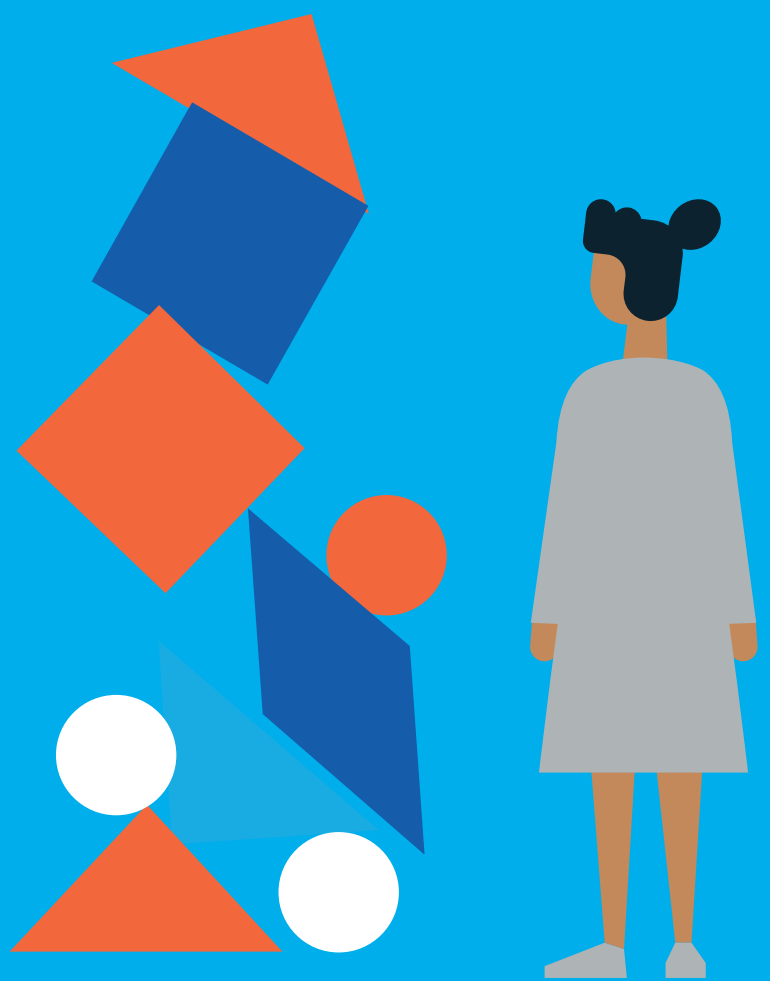


HOW TO COPE WITH CARING

A practical and emotional support book for people who are looking after someone with bladder cancer.



This handbook is intended for caregivers of people living with bladder cancer and has been co-created by Astellas Pharma Europe Ltd and representatives of the following organisations:

World Bladder Cancer Patient Coalition (WBCPC), Norwegian Bladder Cancer Patient Society, Fight Bladder Cancer UK

What's inside

The handbook is in three sections:



THE JOB DESCRIPTION

What's usually involved in caring for someone with bladder cancer?

This section will outline what to expect and describe some of the tasks and responsibilities you may need to tackle.



EMOTIONAL CHALLENGES

Dealing with your own feelings about bladder cancer and being a carer.

You're not alone in finding this emotionally tough. This section covers some of the perfectly normal thoughts and feelings other bladder cancer carers have experienced.



LOOKING AFTER YOURSELF

This section talks about the importance of self care and how to avoid putting your life on hold despite the extra responsibilities of care giving.

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The contents of this booklet are not intended to replace medical advice.
For any medical matter, a medical practitioner should be contacted.

WELCOME

If you're a carer of someone
with bladder cancer,

THANK YOU.

This book is for
YOU.

Most cancer support guides are for
patients. This one is different.

**It's for the
CAREGIVERS.**



No-one applies for this job.

It isn't a choice, it's just what you do when someone you know is diagnosed with bladder cancer. You step up and take on the role. Which is why we start with a huge 'thank you'.

You might think 'well, of course I'm going to do it, there was no question'. But as any doctor will tell you, the role you've taken on will make a huge difference to the person you're caring for.

It's proven: bladder cancer patients do better when they have a carer giving them the practical and emotional support they need.



“

I'm not going to lie... this is going to be tough. Being a carer will test your relationships 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.

The Carers' A-Z Survival Guide by
Fight Bladder Cancer UK

THE JOB
DESCRIPTION

EMOTIONAL
CHALLENGES

LOOKING AFTER
YOURSELF

Who cares for the carers?

Being a caregiver is tough.

It could well be one of the hardest things you'll ever do.

Chances are, you're looking after a loved one or a friend, and therefore you're reeling from their cancer diagnosis just as much as they are. They are coping with their cancer, but so are you, along with many other aspects of your life.

“

Over a decade later and I understand just how important being armed for the battle ahead is in terms of keeping your sanity as a carer. I learnt the hard way the best route to staying sane in a situation over which you have absolutely no control. Andrew and I talked a lot over the years of his illness about the difficulties of loving someone with a cancer diagnosis and we agreed that emotionally it's as tough a journey as being the patient... in fact, sometimes it's worse.

The Carers' A-Z Survival Guide by
Fight Bladder Cancer UK



So this handbook is for you.

It doesn't have all the answers but it aims to give you some support and advice in key areas where support is often hard to find.

Of course, not everyone will experience everything in this handbook. But forewarned is forearmed: if you know what might be coming, it tends to be easier to cope with if it happens.

We hope that you will find something useful here for you at the different stages of your caregiver journey

“

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.

Henry Scowcroft,
Cancer Research UK Science
Writer and Fight Bladder Cancer
Forum Member



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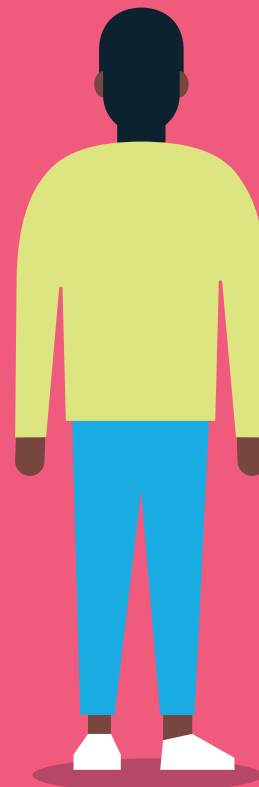


THE JOB DESCRIPTION

What's involved in caring for someone with

BLADDER CANCER

This section outlines what to expect and describes some of the tasks and responsibilities you may need to tackle.



INTRODUCTION

THE JOB DESCRIPTION

EMOTIONAL CHALLENGES

LOOKING AFTER YOURSELF



Everyone's bladder cancer journey is different.

And patients need different types of support at different times. You'll find yourself doing more of some tasks and less than others for a while. But the vast majority of caregivers will find themselves involved in these five types of tasks and responsibilities at some point:

1. COMMUNICATION

- Dealing with doctors and nurses and other healthcare professionals
- Updating friends and family
- Online research for facts and opinions

2. PHYSICAL CARE

- After Trans urethral removal of bladder tumour (TURBT)
- After the radical cystectomy operation
- Learning how to use a stoma bag

