

A Guide to caring for someone with Colorectal Cancer







From carers to carers

You care. You care for someone with colorectal cancer.

You might be their partner, their child or other relative, a friend, a neighbour – the term “Carer” can include many different people with many different situations.

However, to someone with colorectal cancer, you are their significant other, someone who is instrumental in helping them to manage from day to day, and someone who is playing a vital role in their care.

We care too. And we care about you, our fellow Carer.

This Guide has been written by Carers and patients who have lived with colorectal cancer.

We have lived through many of the challenging moments that caring for someone with colorectal cancer can bring (and many of the positive moments too!)

While the level of care required can vary considerably according to the stage and severity of disease and your own personal circumstances, and the experience is different for everyone, we hope that this Guide contains information that you will find useful and reassuring. Not all of it may be relevant or right for your own personal situation – but simply take the parts that apply to you.

On behalf of patients with colorectal cancer and Carers everywhere, thank you for doing what you do. You are performing an invaluable role – not only for the person you care for but for society as a whole.

Thank you for caring.



PLEASE NOTE: this booklet should not replace and/or substitute the interactions with and advice you are given from your Healthcare Professional. If you have any medical concerns, then please discuss them with your Healthcare Professional at the earliest opportunity.

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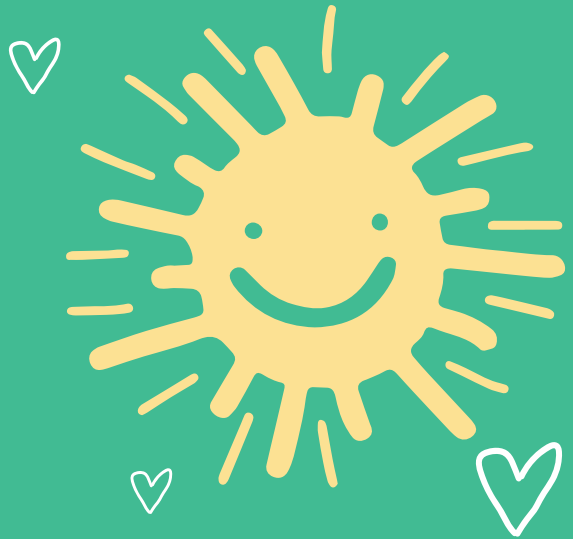


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1. Caring for someone with Colorectal Cancer





What does it mean to be a Carer?

Unless it is the job we do, people do not choose to be a Carer. It is a situation that is thrust upon us. It can happen quite suddenly, and generally, we do not receive any training or instruction for it. We just “get on with it”.

Indeed, many of us do not even think of ourselves as Carers – looking after someone is just what we do. Particularly for partners and family members, it is just the “expected” thing to do if someone close to us is seriously ill.

However, it is important that we do recognise ourselves as Carers.

For one thing, it gives a name to the important role that we do. With the hours and effort that can go into caring, it is often like a fulltime job in itself. It is important that we recognise that ourselves and that others do too.

Secondly, it means we are more likely to identify and access our rights. While these vary significantly from country to country, Carers usually do have rights. It is important to know what these are and access the assistance that we are entitled to.

What is my role and how much of my time will it need?

The level of care required is related to several factors, particularly the stage of colorectal cancer, the prognosis, the outcome of any surgery, whether the patient requires a stoma, and the age and level of independence of the patient.

It is best if you and the patient can sit down and talk to determine what he

or she can take care of themselves, what will be done together with you, and where your role as a Carer will be absolutely essential. Establishing those roles and setting boundaries early on will be hugely beneficial for both of you.

The main task of the Carer is generally not medical, although there will likely be elements of medical support such as changing wound dressings, administering medication, dealing with feeding tubes and so forth, for which you may need support and guidance from healthcare professionals. Your main role will be to help Guide and support the patient through all aspects of the illness. The role will likely encompass providing practical, psychological, social and emotional support. Day to day activities may involve driving the patient to doctor appointments, preparing meals, managing financial matters and just being there to talk and listen.

If the patient's colorectal cancer is at an advanced stage, then it is likely that they will require a significant amount of support. There may be many things that the patient could do before that they can no longer do, which may now fall to you.

For a while at least, your own day-to-day role may change considerably.

