
Don't be embarrassed to ask your medical team for help. A good sex life is important and there are many treatments to help if you are having problems after bladder cancer treatment.

S is also for ...

sleep

Sleep and rest apply equally to physical and mental wellbeing – and you will need your sleep. Try progressive muscle relaxation (see **Relaxation**) to reduce tension and help you get to sleep. Or there are other things in your bedtime routine that can help:

- warm but not too warm
- hot milky drink such as hot chocolate
- no phones, iPads or tech in the room
- soft music or a warm bath



If your partner is likely to suffer leaks at night, it can be very disruptive of your sleep as well as theirs. If you have their stoma supplies and a spare set of bedding ready, you can change the sheets with the minimum of disruption and get back to sleep.

smoking

We all know smoking is bad for our health and it can contribute both to developing bladder cancer and making it worse. The simple advice is give up and make sure your partner gives up too. Contact the NHS helplines for all kinds of help and support. Pledge that you will both give up and do it!

nhs.uk/live-well/quit-smoking/

wales.nhs.uk/healthtopics/lifestyles/smoking

nhsinform.scot/healthy-living/stopping-smoking

stopsmokingni.info



support from local authorities

Most carers will not need additional support of this kind; this section is specifically for those caring for someone with advanced disease.

Apart from your personal team of supporters, you are entitled to a carer's assessment by your local council. An assessment should take a wide-ranging review of the situation, covering the carer's role and how it affects your life and wellbeing; how you feel about it; health, work, study and leisure; other relationships and social activities, and any impact the caring role is having on the carer's own life goals. It also covers more practical issues such as housing and what to do in an emergency.

Following the assessment, a range of support services may be available, including driving lessons, IT equipment or help with housework. Support is dependent on the financial situation of both carer and patient, but everyone is entitled to information and advice.

The person being cared for should also be offered a needs assessment by their local authority, no matter what their level of need or financial means. This will look at their physical, mental and emotional needs, and the carer is entitled to be involved in this assessment. This could lead to home adaptations, allocation of a care worker or respite care.

T is for talking

Talking is a great way to let off steam, to share information, to help you feel more in control. Try not to bottle things up – it is much better to talk about things, even if you end up coming to different conclusions.

In general, people tend to fall into one of two broad camps: they either like to talk things through or they prefer to put a lid on things. That can

‘I wanted to talk but he didn’t, so I just had to go with that and worry silently. I guess that was the first lesson; you have to let the patient set the agenda.’

be difficult if you and your partner fall into the different camps. A compromise is ideal, but you may have to accept the way the patient prefers to deal with things. If that leaves you exasperated, you’ll need to find someone else you can talk to in confidence to allow yourself to let off steam.

‘Even if you can’t talk to your partner, find someone to talk to about how you feel.’

‘At the time I didn’t realise that was his way of dealing with things: to listen to the absolute minimum amount of information, tell no one except our grown-up children, and only mention it when an appointment was looming.’

T is also for ... terminal

As a carer you can veer between bouts of extreme optimism and pessimism, depending on where you are in your loved one’s cancer journey. That is entirely normal. Although the vast majority of bladder cancers are treatable and often lead to full remission, there are some patients who are told that they are facing an end-of-life outcome – as a carer this is about as tough as it gets. You will need extra support during this time. Ask your CNS for Fight Bladder Cancer’s *Advanced Bladder Cancer Patient Information Booklet*, which has plenty of advice on coping at this difficult stage.



tests and treatments

There will be more than enough tests and treatments during your partner's cancer journey, and the longer the journey, the more it will test your strength. Knowledge is your friend. Try finding out in advance as much as you can about the procedure:

- what it involves
- how long it takes
- likely knock-on effects
- length of time before you get the results

If you understand any potential pitfalls up front, you can be well prepared for every eventuality.

It's the little tips that help immensely, so look through your FBC information booklets or visit the forum and you'll get plenty of practical advice that will make things run more smoothly and make your job easier. For example, appetising foods for someone who has lost their appetite, the right kind of bed sheets to protect against night-time leaks.