3. MANAGING THE TREATMENT DIARY AND LOGISTICS

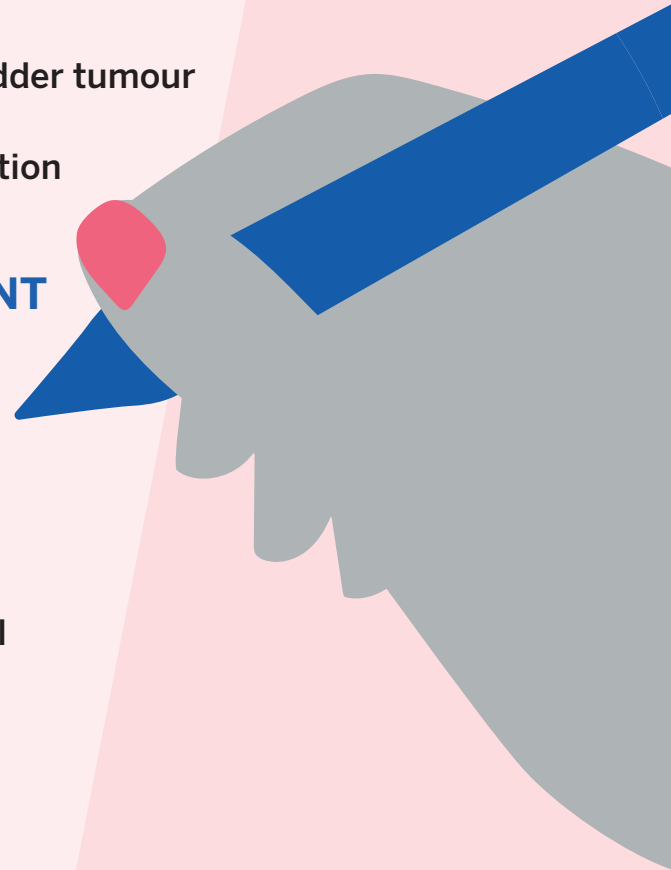
- Medicines
- Appointments

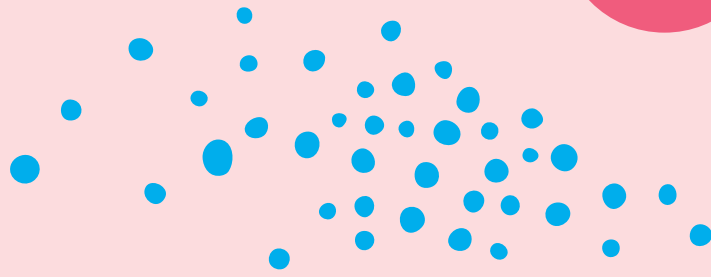
4. EMOTIONAL SUPPORT

- Being there for them
- Helping them find their new normal
- Keeping them going
- Crisis support

5. DOMESTIC CHORES

- Cleaning
- Meals
- Home environment





THE JOB DESCRIPTION





Team carer

Yes, it's a big list and it's a varied list.

You might play all these roles yourself but you'd be super human if you did. The chances are you'll need a team around you.

Gather your support squad from the start, you're going to need them!

As you go through this section, consider who could help you with each task.

E.g. – know someone with a car and some spare time? They could drive you and the person you're caring for to some of the many hospital appointments. A willing 'taxi service' friend is really useful.

E.g. – know someone easy to talk to with a lot of empathy and patience? They could really help with emotional support.

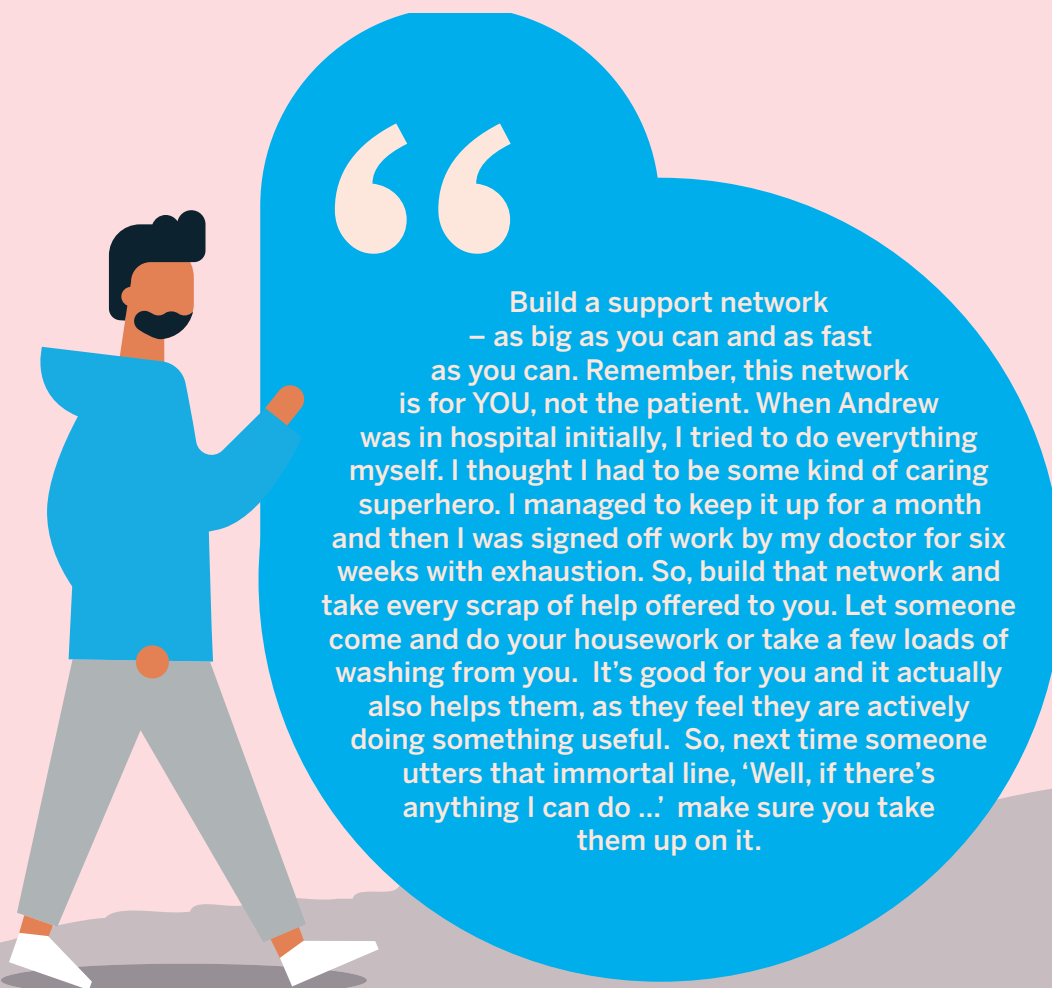




Think about your friends and family and let people play to their strengths!

People are often frustrated at not being able to do anything because they think unless they're a doctor, they're no use to you. You know better! Give them a support task that fits their strengths and people will love to feel useful.

Often friends or other family members want to help you out, but they are unsure what to do or don't want to overstep. Asking them for something specific or tangible (e.g. "If you dropped us off a meal once a fortnight, that'd be a huge help") is often a huge relief for both parties.



“

Build a support network – as big as you can and as fast as you can. Remember, this network is for YOU, not the patient. When Andrew was in hospital initially, I tried to do everything myself. I thought I had to be some kind of caring superhero. I managed to keep it up for a month and then I was signed off work by my doctor for six weeks with exhaustion. So, 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. 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.

The Carers' A-Z Survival Guide by
Fight Bladder Cancer UK



Communication

There are three main communication roles you're going to play:

- Dealing with doctors and nurses
- Updating friends and family
- Online research for facts and opinions

Dealing with doctors & nurses

The person you care for will often rely on you to deal with the medical team for them. It's hard for them to take it all in and they'll need you as a second pair of eyes and ears in every consultation.

TOP TIPS ✓

Prepare key questions and topics you want to ask about in advance

When the doctor is explaining, jot down a few notes – then you can look through it again afterwards

Ask if you don't understand. It's the doctor's job to make sure you're both clear so get them to tell you again if you're confused.

Try repeating back what you think you heard but in your own words: this can help the person you're caring for understand and also helps the doctor check you got it.



Dealing with doctors & nurses

Forming a good relationship with the doctors and nurses in the team will really help you. Getting on well often means a better conversation.

Sometimes, if you or the person you are caring for is not happy with the treatment or you want to understand alternatives, they will need you to be confident to ask the doctor challenging questions. Go ahead! You have every right to and they'll be happy to answer your queries.

“

First of all, speak honestly and openly with your medical team about what to expect both for your loved one and for you as a carer. They'll be able to give you a good idea about the road ahead and the tests and procedures that come with it. Then do your research. Go back to the reputable websites (see page 18) and read as much as you can about what's going to happen.

“

As the informal carer of a person with cancer, you are part of the health and care team. It is important you establish good communication with health and care professionals so that you can get the information, you and the person you care for need. Asking questions can make it easier to cope during diagnosis and treatment. Knowing what is happening can make you feel more in control.