Equally, it does not need to change everything. Many patients are still very capable of doing many of the things they were doing before the diagnosis. It is about finding what is right for each individual.

From your perspective, it also depends on your own situation and how much time you can realistically dedicate to caring. For example, if you are looking after a parent and you have a young family and fulltime job yourself, it is likely you will have less time than some. It is important to be realistic with yourself and your loved one, so that you can get other help / assistance at an early stage if required.

Remember, you can always talk to a Healthcare Professional at any point – they are there to support you.

The upsides of caregiving

While it can be very challenging, many Carers agree there are positive aspects of caregiving. It is a life-changing experience, which makes us reevaluate our lives and relationships, often bringing us closer to the patient, which can be very rewarding. It can also help us to have a better perspective about other events in life – when you have faced something as challenging as colorectal cancer, you do not always worry about the little things in life anymore!



Not all Carers live with the patient, or even nearby. Sometimes we need to provide care from a distance, due to work, family or other commitments.

If that is the case for you, keep the following in mind:

1.

Arrange a regular time for calls.

If possible, try to establish a regular routine for when you will be in contact. The regularity will give both of you peace of mind.

2.

Have a plan in place if something goes wrong.

If the patient ever has an issue, it is important they know what to do and who to contact. Agree a plan together.

3.

Ensure you have all key contacts to hand.

If you are ever worried, whether by something the patient says on the phone, or you have not heard from them for a while, have a list of people you can contact to hand. This may be their Healthcare Professional, a family member, a friend or neighbour.

4.

Consider professional support.

If the patient is living alone (or they are living with someone who is unable to care for them alone), they may need intermittent professional support. Consider talking through the possibility of an assessment with the patient.

A Colorectal Cancer Caregiver's Charter

Before we go into the practical elements of caring for someone with colorectal cancer, we would like to start with a very important subject – YOU.

It is important that we never underestimate what an important role caring for someone with colorectal cancer is. What you do is very meaningful and has a

hugely positive impact not only on the patient themselves but on your wider network – friends and family – and society as a whole.

With that in mind, we would like you to remember a set of principles that are pivotal in helping you to take care of yourself as well as the person you are caring for.

Remember, we care best for others when we take care of ourselves.

- ♥ We must always make time for ourselves. We must try to still do the things we enjoy doing ourselves, even if it does not involve the person we care for. There should never be any guilt associated with this. We care best for others when we take care of ourselves.
- ♥ As Carers, we do the best possible job that we can. It does not always go perfectly – that is impossible. But we must always remember to take great pride in what we do.
- ♥ We may need to establish clear boundaries on roles between the Carer and the patient. If there is something we are not comfortable doing, we need to communicate that, and seek help.
- ♥ We must always ask for support when we need it. Nobody can care for someone with colorectal cancer alone. Never be afraid or embarrassed to ask for help.
- ♥ We must look after ourselves as well. We must not neglect our own healthcare needs and appointments.
- ♥ It is important that our role is recognised by others (e.g. family and friends and Healthcare Professionals). Never be afraid to communicate what your Carer role involves, so that others can understand and empathise.
- ♥ Difficult emotions are normal. At some point, we will feel angry, upset, depressed, or anxious. We will have good days and bad days. We are all human. On the days we become angry or upset, we must try not to feel guilty. The pressure we are under as Carers can be significant.
- ♥ We should recognise that caregiving can also be extremely rewarding, and at times can even be fun and exhilarating. When we see what we do have a positive impact on the patient, we can (and should) feel an enormous sense of achievement and pride.
- ♥ It is our right to be informed. We may have a central role to play in the patient's care and Healthcare Professionals should always respect that and provide us with the information we need to help care for the patient.
- ♥ It is our right to seek and receive psychological support, if and when needed, to avoid burnout.

2. Medical aspects

After the diagnosis

Someone close to you has recently been diagnosed with colorectal cancer.

The diagnosis of colorectal cancer is based on the examinations that she or he will have undertaken (e.g. colonoscopy, clinical, radiological and laboratory investigations).

You will probably have a lot of questions:



What is it?

Will she/he survive?

What are the treatment options?

How long will they need treatment?

What will be my role?



The uncertainty – the unknowns – can make you feel emotional and frightened. That's perfectly normal. The initial period during diagnosis and initial treatment (often surgery) is often the most challenging.