'Try and have something to look forward to during and after treatment ... we would go to a restaurant ... or take a picnic and go for a walk.'

tiredness

Extreme fatigue is a side-effect of some treatments and it is likely that your partner will experience this at some stage. But don't forget how much you are coping with so you need to acknowledge that you may also feel exhausted at times. If you need to rest and an opportunity presents itself – take it. Don't feel that power naps are only for your granny at Christmas. Even a ten-minute rest can give you enough of an energy boost to face the rest of the day.

'Eat, rest and sleep – you need all the energy you can muster.'

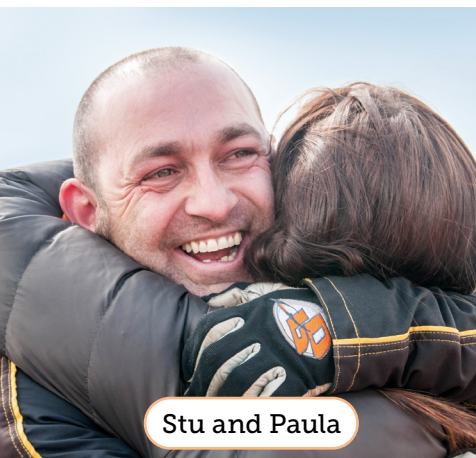
'Don't allow them to be "the patient" for too long or you will have no time to yourself!'



U is for uncertainty

You may be wondering how you can continue everyday life, with no idea about what the future holds. But actually, if you think about it, that's true for every single one of us. No one has any guarantees about what's going to happen tomorrow, next week or next year – with or without a cancer diagnosis. Don't worry about your mortality. Get busy living and try to enjoy every day.

'This is an opportunity to make changes: life is a verb!'



Stu and Paula



John and Val

'It helps that my husband and I are very open and talk honestly about how we feel.'

U is also for ...

understanding

Try to establish a mutual understanding of each other's needs – there will be times when they diverge so if you cannot face talking something through, when your partner clearly wants to, you have to tell them and perhaps arrange a time in a few days when you feel you can cope with that difficult conversation.

understatement

When consultants have difficult news to break, they will be professional and caring, aiming to reduce the shock that you will inevitably feel. This can mean the reality of the news only hits you some time later. Be prepared for that.

'Her oncologist told us, with gentle yet devastating understatement: "Our aim will be to contain things as best we can."'

V is for virtual friends

Technology is a wonderful thing and gives you huge opportunities for communication and support, so start now to get the hang of it – if you are not already switched on – and use it to your advantage.

The Fight Bladder Cancer private forum is full of patients and carers living and dealing with bladder cancer. You can go on the forum any time, day or night, and let off steam, ask questions or just reach out to others in a similar situation. The advice and support offered on a daily basis from other people – patients, carers, professionals, families, friends – is astounding and inspiring. When you are wondering how to get through the next day, or waiting for results, there is a virtual member of our 'wee family' on hand to pick you up, dust you down and put you back on your feet. Often the best answers come from someone who has trodden the same path, and with every type of diagnosis represented, the shared wisdom is awe-inspiring.

Go to www.facebook.com/groups/bladdercanceruk and join up.

Bladder Buddies

At FBC, we can team you up with your own Bladder Buddy – whether you are a patient or a carer – someone whose partner has had a similar diagnosis and treatment as your loved one so you can contact them to get moral support and practical advice.

V is also for ... visiting

This can take a huge chunk of your time, which is especially difficult if there is a long journey involved or you are working. Try not to do it all yourself. Create a rota so everyone takes a turn, or ask someone else to be in charge of the visiting rota. If you set up an online calendar, friends can fill it in for themselves. Check times and restrictions.

'Sign up for the parking app or have spare change for the machine.'

'We made short videos for our grandchildren and talked about Grandpa being poorly to lessen the shock of how much he changed between visits.'

W is for waiting

You are going to get really good at waiting. For every test you must wait for results, then wait for letters to arrive detailing appointments and then wait for operations or treatments. After all this, there is still the longest kind of waiting, the surreal time between check-ups when you can almost convince yourself that things are back to normal (until the pre-check-up nerves kick in). Added to this for the carer is the waiting to visit in hospital, waiting to find out how your loved one is, waiting for the doctors to tell you how it went. Tracy told us, 'I've tried every way of dealing with the waiting over the years ... to be honest, there's no quick fix. It just comes with the territory. Try being patient. If all else fails learn to crochet ...'