“

Within a few months, the hospital was like my second home, I knew all the staff and would happily while away the hours at my bloke's side with not a care. 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 battle 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. You should feel confident and happy with the treatment your loved one is receiving, and if you are in any doubt at all, you can always ask for a second opinion.

All three quotes from The Carers' A-Z Survival Guide by Fight Bladder Cancer UK



Updating Friends and Family on latest news

This is sometimes one of the toughest tasks. Especially if the news is only just sinking in for yourself. Finding the energy and the words to update others might be the last thing you want to do.



One of the most exhausting roles for a carer is that of news. 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 and make it easier for you to keep everyone up to date. A closed Facebook group can be a brilliant way of getting the current status out there with minimal effort – you post once and then everyone can see the information and comment on it. Or task others with calling and feeding the news through to other family and friends.

The Carers' A-Z Survival Guide by
Fight Bladder Cancer UK



TOP TIPS

Prioritise updating people **YOU** want to. If it helps you to chat to a particular friend, speak to them first. Then the first update is therapy for you, too.

Ask them to update others for you. A 'pass-it-on' approach can take some of the pressure off you.

Use private social media platforms such as a closed Facebook or WhatsApp group to update larger numbers without the strain of lots of individual calls.



Online Research for facts and opinions

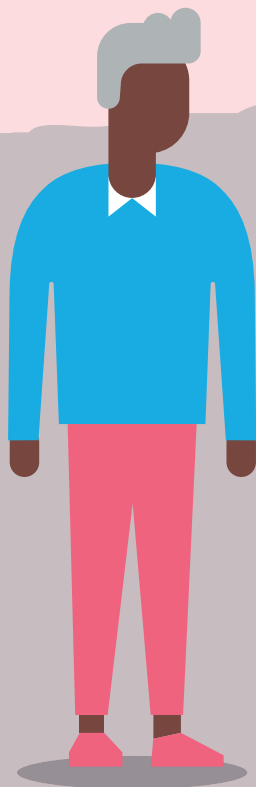
Many patients and carers who've been through this recommend finding out as much as you can about bladder cancer. Often this task falls to the carer as the patient doesn't have the energy or they're just not ready to look.

Not everyone wants to know but many people find it helps them to be well informed and they can have better conversations with their doctors and nurses.

You have two main sources of information:

For information: reputable websites

For opinions and experiences: patient support group chat rooms





Searching for Information: Websites

Be careful and stick to ones you know and trust. There is a lot of misleading information out there on the internet and you don't want you or the person you're caring for to end up reading something that's just plain wrong!

Here are some good places to start if you want to get all the facts about bladder cancer and its treatments.



Searching for opinions & experiences:

Patient support group chat rooms

Several of the bladder cancer support group websites have forums where you can go and join a conversation or post a question.

These are a great way to hear first-hand the experiences of other patients and carers. They can help any feelings of loneliness when you realise there's a whole community of people going through this too. For many carers, these can be an important source of support and encouragement throughout this experience.

In many countries there are carer-only support groups, for times when you need your own outlet or you are worried that expressing a specific carer-experience you have had may upset or embarrass the person you're caring for. Connecting with other carers can make you feel less alone.



But do remember that these are opinions and experience, not hard facts about bladder cancer. What worked for one patient may not work for the person you're caring for.

So use them wisely and don't take one opinion as medical truth!

Before following any online guidance, patients should talk to their doctor.

The amount of information they want may change day-to-day. This can be frustrating for a carer, so try to remain flexible in your support.

“

The great thing about the forum is being able to post questions, no matter how silly they may seem, and get answers from others in the same position.

Fight Bladder Cancer UK

TOP TIPS ON ONLINE RESEARCH

If you don't feel very confident online, could you ask a friend or family member who's knowledgeable about technology to do this for you? This could be just the task to make a younger family member feel really useful.

Don't spend too long looking things up. There's only so much information you can handle and not everything will be relevant to the person you're caring for.

Be sensitive to how much information they want to hear.



Physical care

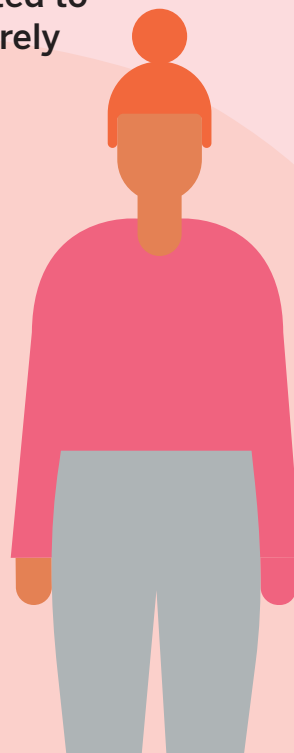
There will be moments when the person you're caring for is going to have physical needs they can't cope with alone.

This can be challenging for both of you as taking physical care of an adult is new to most of us.

- The person you're caring for might find it uncomfortable or embarrassing to have to rely on you. They might resent a loss of privacy.
- And so you might feel they're a bit ungrateful for your efforts. And you might feel a bit embarrassed too.

It's a challenge to your relationship, but if you're open with each other - and maybe keep a sense of humour - physical care can be a very tender way of supporting them when they really need you.

Again, you might feel there's someone else in your entourage who's better suited to physical care. Don't feel bad if you rely on someone else.



Physical care

The situations that might need more physical care include:

- After TURBT
- After the radical cystectomy operation
- Learning how to use a stoma bag

After TURBT

Repeated TURBT (trans urethral resection of bladder tumour) operations can be painful and the person you're caring for will probably be in need of tea and sympathy.

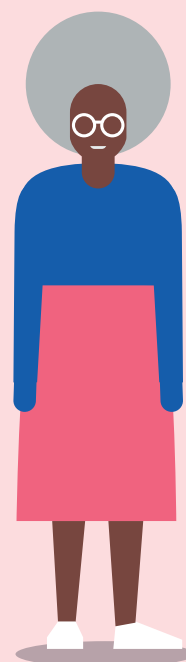
Always seek medical advice, but some physical needs to look out for might be:

- If they have a general anaesthetic (fully asleep during the operation) they will need you to stay with them for 24 hours afterwards
- Make sure they drink lots of water
- You may need to be in charge of their pain relief medication. (When they first start passing urine it may burn and sting for several days).

Of course, the person you're caring for may be happy to manage all this themselves.

It varies from person to person.

Just be aware in case they need you





After the radical cystectomy operation

A radical cystectomy means taking out the whole bladder, the nearby lymph nodes and sometimes other surrounding organs. This is a big operation with a long recovery time.

After the person you're caring for has had this operation they will stay in hospital for up to two weeks but when they're home they will need your physical support more than ever.

Don't worry, the doctor and nurses will give you all the information you need. Take lots of notes if you can. When you're home, go through your notes and write yourself a checklist of what you need to do.

YOU'LL PROBABLY NEED TO THINK ABOUT:

A comfortable space for the person you're caring for to rest and recuperate (other than their bed)

Nutritious and tempting meals – small ones that they can digest easily

Keeping them hydrated - encourage them to drink plenty of water

Managing medication including pain relief and anti inflammatories

Wound care and dressing changes

Dealing with day and night time leaks from the new stoma bag (if the person you're caring for has one)

Arranging the follow up appointments with the stoma nurse and the doctor or surgeon

Collecting medicines and/or stoma bag supplies from the pharmacy

Helping someone cope after surgery for bladder cancer can be difficult. In the UK you can call the Cancer Research UK nurses on freephone 0808 800 4040, from 9am to 5pm, Monday to Friday, to talk things through.



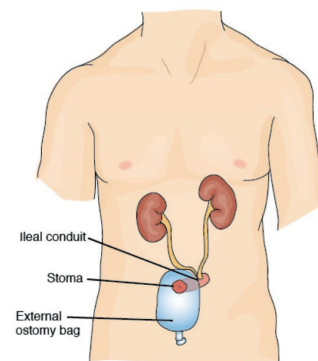
Learning how to use a stoma bag

When someone has their bladder removed the surgeon will either surgically reconstruct a new bladder ('neo bladder') during the operation or they will have a stoma created. This is an opening in the tummy to which a stoma bag is attached to catch urine.