In the early stages, try to inform yourself as much as possible with the medical side of things. You will hear a lot of medical jargon throughout the treatment journey. If you hear a word or phrase you don't understand, just ask the Healthcare Professional you are speaking to.

To learn more about 'what is colorectal cancer' please visit the DiCE website.

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We found the first year the hardest, trying to learn so many new things and adapt to the new situation with high pressure and high emotion. It just takes a little while to settle down and adapt, but you get there. ”

Ed
Patient, UK



Caring for someone with a stoma

Sometimes after surgery, patients require a stoma. A stoma is an opening on the abdomen that can be connected to either the digestive or urinary system to allow waste (urine or feces) to be diverted out of the body.

These can be either temporary or permanent and are described according to the organ in which they are created. When the stoma is created in the colon for elimination of feces or secretions, it is called colostomy.

It can be a really difficult thing to go through for a patient. They may feel as if they are losing a part of the body and might feel very self-conscious about the look. You may also have concerns. You will probably both need time to adjust. This adjustment period can take days, weeks, or months depending on the person.

Talk to each other. Talk to your Healthcare Professionals. Don't feel embarrassed – they deal with stomas all the time. There may even be a specialist Stoma Nurse available for you to talk to.

As a Carer, you can play an important role in helping to reassure the patient and making him/her feel safer when performing self-care with the stoma.

Treatment options

Healthcare Professionals will need to consider many aspects of the patient and the cancer in order to decide on the best treatment.

The treating clinician will advise you and the patient on the best approach to take. You can read more about the various types of treatments and the various Healthcare Professionals you may come into contact with here.

Before a treatment starts, talk together with the patient and with the Healthcare Professionals about the goal of any suggested treatments. Talk about what they think the chances are that he / she will improve. Talk about the long-term treatment pathway – what happens if this treatment fails? What happens if it works? What next? Ask about side effects and how you cope with them if they occur. What signs should you look out for?

Clinical trials

The Healthcare Professional may raise the prospect of a clinical trial, or it might be something that you decide to look into yourselves. A clinical trial involves testing a new treatment, although there are no guarantees that it will be effective for the person you are caring for. This may be something to enquire about if other treatment options have been exhausted. The Healthcare Professional may know about clinical trials that may be a good match for the person you are caring for.

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It is a good idea to be aware of all the treatments available. There are many, many different types, but it can make all the difference if you are fully informed. It's not easy – it is a completely new language for most people – but it is worth the time.

Barbara,

Patient, UK

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Helping the patient to take medication

Adherence – that is, taking medicines exactly as prescribed by the Healthcare Professional – is very important to ensure the medicine has the full long-term effect.

Of course, if either you or the person you care for have concerns or questions about a medication – for example severe side effects – then arrange an appointment with the Healthcare Professional.

Otherwise, here are some tips to help adherence to treatment:

1. Partner with prescribers

As a Carer, you have the right to be involved in conversations with prescribers (oncologist, clinician, nurse, pharmacist) – that is, if both you and the patient agree that is what you both want. Your involvement may help to facilitate conversations around how the patient is feeling on the medication, or if they are experiencing any side effects, for example, which in turn can help to get the medication right for the patient.

Above all, do not wait until the next appointment if medication is not working or is causing bad side effects. Contact your Healthcare Professional right away.



2. Consider support tools

Pill card

As the number of prescriptions can increase, the more difficult it can become to keep track of which medicines to take, when, and how.

You could ask for a chart that includes these details, or create one, as simplified as possible. Make sure that you include who prescribed the medication and the relevant contact information if you have questions or concerns.

Pill organiser

A simple but effective tool is a pill organiser. In its simplest form, these are boxes with separated sections labelled for the day of the week. More detailed versions include containers for each day of the week divided further by time of day (e.g., breakfast, lunch, dinner, before bed). This can also be a digital device, including alarms, automatic dispensers, display with educational information, etc.

Mobile apps

If you and the person you care for rely heavily on your smartphone, a medication adherence app – such as Medisafe Medication Management – may be the solution you need.

These apps can offer scheduled reminders/notifications, quantity tracking, refill alerts, drug interaction warnings, side effects reporting and so on.

3. Check drug/food or herbal interactions

It is worth double checking with the prescriber about drug, food or herbal interactions. Usually, the doctor and pharmacist will have already done this with the prescription medications, but it is a good idea to double check and learn about these medications yourself.