W is also for ...

worrying

If someone tells you not to think of an elephant, of course, that's the first thing that pops into your head. Telling a carer to stop worrying is about as useful – there's no doubt you will worry. But when you do, try to think of techniques to stop yourself going round in circles wondering what-if this, that or the other happened. Let go of the things you cannot control and do something about what you can – something practical that will put a brake on the spinning.

'You are not to worry. Worrying is the doctor's job. They will tell you what's happening. They will tell you what needs to be done and when it needs to be done. Do what the doctor says and do not worry.'

X is for X-rays

For many patients, X-rays will become commonplace. When you go for an appointment, try to find out how long it is likely to take, and make sure you both take something to do while you are waiting. Paying for your car parking by the online app, if available, can be a good idea if you can't predict how long you are going to be there.

Y is for you

Being a carer is a demanding job. While everyone else is focused on the patient, you must make sure that someone is also looking out for you. And don't forget that you need to take care of yourself, too! Make sure you eat a balanced diet and take regular meals. This can be particularly challenging when you are managing hospital visits but this is where that wonderful network of supporters comes in. Take time out for yourself in the day even if it's just for a short walk and some fresh air to gather your thoughts. Me time is as important as ever. And sleep ... To be on tip-top form as a carer you need to get good-quality and substantive sleep. Don't put your own needs last.

'Find something you love doing and do it for yourself.'

'As a partner you have to look after yourself or you won't be fit to look after anyone. That's easier said than done when there are days when it all seems too much to deal with but that's when you ask for help.'

Y is also for ... young carers



The current estimate of the number of young carers in the UK is 800,000 – that's children aged 5–17 who care for an adult or family member who is recovering from treatment or suffering chronic illness². This is a huge challenge for these young people, changing the dynamic of the family, resulting in about a quarter of them missing schooling, and generally changing their childhood irrevocably.

There are not many hard and fast rules, but the underlying aim of local councils is to give close consideration to the needs of all children or adults who are involved in a caring role, and to ensure that young carers are not taking on inappropriate tasks or being overburdened. Talk to your GP or CNS and they will put you in touch with the right people to find out more.

'I feel bad leaving him home alone even though he is quite happy to have some quiet time.'

Z is for zen



As a carer for someone you love, your experiences will change you and change how you live and experience life. There will be some immeasurably hard times. There may be blue-light dashes to A&E in the middle of the night, seemingly endless waits for results, treatment highs and lows, hopes dashed and hopes rewarded. At times you may think that you'll not get through, but you will. And in between those times, over what may turn out to be a battle with cancer that lasts years, there is so much to be learnt about what in this life is real and important.

Let's listen again to Tracy, who spent over ten years as her husband Andrew's carer:

'Over those years when we felt like we went to hell and back, we learnt a lifetime's wisdom about what really matters. About friends who become like family. About good people who are so brave and fight so hard but yet don't make it. About sadness and immense pain. But most of all about love. It transformed my life and led me to a new career as a Humanist Celebrant – bringing comfort to others who are going through some of their darkest moments. Remember that life is a thing of beauty and something to treasure. And the very best we can do – for ourselves, for our loved ones and for those we have lost – is to go on out there and LIVE.'



Catherine, Tracy and Kim

Don't forget ...

The aim of this series of information booklets is to provide both patients and carers with comprehensive but straightforward information to support you in your fight against bladder cancer.

We understand what you are going through and we know you will have other questions.

We are here to help.

**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**

by phone on **01844 351621**

References

¹ maggies.org

² carersuk.org

³ macmillan.org.uk

⁴ contact.thomsonc@edgehill.ac.uk
for further information

⁵ gov.uk/power-of-attorney

⁶ <https://bit.ly/3F5rFsC>;
£82 for each PoA in 2022

⁷ macmillan.org.uk/cancer-information-and-support/get-help/financial-help

⁸ citizensadvice.org.uk

⁹ carersdigital.org/mybackup

¹⁰ nhs.uk/nhs-services/help-with-health-costs/healthcare-travel-costs-scheme-htcs

¹¹ headspace.com

What do carers say?

Despite being a health writer for Cancer Research UK, Henry Scowcroft discovered just how much he had to learn when his partner, Zarah, was diagnosed with bladder cancer.