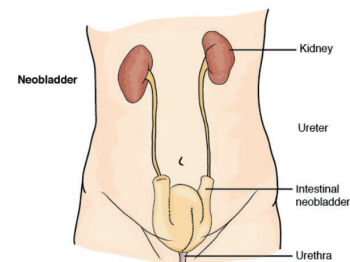


Check out Fight Bladder Cancer's fantastic download Living with a stoma which is full of practical information that the person you're caring for will need.

A special stoma nurse will show them how to use a stoma bag and will change it for them while they are in hospital. It takes a while to get used to it, and there will be a few leakages along the way.



Most people wish to manage their stoma themselves. They will learn how to keep it clean, how to change the bag, how to manage the seal to avoid leaks, how to choose clothes that keep them comfortable while they are getting used to such a big change in their daily lives.



It will be helpful if you can monitor the supplies the person you are caring for will need. Always ensure there are sufficient day and night bags and that you order in good time.

Your biggest role will probably be empathy, emotional support, patience & reassurance for the person you're caring for.

THE JOB DESCRIPTION

EMOTIONAL CHALLENGES

LOOKING AFTER YOURSELF



Managing medicines & appointments

As their journey through bladder cancer continues, there will be lots of things to keep on top of, and the person you are caring for may need you to take on some or all of this organisation.

Reporting of side effects

If the person you take care of gets any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the medicines' package leaflets. In the UK, you can also report side effects directly via the Yellow Card Scheme at <https://yellowcard.mhra.gov.uk>

By reporting side effects, you can help provide more information on the safety of medicines.





MEDICINES

People with bladder cancer will be on a range of medication which will change over time. The medicines will be prescribed for a number of reasons and it will be very important that the person you're caring for keeps taking them all at the correct time.

THINGS TO THINK ABOUT INCLUDE:

Having a list or spreadsheet of all the medicines they are taking at any one time and what each medicine is for.

Knowing the dose and timing of each one.

Keeping an eye on supplies so that you can organise and collect repeat prescriptions as needed so a complete and up-to-date list is very important.

List and separate the “everyday medicines” from the “when required” medicines. For example, some medication won't be taken every day and only if the person you're caring for experiences a burst of pain, nausea, constipation etc.

Bladder patients get seen by a variety of healthcare professionals. Often the carer is the consistent presence at the centre of all these people, knowing what medication has been taken. Some medicines can't be taken together so your complete list is very important.

Always seek medical advice on medication.



APPOINTMENTS

There are so many things happening, and diary management will probably fall on you. There will be appointments with a wide variety of people, for example stoma nurses, chemotherapy nurses, the surgeon, oncologist, urologist, physio, phlebotomist (blood tests), general practitioner.

Sometimes you may find you need to get on the phone and arrange appointments and tests by ringing round different departments. Sometimes it takes you, the carer, to make sure all the different parts of their care are joined up.



TOP TIPS

Get a diary

Write everything down

Think and plan in advance

Next to entries in a paper diary is a good place to write notes and questions you want to ask at the appointment



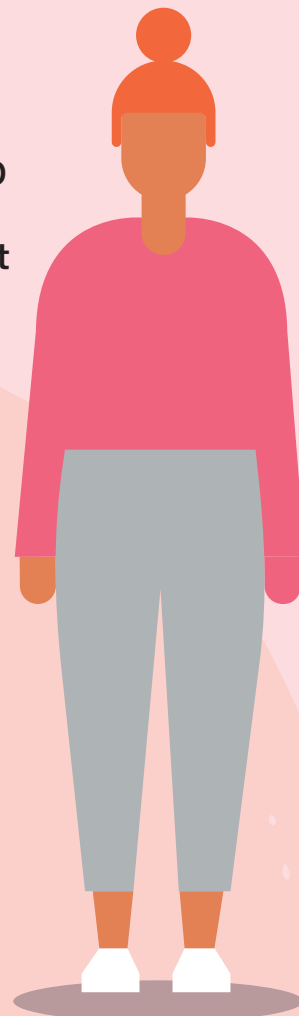
Emotional support

Everything on the list so far has been very practical.

This next part of the carer job description requires a very different skill set.

You'll need to be a good listener, a counsellor, a therapist. Not a professional one, of course – you don't need any qualifications to do this other than kindness and empathy.

Even if you think this is just not your cup of tea, remember this is probably the single most important role you can play. They **NEED** emotional support from you more than anything. If you really feel you're not the right person, find the person who is. Research has shown us many female patients choose female buddies to play this role.*



*Real Sky Qualitative Research UK 2021



Emotional support

There are different ways of giving emotional support.

BEING THERE FOR THEM

For this, you just need to listen.

Give them time and space to just let it all out.

HELPING THEM FIND THEIR NEW NORMAL

Listening to what their new life feels like so far

Gently supporting them with ideas to adapt and cope.

KEEP THEM GOING!

When their optimism or their energy sags, you need to be the cheer leader motivating them with your positive energy.

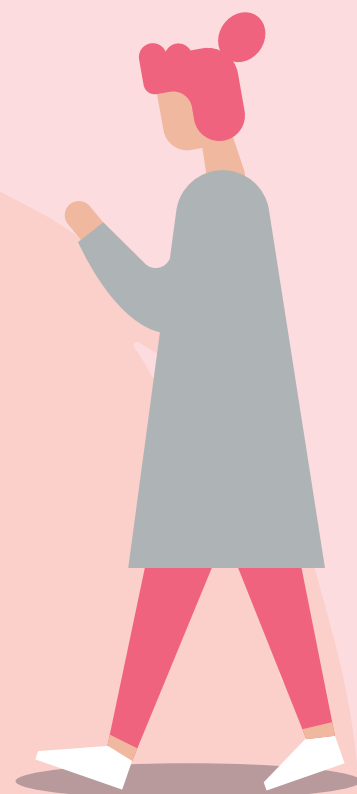
CRISIS SUPPORT

Immediate techniques to calm an attack of anxiety.

Reassurance: they're doing great and you're there for them.

KEEPING UP WITH THINGS THEY ENJOY

While they might not always have the energy or motivation to do so, catching up with friends or keeping up with hobbies or activities they previously enjoyed can be very good for their mental health during their cancer journey.





TOP TIPS

A good rule is listen a lot more than speak

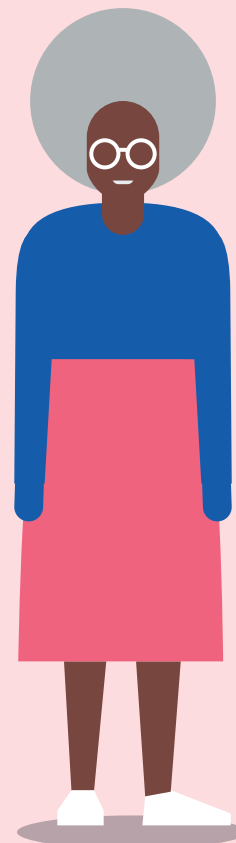
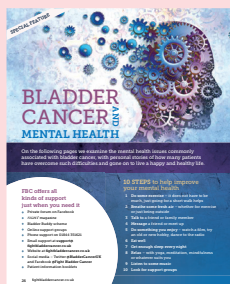
Brace yourself for raw emotion. They need to cry. Don't try and stop them.

Don't judge.

Don't impose your own solutions on them. Empower the person you're caring for to think and decide for themselves where possible.

Mental care is tough if you're not used to providing this kind of support. Go onto the bladder cancer support chat rooms and ask for others' experiences and advice. Join a support group. Great mental care ideas are often best found in the experiences of other carers and patients.