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If you are preparing for end of life then of course that time is really important. You don't want to spend it with constant visits to hospital at this stage. I think Carers can help to fight for what the patient really wants and needs at this stage – whatever is right for them.

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Barbara,
Patient, UK



Watching out for side effects

Side effects of anti-cancer therapies are relatively frequent – the patient’s Healthcare Professional should warn you about the most common ones and most tend to be mild and something the patient can live with.

However, there are sometimes more severe and unpleasant side effects, which you may need to help look out for. Severe side effects are described as when “daily activity is markedly reduced” and more assistance than normal is required – if you feel the medication has had this effect on the patient, contact your Healthcare Professional.

Stopping treatment

If the cancer is very advanced, and the patient has attempted several treatments without progress, the Healthcare Professionals may suggest that

undergoing another new treatment is not the best choice. They will discuss with you and the patient the option of stopping treatment and moving to palliative care.

Making the decision to stop active cancer treatment can be very painful emotionally; it is a tough decision that requires careful thought.

Choosing to stop active treatment for his/her cancer does not mean that you are all giving up. Rather, it is an active choice to live their last days in the way she or he wishes to live them.

This decision does not mean the patient will need to stop all treatments. In fact, switching the focus of treatment towards managing symptoms places a higher priority on making them as comfortable as possible.

Palliative care or supportive care is focused on comfort, quality of life and a person’s total well-being during and after cancer-fighting treatment. It can be delivered anywhere, including at home, in a hospital, through outpatient care or in any other setting.

Throughout the treatment journey, keep asking questions

1.

Ask to have a handover from the medical team to both of you together, when you leave the hospital to go home.

2.

Ask for a treatment summary: after each treatment. This describes the treatment, what happens next and possible side effects of treatment.

3.

Ask questions: Make a notebook your best friend: Take a notebook with you to appointments. Write down all your questions and do ask them. Write down what has been discussed. Ask the doctor whether the consultation can be recorded, and where to go in case of questions afterwards.

4.

Ask the person you care for what they think: you are not alone! Do not try to protect the person you care for by being stoic or silent. Ask about how they feel, discuss it all together. Talk through the appointments afterwards. Write down new questions, develop an adapted new list of questions together.

5.

Ask for help: Caregiving can be a fulltime job. Asking for and accepting assistance may be hard but will give other loved ones the opportunity to serve and feel good for doing so. Talk to family members, loved ones, and friends about when and how they can help and give them specific tasks to do, such as grocery shopping, housekeeping, or picking up prescriptions.

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In hospital, you get good treatment, good advice, and it is all out of your hands. But suddenly at home, it is down to you. You need to use your own common sense, and make things happen. It wasn't made explicit that the caring role transferred over to me when we left the hospital, it was more a dawning realisation.

Mark

Carer, UK

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3. Psychological and emotional aspects

Caring for someone can be challenging and each situation is different.

There is no right way or wrong way to feel. It is likely that both you and the person you are caring for will experience a wide range of often difficult emotions during the course of their illness, including stress, anger and resentment.



The important thing is to keep an open line of dialogue between you and the patient, and to both find ways to cope when you are finding things difficult.

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Communication is key. Arranging regular meetings between the patient and Carer is a good idea to make sure you have a regular opportunity to talk.

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Dora,
patient, Cyprus

Different people will deal with the disease differently

It is important to note that just as there are many personality types in society, so this is reflected in the patient population for any disease, including colorectal cancer. Different people will react differently to the diagnosis and the treatment journey. Some will withdraw. Some will come out fighting. Some will stay positive. Some will become pessimistic. Some will welcome the support of others. Some will shun it. Some people will remain exactly the same before and after diagnosis. Some will change profoundly.

Of course, all of this can have a major impact on the Carer. If the patient's personality change, or they become depressed, anxious, angry or resentful (all of which are very common and normal in this situation), then it can be a shock to the Carer, and can be extremely challenging.

Talk, talk and talk some more. Communication between patient and Carer is vital. Be honest with each other, in an understanding way. Get things out in the open early, before resentment builds. Talk to each other when you have time and are both feeling calm. Empathise with each other and understand the way the other person is feeling. This may help prevent resentment building up in the future.