The first TURBT revealed that Zarah's cancer was muscle-invasive and at an advanced stage, already spread beyond her bladder. When we were given the diagnosis, the oncologist told us that the aim would be to contain things as much as possible.

And so began a whirlwind, manic, exhausting experience of being the primary carer of someone with advanced, life-limiting cancer. Diary management. A second pair of ears in appointments. Helping check if her nephrostomy bag was showing below the hem of her dress. Being a shoulder to cry on. Helping keep

friends and family informed. Pain management. Shuttling clean pants and freshly made smoothies to the ward. Trying to be, and remain, a rock, not a burden. Looking for options. Helping get the catheter in. Holding her hand.

I learnt many things over the following months. Patience, for one thing. How to distract and calm an acute needle-phobe, before injecting her with anticoagulant, another.

A friend, herself a cancer survivor, also gave me some sound advice: 'Find something you love doing, and carve out time to do it.' But the most important advice was to try and focus on the positives – on the hope, on the next milestone, on the next day, to keep on moving forward, one step after another.

As carers, all we can do is offer the best support we can; and all we can ask for is a bit of space to allow us to be the best carer we can be. We do the best we can – we can do no more than that.



How Fight Bladder Cancer can support YOU

Fight Bladder Cancer is a UK-based charity that was founded and is led by bladder cancer patients and their families, so we know exactly what you are going through. Depending on whether you are a carer or a patient and where you are on the cancer journey, you are likely to experience a range of emotions from panic and fear to confusion and anger – this is completely normal. The most important thing that you should know is **you are not alone**. We're here to support you and guide you to the people and resources you need.

Our four main principles are: **offer support, raise awareness, campaign for research and affect policy**. So as well as being involved internationally in the development of knowledge about bladder cancer and its treatment, we have a strong support network that includes:

- a **dedicated website** at fightbladdercancer.co.uk with a wealth of information about bladder cancer, its treatment and how people cope
- **our private online Facebook forum** at facebook.com/groups/BladderCancerUK
- **our *Fight* magazine** – sign up for your free digital or print copies at fightbladdercancer.co.uk/contact-preferences
- download back issues of *Fight* from fightbladdercancer.co.uk/downloads
- **Support groups** in many locations throughout the UK and online
- a **Bladder Buddy service** which will team you up with a carer or patient who has gone through similar experiences
- a **regular e-newsletter**
- a **public Facebook page** at facebook.com/BladderCancerUK
- a **Twitter feed** [@BladderCancerUK](https://twitter.com/BladderCancerUK) and **Instagram** [@BladderCancerUK](https://www.instagram.com/BladderCancerUK)
- a **LinkedIn company page** linkedin.com/company/fight-bladder-cancer



Patient Information Booklets

Cited by the NHS as best practice in patient communication.
Ask your CNS for advice on which booklets are suitable for you.

- Tests & investigations
- What is a TURBT?
- Low-risk & intermediate-risk, non-muscle-invasive bladder cancer
- High-risk, non-muscle-invasive bladder cancer
- Muscle-invasive bladder cancer
- Living with a stoma
- Living with a neobladder
- Advanced bladder cancer
- Surviving bladder cancer
- Diet & nutrition
- Carers' A to Z guide
- New developments in treatment for bladder cancer



Fight magazine

We now have a series of magazines covering a range of themes and topics. Each one includes articles on topics of interest, personal stories, a glossary of useful terms and a list of current research trials.

To obtain digital or print copies of either the *Patient Information Books* or *Fight* magazines go to fightbladdercancer.co.uk/downloads

email info@fightbladdercancer.co.uk

telephone (01844) 351621

To sign up to our newsletter and receive future *Fight* magazines go to fightbladdercancer.co.uk/contact-preferences

Fight Bladder Cancer Support – our private forum

On our private online members-only forum, patients, carers, families and professionals can discuss any worries or issues 24/7, find out about treatment options, or raise any other questions. Everyone is welcome.



‘Especially during this time of isolation I would say: if you are struggling, if you are in despair, or you need a kind ear, reach out on the forum. There is always someone there for you.’

‘The superb FBC forum is there day or night for every one of us in our times of need. I still need them.’