Places to go for more help include:





HELP ME NOW

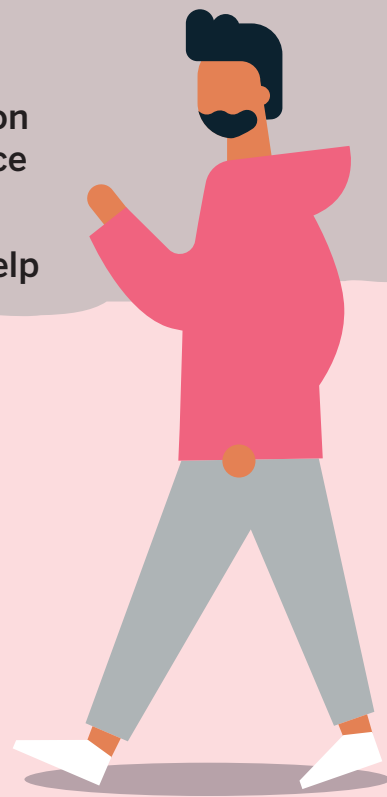
If someone with you is struggling to control their anxiety, you can help them by doing this easy exercise to bring their brain into the 'now' by asking them to tell you:

- Five things that they can see
- Four things that they can hear
- Three things that they can feel
- Two things they can smell
- One thing they can taste

The order doesn't matter but by the time they have tried to do all of these, then things should have calmed down somewhat.

Another tip is counting backwards from a hundred, or asking them to spell a word backwards. They will be focused so much on this that their brain will not have the chance to wander off.

And of course breathing exercises really help to create calm.





Domestic chores

**We know...
the most boring
part of the carer job
description.**

But necessary. It's mentioned in this handbook because:

- a) If you shared domestic chores before they were ill, it'll probably all fall to you now so you need to carve out time for it
- b) There are some extra needs with a bladder cancer patient in the house

Bladder cancer can mean more cleaning and more laundry (and after surgeries an extra clean and hygienic home is obviously really important).

Be prepared for

- Urine leaks on furniture and car seats
- More laundry especially sheets after night time leaks

You might want to invest in specific continence bedding . Some people prepare the bed with two layers of mattress protection and fitted sheets so that if there is a leak, the top layer can be easily pulled off and the next layer is ready to go (especially convenient in the middle of the night).



Cancer of any sort means food and nutrition is key so meals need to be thought about more. Tastes change, manageable portion sizes change when people are ill.

Take into consideration any dietary recommendations from the hospital in the early days after an operation – for example, if they have had bowel removed to fashion a neobladder, they may be on a modified diet in these early days.

When you find something they'll eat, stock the freezer up. Shop online. Whatever makes it easier for you.

Do you have a friend who loves to cook family meals? That could be their contribution to Team carer – the occasional delicious home cooked meal. Nutritious food is also emotionally nourishing:

food is love!

For more ideas, check out this leaflet from Fight Bladder Cancer: give it to the person you're caring for to read and together you can plan the right food for them.





Creating a caring environment

You'll need to think about creating a cancer patient-friendly environment in your home. It might take only a few small changes to create a nurturing space to make the person you're caring for feel their home is helping them feel better.

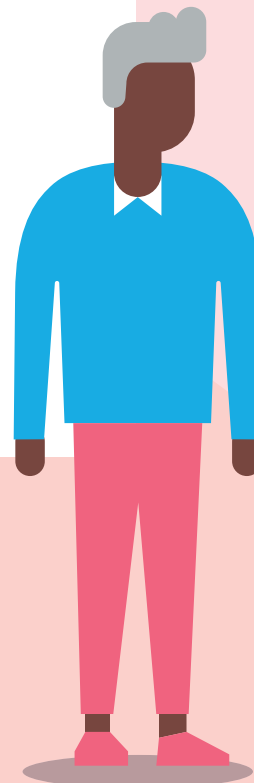


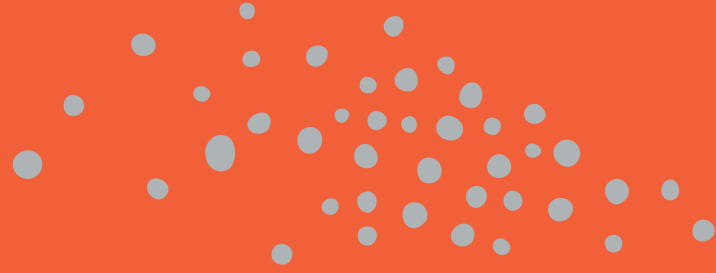
THINGS TO THINK ABOUT

What makes them comfortable?

Is their bedroom layout right and their bed suitable?

Do they have space to manage their stoma in privacy from the rest of the family? Storage for spare bags and other equipment?



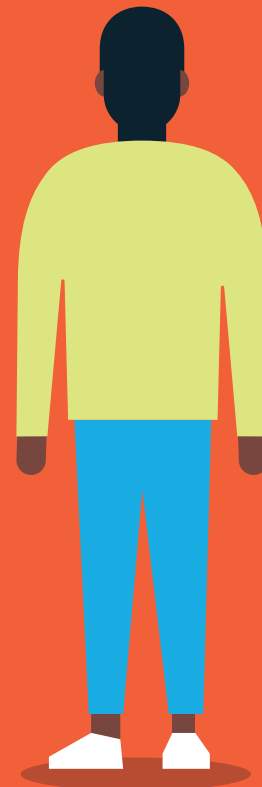


EMOTIONAL CHALLENGES

Dealing with your own feelings about bladder cancer and being a

CARER

You're not alone in finding this emotionally tough. This section covers some of the perfectly normal thoughts and feelings other bladder cancer carers have experienced – which you might experience too.





How can it feel to be a carer?

Expect to experience a whole range of different emotions and thoughts during your time as a carer. The role of carer comes with many emotional challenges.

In fact, the more you expect this, and realise it's normal and ok, the easier it will be to cope with.

This section of the handbook covers:

YOUR FEELINGS ABOUT BLADDER CANCER

- You're only human too
- Embarrassment

YOUR FEELINGS ABOUT BEING A CARER

- Fluctuating emotions
- Resentment
- Guilt

COPING WITH OTHER PEOPLE'S REACTION TO BLADDER CANCER

- Tips to cope with other people's poor communication

YOUR RELATIONSHIP WITH THE PERSON YOU'RE CARING FOR

- What sort of care do they want?
- When you disagree on treatment
- Sex and intimacy
- Unspoken emotions



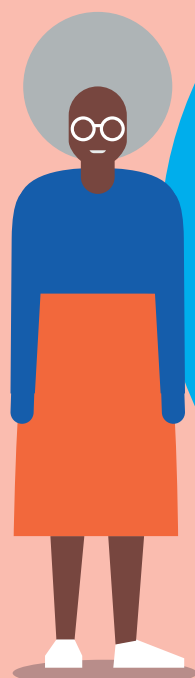


Your feelings about bladder cancer

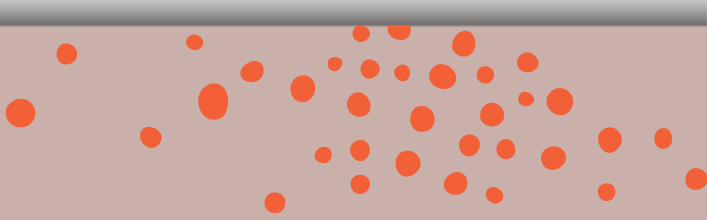
Someone you love has been diagnosed with a horrible disease.

That's shocking and distressing. Before you even think about being a carer, give yourself a moment to acknowledge those normal feelings of shock, disbelief, anger, sorrow.

At the centre of every carer is just a person who is suffering because someone they care for has cancer.



I was outraged that this could happen to us and that cancer had stomped its way into our 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. 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 life outlook... for the better.



Many people who have bladder cancer say it sometimes makes them feel dirty. They can feel ashamed and embarrassed.

Of course you don't want them to suffer by feeling those things. But it's important to respect their genuine reaction and instead of dismissing it, comfort and reassure them.

You know that none of this is their fault. But it doesn't stop people feeling bad about having an unpleasant disease.

And what about your feelings about bladder cancer?

Do you sometimes feel it's dirty and smelly too? Are you embarrassed by the intimate nature of the illness? Would you never ever say those things out loud but do occasionally think them?