Find someone you can talk to that isn't the patient. Caring for someone can feel quite lonely and isolating. As well as talking lots with the patient, it is also important that you have someone else – or several people – that you can turn to and talk about your feelings. Whether it is your family, your partner, a friend or a social group, try to find someone who is happy to take the time and listen properly.

Consider contacting patient groups or Carer forums. Nobody can empathise as well as someone who is going through the same situation. Research to see if there are local support groups that you and the person you are caring for can connect with. Alternatively, look online to find online patient or Carer

forums. You might be surprised just how many people are experiencing similar situations to you.

Carers UK in the UK has an excellent online forum where Carers can connect with each other. While this isn't colorectal cancer specific, you will find many Carers of patients with colorectal cancer.

<https://www.carersuk.org/forum>

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**A nurse or other
Healthcare Professional
may be able to act as
a mediator to help you
discuss difficult topics.**



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Dealing with anger and resentment

It is likely that anyone who spends considerable time caring for someone will have feelings of anger or resentment towards at some point. It's perfectly normal.

Cancer feels unfair. It spoils your plans. You have less time for the things you enjoy. The future you had mapped out may have changed dramatically. The patient often changes as well – perhaps they are in pain a lot and more irritable as a result, or perhaps they have become quite depressed, or are just simply unable to do much or interact with you very meaningfully. It can feel extremely difficult to deal with. Mix in all the tiredness and stress associated with caring for someone, and it is understandable if occasionally you lose your temper or start to snap at them more than usual.

But it is important to find a way of dealing with it before it builds up too much. As mentioned above, talking is the best solution – whether to the patient or someone else. Get it all out, in as calm a way as possible. If it is difficult to talk about, try writing it down. Perhaps you and the patient could both write down a list of your frustrations and difficulties and use those as a basis for discussion. Consider keeping your own diary to have an outlet for your emotions.

Dealing with feelings of guilt

Unfortunately, guilt is a very common feeling among both patients and Carers. Patients sometimes feel guilty about how much time and energy the Carer has to devote to their illness. Carers may feel guilty if they have become angry or frustrated with the patient.

There is no use dwelling on feelings of guilt. Try to think positively. Remember all the good you are doing for the person you are caring for.

Try talking to someone not involved in the care of the patient, who may be able to give you the objective view you need – you are doing a great job and there is no need to feel guilty. Also try talking to other Carers if you can, as they will be able to understand exactly what you are going through.



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Guilt is a common feeling but it can be very dangerous. Sometimes I didn't want to mention my symptoms because I didn't want to complain and make a fuss. My husband was already doing so much. But because of saying nothing, I could have died due to a serious infection. Open communication between patient and Carer is so important. ”

Barbara,

Patient, UK

Dealing with feelings of embarrassment

It is very normal for patients and Carers to feel embarrassed about discussing colons, bowel habits and going to the toilet. These are very private matters for many people. It can be difficult for two people – whether partners, relatives or friends – to suddenly have to start talking about these topics. Perhaps start by involving the Healthcare Professionals involved in your care in the conversations. They are very used to talking about these things and so you don't need to feel embarrassed. Once you are over the initial barrier, you should find it gets much easier, and will soon become part of natural conversation.

Depression – are you feeling low all the time?

It is normal to feel a bit down from time to time, but if you find these feelings are not going away, and that you consistently feel low or tearful, it could be depression. Make an appointment with your family doctor to talk it through. They may refer you to a specialist or prescribe medication.

4. Social aspects

Stay connected

Caring for someone can make you feel quite isolated and lonely. It can take up a lot of time and it can become difficult to see other people.

It is important to see other people if you can. If you gradually stop seeing people, it may make it harder to reconnect, and they may believe you would prefer not to be contacted. Make a regular meeting with people if possible, even if that's as little as once or twice a week.

If it is difficult to meet up with people for whatever reason, try to talk on the phone or via Skype, or talk with people online who are perhaps going through a similar experience. You must never feel as though you are completely alone – you are not. There will always be someone there for you.



Acting as a “gatekeeper” for the patient

Many friends and family do not want to bother the patient directly, so they call the Carer to ask how things are. This can be very burdensome for the Carer. Some people ask questions to the Carer that they would never dare ask the patient (about prognosis and side-effects, etc.).