Join our private online forum at:
[facebook.com/groups/BladderCancerUK](https://www.facebook.com/groups/BladderCancerUK)

Can you help us in the fight against bladder cancer?

Supporting bladder cancer patients and their families is our primary objective. We are facing a growing demand for our services and urgently need more funds, so we rely on the generosity of friends like Henry to support our work.

Listen to what Henry said about FBC:

‘It can feel very lonely when you are caring for someone you love. You want to support them in every way you can and to do that, you need support, too. Fight Bladder Cancer is there for you when you need it most – with reliable information, someone to talk to, or just to know that you are not alone.’



Your donations matter

A donation from you would ensure that we can be here when it matters most, to help improve the lives of people affected by bladder cancer.

Ways that your donations can help:

- providing support and information to everyone who calls and emails
- setting up and running patient support groups (Fight Clubs) around the UK
- connecting patients through our Bladder Buddy scheme
- spreading awareness of bladder cancer and campaigning to improve early diagnosis

We rely on voluntary donations and with your support can make a difference to the lives of thousands of people every year. Whatever you choose to do – whether you want to make a one-off donation or set up a monthly gift, do some fundraising, volunteer or raise awareness – we **thank you** – from the bottom of our hearts.

Fundraising with transparency & credibility

- we are open, honest and transparent
- we will always comply with the law as it applies to charities and fundraising – we will be respectful of your rights and your privacy
- we will be fair and reasonable – treating all supporters and the public fairly – showing sensitivity and being adaptable
- we will be accountable and responsible – managing our resources wisely

We are committed to ensuring that we meet the requirements of the Fundraising Regulator and follow the Code of Fundraising Practice to ensure we meet the highest standards, so you can donate and fundraise for us with confidence and trust. You can read our fundraising promise at fightbladdercancer.co.uk

This is how you can make a donation to Fight Bladder Cancer ...

Online: The easiest way to donate is via the donation button on our website fightbladdercancer.co.uk/make-a-donation where we offer a secure platform to make donations.

By post: If you prefer, you can send a cheque (payable to Fight Bladder Cancer) to our office at **Fight Bladder Cancer, High Street, Chinnor, Oxfordshire.**

Call the office: If you'd rather speak to someone in the team about donating, fundraising or volunteering – then call us on **01844 351621**. We would really love to chat with you.



My carer notes

Jot down anything you have found particularly useful. It will help others if you send us your ideas by email or letter, or post them on the forum.

My useful information

Name _____

Mobile number _____

Patient's details

Name _____

Mobile number _____

Hospital number _____

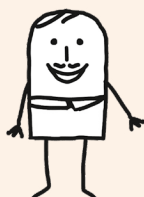
NHS number _____

GP _____

Consultant _____

CNS _____

Other MDT Members _____



If you come across terms you don't understand, you will find a comprehensive glossary in our *FIGHT* magazines or online at

fightbladdercancer.co.uk/get-help/glossary

Everyone associated with the preparation and production of these booklets has made every effort to ensure that the information was correct at the time of going to press. However, the booklets are not intended as a substitute for professional medical advice. Anyone affected by bladder cancer, or any other medical problem, must seek the care and guidance of a suitably qualified doctor or medical team. Neither the publisher, nor contributors, nor anyone associated with them will take responsibility for any actions, medical or otherwise, taken as a result of information in this book, or for any errors or omissions.

This booklet is part of a series that covers all aspects of bladder cancer. The booklets are available free in print or digital format. You can order them via your clinical nurse specialist or download direct from Fight Bladder Cancer at fightbladdercancer.co.uk/downloads

THE SERIES INCLUDES:

- Carers' A to Z guide
- Tests & investigations
- What is a TURBT?
- Low-risk & intermediate-risk, non-muscle-invasive bladder cancer
- High-risk, non-muscle-invasive bladder cancer
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- Living with a stoma
- Living with a neobladder
- Advanced bladder cancer
- Surviving bladder cancer
- Diet & nutrition
- New developments in treatment for bladder cancer

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Fight Bladder Cancer is a registered Charitable Incorporated Organisation in Scotland (SC051881), England and Wales (1198773), and was initially established as an unincorporated charity in England and Wales (1157763). It also operates in Northern Ireland.