That's understandable. You're human. Don't feel guilty, don't feel bad. It's ok to have a human reaction to an unpleasant illness with nasty symptoms. Don't beat yourself up for it, just acknowledge it and know you are not alone.



“

It makes me feel a bit squeamish. It's intimate. I don't really like it. I feel guilty towards her.

”

I feel really awful saying it but I feel quite awkward about it. It's so personal, it's that person's personal dignity.

Real Sky Qualitative Research UK 2021

It's hard to deal with incontinence in adults. We all naturally associate lack of bladder control with infants. So caring for a partner, friend or parent who are suffering this is hard.

But hang in there – it's not forever. You might feel like your relationship with them has changed because of the intimacy and stigma of incontinence, but just focus on giving them the help they need.

- Some people want help in dealing with it, clearing up, sharing the task of learning to use the stoma bag – sometimes even sharing a laugh about it.
- Others will want privacy for these intimate moments.
- Some people will want to talk about it, be open, share their feelings. Others might want to keep that part of the disease to themselves.

Be guided by the person you're caring for, tune into their feelings and preferences. Try and make sure they're not 'suffering in silence', and that you've understood correctly what involvement they want from you.



Your feelings about being a carer

Most people experience a range of emotions about being a carer.

Sometimes it can be incredibly rewarding to care for someone you love at a time when they need you so much.

At other moments it can be frustrating, exhausting, upsetting, depressing.

This disease will impact your relationship with the person you're caring for. It's inevitable. There will be moments that make you closer, that add a new dimension to your relationship. There will be moments that really challenge you both, where things will feel tough.

“

Be kind to yourself. 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.

The Carers' A-Z Survival Guide by
Fight Bladder Cancer UK



We said before “at the centre of every carer is just a person who is suffering because someone close to them has cancer”.

Don't underestimate this. You're not a professional carer, you're just someone doing your best for someone who's important to you.

Which makes you amazing

Dealing with resentment

Some days you will resent having to be a carer. There. We've said it.

It's no crime to yearn for that freedom from the hard work and responsibility of caring.

Did you know, **36%** of carers say they feel resentment? That rises to **HALF** of all younger carers. You are not alone in feeling this.

We have plenty of advice and ideas in the third section of this handbook to help you look after yourself. Because you matter too!

But the first step is to recognise that this is normal and common. And totally human.

Of course if it becomes what you're feeling most of the time, and you start to feel anxiety, depression and constant stress, then you need to act. Turn to page **59-61** now for advice on mental health and support.





Dealing with guilt

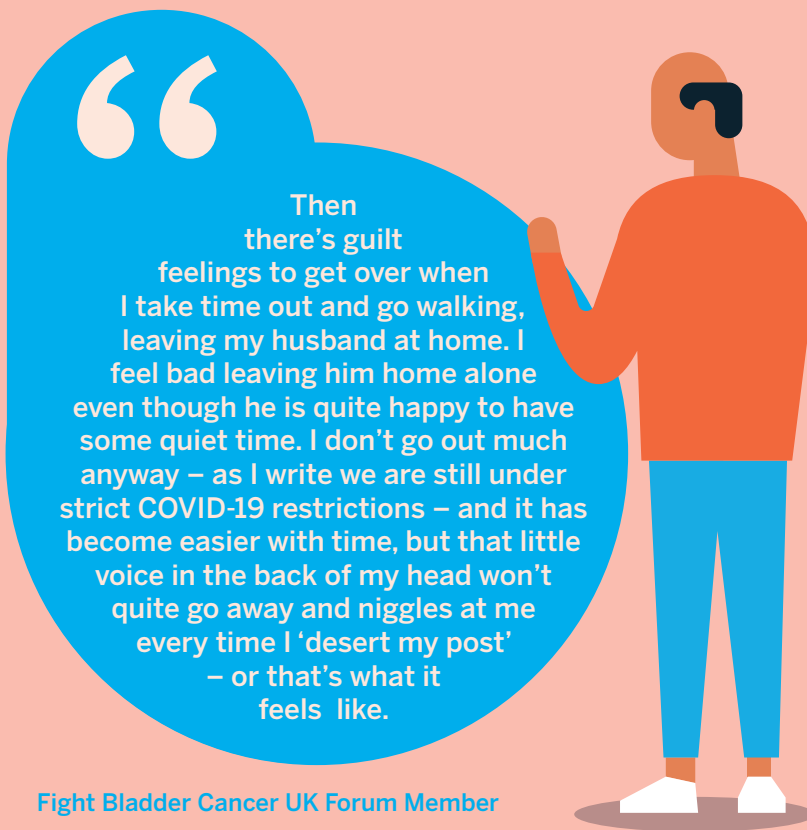
Then there's the **big G** to deal with – and you can't escape it:

Guilt.

Should I have suspected this?

Should I have pushed for more tests?

And then there's - "They have this and I don't"



“
Then there's guilt feelings to get over when I take time out and go walking, leaving my husband at home. I feel bad leaving him home alone even though he is quite happy to have some quiet time. I don't go out much anyway – as I write we are still under strict COVID-19 restrictions – and it has become easier with time, but that little voice in the back of my head won't quite go away and niggles at me every time I 'desert my post' – or that's what it feels like.

Fight Bladder Cancer UK Forum Member

You need to put the guilt aside. If you're finding it hard to silence that "little voice" in the back of your head, then phone a friend or jump online and chat to a fellow carer. Let them know how you feel. They will put your mind at rest. There's no need to feel guilty. It's not your fault. Sometimes you just need a friend or a fellow carer to tell you that truth.



Other people's reaction to bladder cancer

We don't, as a society, really know how to behave around cancer and we don't know how to communicate with people who have it.

People with bladder cancer often report that other people don't have the words to respond to their diagnosis. Many will literally cross the street to avoid the awkwardness.

You're going to have to cope with how that makes you feel.

Angry with people? Disappointed? Protective of the person you're caring for? Frustrated? Lonely because if people avoid you and your family it can make you feel isolated?

You will also find yourself coping with how the person you're caring for feels about this. Again, you've got the double to cope with – your reaction and theirs.

Welcome to caring!



Other people's reaction to bladder cancer

THESE MIGHT HELP

Try and give people the benefit of the doubt. They could be saying nothing because they don't want to say the wrong thing. So they have good intentions.

Turn awkwardness into practical action: if they don't know what to say, maybe they can DO something instead. A meal, a lift to hospital, a load of washing.

Give them the words: we talked on page 16 about keeping people updated. A private social media page is the easiest way of covering off a number of people. You can guide people with the right words in a simple post.

Value and embrace those friends who are there for you. You'll soon find out those you can rely on and they often become a huge source of support.

Some might struggle to find their own way for supporting you and that's also ok.

“

It's sorted out the real friend

Real Sky Qualitative Research UK 2021

“

Some people walk on the other side of the street. There's awkwardness.



Your relationship with the person you are supporting

Being the carer they want you to be

Have you discussed what they want from a carer?

It's tempting to launch straight into what you think they need. But it's worth chatting to see what kind of support would help them most.

In the 'Job Description' in section one there may be areas that they feel able to do themselves at first.

Don't forget to keep checking in with them. Their needs will undoubtedly change over time: as the disease and its treatments progress and as their mental and physical health fluctuates.





SOME TOP TIPS & WATCH OUTS FROM OTHER BLADDER CANCER CARERS

Beware of wanting to take over

You can't do everything for them and they probably don't want you to. It's their fight and you need to support it on their terms.

Make room for their independence in your caregiving

Just because someone has cancer, it doesn't make them incapable of living their life and making decisions for themselves. In fact, retaining their independence is of huge importance to most people with bladder cancer. Careers, the ability to provide for your family, sporting achievements, being the world's best parent, telling the best jokes. These are all sources of pride and self esteem: whatever their sources are, be careful to not to let your caregiving intrude where it's not needed.

Conflict of purpose: when you have different treatment goals

Sometimes you won't agree with each other on the way forward. Maybe they're keen to have a radical cystectomy but you think it's too soon, there are other options still. Maybe they're ready to give up chemo and you're desperate for them to keep at it. They're the patient; you don't get the decision making rights as a carer. You're there for reflection, support, to give another perspective but to ultimately listen to what they decide.