Other people may approach you come with comments that you may think are inappropriate, sometimes exacerbating feelings of guilt (e.g. “did he / she not eat properly, not have enough fibres or fruit?”), or may have treatment suggestions. The Carer acts as the “gatekeeper” for all of this, trying to protect the patient, and sometimes not willing to discuss some of the less appropriate comments with the patient.

This can be challenging and emotionally draining. Ultimately, there will be friends and family who are genuine carers, who will engage with you and help out wherever they can. Identify these people and spend more of your time engaging with them and less of your time fielding any intrusive questions, if possible.

Impact on sex life / intimacy

Many colorectal cancer patients and their partners have reported an impact on their sex life. The effects of surgery or radiotherapy can have a physical impact – men may be less able to have an erection and women may find their vagina feels smaller or drier, impacting the ability and desire to have sex. In addition, many patients do not feel like having sex while they are having treatment, and those who have a stoma may feel self-conscious or experience concerns about their body image.

Sometimes, it is just about taking a bit of time to adapt to situations, and you and your partner can get through it together. There may be other ways to enjoy your sex life. Keep talking and be empathetic and understanding of each other.

We care best for others when we take care of ourselves.

Impact on children

Many children experience situations where their mother, father, a sibling or grandparent, or other person they are close to, has cancer.

It is important to include children and young people in conversations about illness affecting a parent or other close family member.

There is a great deal of advice on how to tell children that their mum or dad has cancer and what this means (for example at MacMillan cancer support). If you need more support, please contact your Healthcare Professional or a local hospice or advice centre.

Despite their youth, you'll notice that children and young people still need to feel that they are important in the situation and children's need for information is often underestimated.

Try to be open and to give information, adapting what you say to the child's age and developmental stage.

Children often have episodes of rapidly changing emotions; one moment they may be angry or sad, only to play happily the next. This is a completely normal reaction.

You can always ask a Healthcare Professional (e.g. a nurse) for support in how to communicate with children about the topic.

Adolescents and young adults can be vulnerable when one of their parents or another family member or dear friend, is diagnosed with cancer. Maybe you can give him/her some practical tasks to help them feel they are helping, such as housecleaning, but make sure not to overload them.

Keep schools, clubs, and children's friends informed about the situation.

Find time for yourself

Caring for someone with colorectal cancer can be a fulltime job. It can be tiring and emotionally draining. You dedicate a huge amount of time to the person you care for, but you also need to ensure that you make some time for yourself.

Find a regular day or night each week when you can go out or just have some time dedicated to something you love – that might be playing an instrument or doing a hobby or attending a group or club or just a night out with friends.

You may also need some time away – whether that is just for the day or evening, or potentially even longer with a mini break. If you think that is what you need, try to think through a practical solution for when you are gone, and talk it through with the patient. Perhaps someone else (another family member or friend, or a professional Carer) can take over for a while.

You should never feel guilty for making time for yourself. Remember, we care best for others when we take care of ourselves.



Holidays

Sometimes when caring for someone with colorectal cancer, the idea of going on holiday with the person you care for might seem unlikely, but as time goes on, you should try to consider having a break. It can be extremely beneficial for both of you.

In the first months after surgery, the patient may need to always be in reach (e.g. within an hour) of the hospital, so going further afield may have to wait until their Healthcare Professional says it is OK.

They can also advise you of any particular considerations, particularly related to the therapy they are taking. The person you care for will likely get tired more easily, so it is advisable to minimise the amount of walking and exertion during a trip.

If you're planning a trip abroad, it is important that the physician writes an explanatory note in

English detailing the patient's condition and any medication being used. This information is important should your loved one become sick while travelling. It will also prevent you from having any problems with Customs if you have syringes and/or other equipment with you.

If the person you care for has a stoma, do make sure you pack spare bags and other equipment before you travel. If you are traveling on an aeroplane, make sure you have the essential items (e.g. spare stoma bags, wipes, washer, nappy bags, spare underwear) in your hand luggage, just for peace of mind in case a leak occurs.

Some transport systems have "hidden lanyard" initiatives where a patient with a 'hidden' condition can wear a lanyard that helps transport staff see they may need assistance, without causing a fuss. It may be worth checking if anything like this exists in your country, or where you are travelling to.