Recognising when to step forward, when to step back

There are moments on the journey when you're really needed and moments when they rally a bit and their old self comes through, capable and in control of life. Be conscious of when to step up and when to quietly step back. You'll probably find yourself getting better and better at tuning in to their needs as time goes on.

Intimacy: lovers & carers

If it's your partner who has cancer, it is going to affect your relationship, and intimacy. Realistically, you will have to work hard to make sure that cancer doesn't come between you in that way.

Operations and treatments can have a very real physical and emotional impact on people. Your loved one may be tired, suffering from side effects, feeling weak or even a wave of depression.

You may also have concerns about what you can and can't do sexually during treatments. Your nurse is the best person to ask about this. You have no need to feel embarrassed – they've heard it all before, it's part of their job. They'll be able to provide you with the information you need to make sure you and your partner are safe when you are intimate.





Intimacy: help and advice

Fight Bladder Cancer UK have devoted an edition of their magazine to sex and intimacy. There's lots of information and people's experiences in here that you and your partner can read about.





Hidden feelings: what if they don't make it?

When people hear any cancer diagnosis their thoughts often turn immediately to death. Fortunately, most people can see a road ahead and approach treatments determined to defeat cancer.

Carers are often a big influence in this, encouraging and cheering them on.

But sometimes, inevitably, your thoughts will turn again to the possibility that they won't survive.

When you're a carer you're close to every treatment, every doctor's appointment, every chemo session, the recovery from every operation. You're there to hear every bit of news with them – and that includes the bad as well as the good news.





Hidden feelings: what if they don't make it?

You might feel it's your job to always be cheerful and positive but sometimes, these feelings will hit you. Again, it's to be expected. All carers say they feel like this sometimes. You can't be the cheerleader all the time.

Getting professional support in the form of a counsellor or psychologist who has a special interest in chronic disease can be invaluable.

Two common experiences that carers often mention are:

*Grief in advance
How would I cope?*

“ 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, because to look ahead too far, at what might be on the horizon, was to look into a place I did not want to see.

Henry Scowcroft, Cancer Research UK
Science Writer and FBC Forum Member

“

Part of me wanted to start distancing myself as self-protection should the worst happen. Yet part of me wanted to be there all the time so as not to waste precious moments.

Fight Bladder Cancer
UK Forum Member





LOOKING AFTER YOURSELF

This section talks
about how to look after
YOU

It's a gentle reminder to try and keep mentally and physically healthy and to avoid putting your life on hold despite the extra responsibilities of care giving.

Section one gave you the **JOB DESCRIPTION** so you get an overview of all the pieces of the carer role

Section two gave you advance warning of some of the **EMOTIONAL CHALLENGES** you might face.

Section three is all about looking after **YOU**.





This section includes:

YOUR PHYSICAL HEALTH

- Prioritising it
- Eat, sleep, move

YOUR MENTAL HEALTH

- Watch-outs
- Your sense of self
- Avoiding isolation

DON'T PUT YOUR LIFE ON HOLD

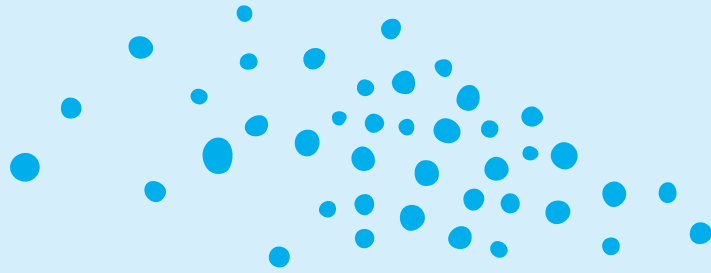
- How to still be all the things you want to be
- Work
- Leisure
- The future



“

My advice would be not to put too many things in your life on hold, despite the uncertainty.

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LOOKING AFTER YOURSELF

YOUR PHYSICAL
HEALTH



YOUR MENTAL
HEALTH

DON'T PUT YOUR
LIFE ON HOLD

INTRODUCTION

THE JOB
DESCRIPTION

EMOTIONAL
CHALLENGES

LOOKING AFTER
YOURSELF



Your physical health

It's so easy to de-prioritise this.

When you have someone in your life who has such an immediate and extreme challenge to their health - bladder cancer - everyone else's physical health can take a back seat. You're not the one with cancer, after all.

"I need to worry about his health, not mine!" is the typical carer reaction.

But please don't forget to look after you

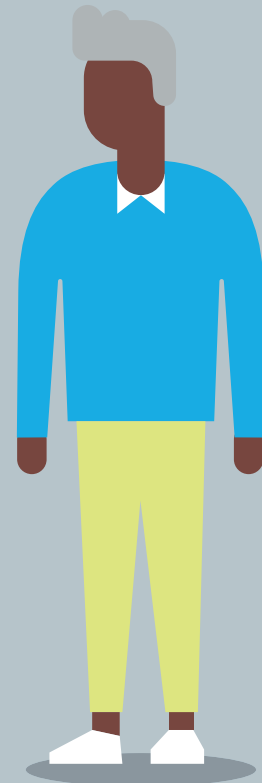
Yes...

We know your time is already stretched to breaking point

We know you only have so much energy

We know that you are constantly putting others first

Don't de-prioritise your own medical check-ups and appointments e.g. keep up your own routine blood pressure checks, annual blood tests or cervical, breast or bowel cancer screening tests.





We get it

It's hard and we don't want to suggest you have two spare hours a day for going to the gym or having a lie in. If you can find those hours occasionally – great!

Most days for most carers are too busy.

But every little helps. So here are some ideas and reminders to...

EAT A LITTLE BETTER

SLEEP A LITTLE LONGER

MOVE A LITTLE MORE





Eat a little better

If you're making nourishing food for the person you're caring for, **make double** and eat healthily too

Friends often offer to cook as a way of helping. Ask them to **contribute a healthy main meal** and “eat a little better” is instantly done for you for that day.

Stock up on healthy snacks and clear out unhealthy ones from the house. Let's be realistic: caring means grabbing food when you can and if you're tired and stressed you need to make grabbing something healthy the fastest and easiest option.

Don't get dehydrated, it makes you lethargic and you need your energy! **Have a water bottle nearby** and take a sip every time you walk past.





Sleep a little longer

Sleep is your secret weapon. The power of sleep is amazing and getting your seven hours will give you the energy to be a great carer without going crazy.

Try going to bed just 30 minutes earlier. It can make all the difference.

If you're at home when the person you're caring for rests during the day, **rest too**. It's an old trick from new mums who resist the temptation to rush around doing things when their baby sleeps – instead, they sleep too.

If the person you're caring for needs help in the night and your sleep is regularly broken, **factor this in** and try and go to bed earlier to compensate.





Move a little more

“Exercise” sounds time consuming. But just trying to consciously **move a little more** everyday will do fine.

Try and **get outside every day**. Breathe in the air. And walk, even if it's just for ten minutes round the block. Or to the shops for a pint of milk.

Combine exercise and socialising: only got time to go out once this week? Join a friend for a Zumba class and a coffee and it's **a two in one**.

Getting outside and going for a walk is brilliant therapy for the person you're caring for. So **piggyback their exercise** and go too.





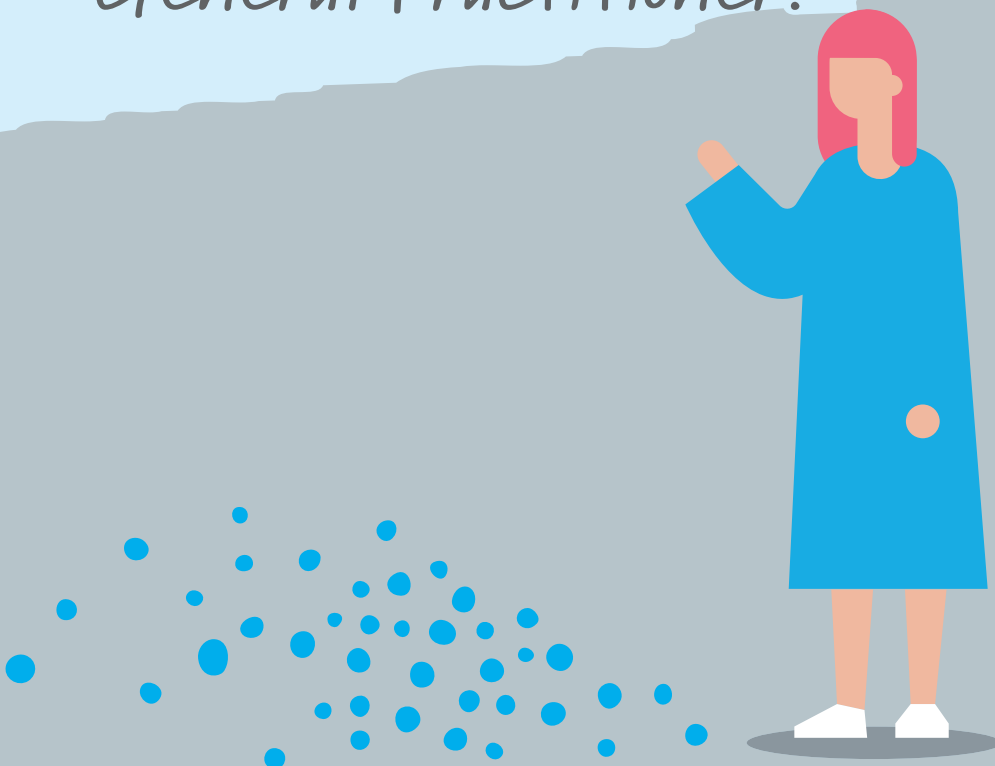
How to look after yourself mentally

Of course it's not just about physical health. Keep an eye on your mental health too.

You're under pressure, of course, but be aware if

- You regularly feel depressed or low
- You have feelings that you can't cope
- You feel constantly stressed
- You worry so much that it has an effect on your sleeping or eating

If you experience any of these, talk to your General Practitioner.





Talking to carers, they have two main pieces of advice for keeping mentally healthy:

1. Do things to hold onto your sense of self

What are the things you do that make you, you?

There will be things you value, hobbies, activities, stuff you love to do that really defines who you are to others but most importantly to yourself.

Maybe you always played Sunday morning football, or sang in a choir, or did up old bikes or told the best jokes and sang the worst karaoke on a Saturday night out with friends. Whatever your thing is, try and still do just a little bit of it. You might not have the time to do it as often, but don't give up on the things that define YOU.

You will spend so much time doing things for others so make sure occasionally you have the space to do things that are just for you.



2. Do things to avoid feeling isolated

Your life has been turned upside down and carers can feel lonely and isolated, in fact nearly half of carers (surveyed in 2021 European and US research) said they were more likely to be isolated or lonely than before the cancer diagnosis.



WHY DON'T YOU

Phone a friend and just talk

Find a bladder cancer support group and chat online or go to some live events and connect with people in the same situation

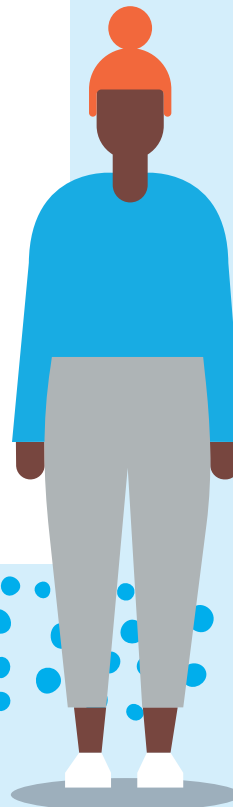


Gather your carer team around you (see The Job Description section) and remember that you can't do all this alone, it's a team effort.

Are there friends and family who've offered support but you've not taken them up on it yet? Now is the time!

Contact carers UK: The charity offers valuable support and information, and has a forum where carers can let off steam, share a problem, and talk to other people who understand what they are going through.

They have just produced a new guide on all aspects of caring, from practical tips to financial support.





Don't put your life on hold

People who have been caregivers often reflect on how much they put their own lives on hold. A cancer diagnosis is like hitting PAUSE on life. It's definitely happened to the person you're caring for and if you're not careful it will happen to you too.

As a family, your plans have stalled. You're in cancer limbo, treading water while hoping for the day when this is in the past and you can all move on.

It's important to try and keep a sense of life progressing. Embrace change and keep looking upwards and forwards. Just making tiny changes around the house, trying out a new cafe that's opened, going to an exercise class you've never done before – making space for change and progress feels good.

If the person you're caring for is between treatments and feeling up for it, perhaps take the weekend away. Do a 'bucket list' item. You never know what the next week or month may bring.





You're more than a carer

You may sometimes feel that being a carer is the only thing you are now.

There will be days when it's all consuming and you struggle to remember that you are so many other things too.

Are you:

- An amazing mum or dad to your kids, with all the responsibilities that entails
- A loving son or daughter with parents who need you too
- The best of best friends – life and soul of your mates' get togethers
- A respected and well liked colleague
- An essential team player in your sport's local league
- A school governor, local councillor, charity volunteer, fundraiser...





The working carer

Many people need to combine being a carer and earning a living at the same time.

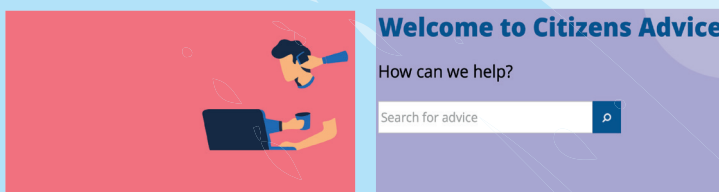
That's hard work but it can also be a real positive in carers' lives:

- It's time that's not focused on caring
- You can stop thinking about bladder cancer for a while and focus on something completely different
- This is what you're good at: it's an area where you can show what YOU are and appreciate the skills and experience you bring to your job

Plus carers have rights in the work place that should help to make life a little bit easier.

Let your Line Manager or HR Department know that at home you are dealing with a bladder cancer diagnosis and you are the carer. Don't be afraid or feel humbled to ask if your work place has anything in place to help a carer. Maybe even be an Employee Assistance Programme that you can access for further support and advice. Maybe additional paid time off for 'exceptional circumstances' such as treatments or attending appointments

The Eurocarers organisation has some really useful informal about your employment rights. Visit their website.



Caring for someone with bladder cancer can of course put a strain on the family finances.

Advice on financial matters can be complicated, with different allowances and benefits available. If you need help with money matters, go to the Citizens Advice website.



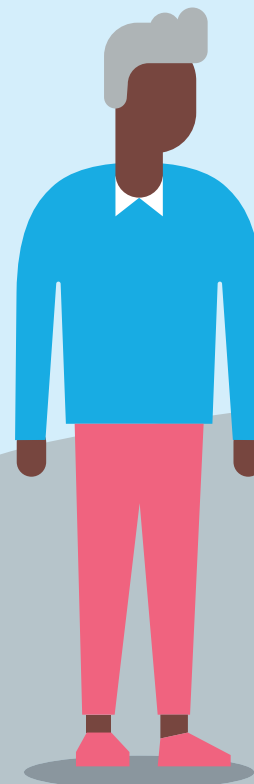
Your journey

The person you're caring for could have a long journey with bladder cancer.

We sincerely hope that you all have the opportunity for many more years together. Things will be different and people talk about finding their “new normal”.

Your roles and responsibilities as a carer will change over time. There will be moments when you're needed more and when you're needed less.

We hope you've found some tips, advice and inspiration in this handbook that will help you on your journey as a carer, looking after yourself as well as the person you're caring for.



"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.

We carry out our task with whatever skills we have, through the prisms our lives have given us.

We do the best we can – even though, sometimes, that isn't quite enough. But that's OK.

We can do no more than that."

Henry Scowcroft, Cancer Research UK
Science Writer and FBC Forum Member



This handbook was created in partnership with



It draws on the experiences of bladder cancer carers across Europe and the USA, obtained through patient and carer associations and through independently conducted research.

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