Holiday insurance

Do check the holiday insurance before you go. Many insurers are reluctant to cover cancer patients, or anyone with a pre-existing medical condition, because they are considered more likely to make a claim. The solution usually is for insurers to insure your trip, but excluding cover for any claim that is related to cancer. If you are concerned, it may be possible to get comprehensive cover, including any cancer-related care, but you will likely pay a high premium.

European Health Insurance Card

If you have – or are eligible for – a European Health Insurance Card (EHIC), make sure you take it with you when you travel. It is issued free of charge and allows anyone who is insured by or covered by a statutory social security scheme of the EEA countries and Switzerland to receive medical treatment in another member state free or at a reduced cost, if that treatment becomes necessary during their visit.

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Holidays can feel like the last thing on your mind, but they can make all the difference in the world. It's good to try to get away if you can. ”



5. Practical aspects

Impact on day-to-day life

Caring for someone with colorectal cancer can have a big impact on your day-to-day life. It can be very time-consuming – not only are you taking care of the day-to-day needs of the patient, but you are probably doing many practical tasks that they are now less able to do.

All of this can be hugely impactful in terms of your own work and career, your social life, how you spend your day, and your finances.

But remember, although caring for someone with colorectal cancer will almost certainly change elements of your life, it does not need to take over your life completely. Your first instinct might be to try and do everything for the person you are caring for, but it is important to take a step back now and then and live your own life too. Remember, we care best for others when we take care of ourselves.



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It is a good idea to establish the boundaries for the roles of the Carer and the patient upfront, so that you are both comfortable with where the lines are drawn. ”

Dora,
patient, Cyprus

Planning ahead

Any serious illness brings with it the fear of the unknown. What is going to happen in the future? Will they get better? How will I cope if they get worse? There will also be times when the unexpected happens – perhaps a colostomy bag bursts or there is a sudden deterioration in health – which cannot be predicted.

So try to keep on top of the things that are predictable. Plan ahead, write lists of the things that need doing. Keep a calendar or electronic diary of all hospital appointments. Try to minimise stress around daily household tasks like shopping – if there is limited time to leave the house, order things online. Perhaps keep a central bank of say 20 or so recipes that you and the patient both enjoy to minimise time spent worrying about what to cook. Do what you can to make life easier for yourself, now and in the future.

Also, if an emergency situation were to happen, do you have what you need to deal with the situation? For example, do you have the numbers of your Healthcare Professionals programmed into your phone or written down somewhere easily accessible? Try to think ahead and be prepared as much as possible.

Helpful equipment

There may be some equipment you can have at home that will make life easier for both the patient and yourself, particularly if the patient is recovering from surgery or is living with advanced-stage colorectal cancer. Equipment may be needed to help them get around, and assist with everyday tasks, such as using the toilet, or enhance their comfort.

Examples include toilet frames / raised seats (to make it easier getting on and off the toilet after surgery), and a specialist mattress or bed linen (night sweats are quite common with cancer because the immune system is attempting to fight the cancer, and the body sweats excessively as a cool-down measure. Avoiding synthetic nightwear and bed linen can help, as can switching to cotton or even wool-filled alternatives, which have much superior ability to manage moisture).

Local patient associations may be able to provide advice on medical equipment or even some of the equipment itself.

“

When I had the strength, I would like to help with the cooking a bit – even if it was just chopping the onions – just so I could feel helpful and part of the family again. ”

Barbara,
Patient, UK

Roles around the house

Some people with colorectal cancer need more help with everyday tasks, such as bathing, dressing and cooking. Many will be unable to do the things around the house that they did previously, because they may feel weak or tired because of the symptoms or side effects of treatment.

The person you are caring for will probably be less able to do day-to-day chores, such as housework, gardening, shopping, cooking, driving and looking after other family members. You may feel as though all of this falls to you, but don't be afraid to ask other family members and friends for support.

Also, don't put undue pressure on yourself. Perhaps not everything has to be done to the same standard as previously – for example, the house does not need to be spotless all the time and it's fine to let the garden grow a little wilder than normal! As Carers, we cannot do absolutely everything, and it is a matter of prioritising what is most important to you and the person you care for.

Diet and nutrition

Diet is hugely important for people with colorectal cancer, so it is likely you will have a major role in helping the patient to eat the right things.

After surgery, your loved one may be advised to start with a very low amount of fibre in their diet and build this up slowly.

Colorectal cancer and its treatment can affect the diet, digestion, person's appetite and taste, depending on the extent of the surgery and the current/past treatment.

For example, people with a stoma may need to alter their diet to ensure their stoma functions effectively.

There are significant differences between individuals in terms of the type and degree of nutritional problems that can arise.

Sometimes there is no need to change the diet at all – if the person you are caring for has no symptoms, a normal diet is okay.

If there is a need to change the diet, a properly adapted diet can significantly reduce symptoms (though it may not remove them altogether).

Ask to consult a dietician, who will assess and adapt the diet based on the patient's needs.

There is an excellent resource on diet and nutrition on the Bowel Cancer UK website, which we recommend you take a few minutes to read. The page can be found here:

<https://www.bowelcanceruk.org.uk/about-bowel-cancer/living-with-and-beyond-bowel-cancer/diet-after-treatment/>



Keep a food diary

A good way to keep track of which foods cause problems is to keep a food diary. Either you or the patient can simply keep a notebook or jot down on your phone or iPad the ingredients of each meal, and make a note if there are any issues, and when. This will help you both to spot the likely causes of any issues. It is also helpful to note quantities to understand when tolerance for certain foods is increasing.



Exercise/physical activity

Physical activity may be beneficial for people living with colorectal cancer. There is evidence to show that regular physical activity improves well-being, muscular strength and mobility. It may also have an influence on side effects of treatment, not to forget the improved feeling of self-control.

But the patient shouldn't push it. The level of activity that your loved one can undertake is affected by on-going treatment, time since previous treatment (e.g. surgery, chemotherapy) and also medication (such as pain killers). Patients should always "listen to their body".

Remember – physical exercise does not mean having to go to the gym! A walk around the garden, taking the dog for a walk, breathing exercises or yoga can all be beneficial and fit in with what the patient is capable of doing.

Your role as a Carer is to encourage when the motivation for exercise is there but also ensure the patient does not push it too much.

6. Employment / financial aspects

Impact on work

Juggling unpaid caregiving and work can be challenging. For people looking after someone with colorectal cancer, the time required can be significant, leading to a large impact at work. Some people have to scale down their hours at work or even give up their job altogether to look after someone fulltime.

Talk to your employer. There may be something they can do to help. One study showed that the top three interventions that people thought were most helpful if caring for someone while working are a) a supportive employer or line manager, b) flexible working and c) additional paid care leave of between five and ten days (Carers UK).

Explain your situation to your employer (both an HR manager and your own manager) and your colleagues and see what support is available. It is also advisable to let them know that there may be days when you are unable to go into work, or need to leave early, at very short notice.



Check your rights.

As a Carer, you may have certain employment rights in your country. These may include the right to request flexible working arrangements and the right to take unpaid time off work for dependants in an emergency. These rights differ from country to country – do take the time to find out what rights you have in yours.

Early retirement and pension withdrawals.

You normally have to wait until you're a certain age before you can start claiming your pension. But if you have to retire early because you're caring for someone, you may be able to access your pension earlier.




Your rights to financial support

You may be entitled to some form of financial support. A common trend across some countries is to introduce cash payments as support for Carers. These are being introduced more as governments increasingly recognise the invaluable role that Carers do (which also significantly reduces health system burden).

Do take the time to find out what rights you have in your country. Your local patient organisation may be able to assist you.



“

On occasions there 
would be an emergency
during the night, then I
would still need to go to
work the next day. It can
have a big impact on
energy levels and where
your mind is focusing.

”

Mark
Carer, UK

7. Reaching out for help

You are never alone in this journey. There are many organisations – Patient Groups, Colorectal Cancer Groups and Carer Groups – set up to provide assistance to people living with colorectal cancer and their Carers. Below are some of the European organisation that serve as umbrella organisations to national groups, so you can find one local to you.

In addition, local social services work with people who need help and support in a difficult life situation. The title and role of a 'social worker' can differ amongst institutions across Europe and the services can be organized in a different way in different countries, but if you need support, do research which local social support services are available.

European organisations



- **Digestive Cancers Europe** digestivecancers.eu/
- **European Cancer Patient Coalition** ecpc.org
- **EuroCarers** eurocarers.org/





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