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About this booklet

This booklet is for anyone who has had treatment for bowel cancer. It may also be helpful for your family and friends.

It has information and practical tips for working, managing money and traveling when you have bowel cancer.

Please speak to your healthcare team if you have any questions about how the information in this booklet affects you. Our contact details and a list of other useful organisations are listed at the end of the booklet.

Get in touch

Please contact us if you have any comments about the information in this booklet: feedback@bowelcanceruk.org.uk

Work

As soon as you're diagnosed with cancer, you're protected from discrimination at work by the Equality Act 2010. In Northern Ireland, you're protected by the Disability Discrimination Act 1995.

This means employers must not treat you less favorably for any reasons relating to your cancer. This includes recruitment, promotion, training, pay and benefits.

Your employer must make reasonable adjustments at work. These are changes to help you carry on working or go back to work after time off. 'Reasonable' depends on the type of work you do and will consider cost, practicality and how much the arrangements will help you do your job. Examples of reasonable adjustments are:

- working different hours or working part-time
- allowing time off for doctor's appointments
- changing your role to remove difficult tasks

If you've had time off work and are thinking of going back, you may want to ask if you can start off with a few hours or days and gradually build them up when you feel able to. This is sometimes called a phased return.

Your employer can also make practical adjustments to help you feel more comfortable at work. These might include:

- moving your desk nearer to the toilets
- having a parking space near the entrance to your work
- allowing extra breaks if you feel tired
- flexible hours to avoid a stressful commute
- having a quiet space where you can rest

Your employer can also refer you to an occupational health advisor or the HR team to discuss other ways they can support you. They will keep your information confidential if you ask them to.

If adjustments are needed at your workplace, Access to Work schemes in England, Scotland and Wales, and Northern Ireland can help. They might provide grants for equipment and can sometimes help with the cost of taxis to work.

If you think you've been treated unfairly at work, you should speak to your employer first. If there's still a problem, you can contact **ACAS** (the Advisory, Conciliation and Arbitration Service), **Citizens Advice** or your union, if you have one.

More information

Macmillan Cancer
Support produces
detailed information
about work and cancer,
including information for people
with cancer, their partners, the
self-employed and employers.

Working With Cancer provides employment support and career advice to people affected by cancer and their partners.



As much as I wanted to rush back to work, I knew I needed to take it slow. I began with a phased return, starting with reduced hours and gradually building them up. Just three hours online on my first day left me exhausted. Regular catch-ups with my manager helped me check in on how I was feeling, adjust tasks if I felt overwhelmed, and review my progress. Nobody expects you to be the office superhero from day one.

Shikha

Money

You may be worried about money, for example, if you're unable to work or you have extra costs, like prescriptions or travel to hospital. You can get help with some costs and you might be able to get some benefits or grants.

When you're diagnosed with cancer you may be entitled to some benefits to help with your living costs. These may include:

- Employment and Support Allowance (ESA)
- Universal Credit (UC)
- Personal Independence Payment (PIP)
- Adult Disability Payment (ADP) in Scotland

If your bowel cancer is advanced or you have a disability, you may be entitled to more financial support. This may include Disability Living Allowance (DLA), Attendance Allowance or other locally available benefits.

Support with managing money

Some people find it hard to get information about what help they can get with money and have had problems claiming benefits. If you need some help, call Macmillan Cancer Support on 0808 808 0000. They can help with questions about benefits and insurance and can send you booklets with detailed information.

If you have a local **Maggie's** cancer support centre, you can speak to a Benefits Advisor in person who will help you find and apply for financial support available to you.

Remember

You can receive Personal Independence Payment or Adult Disability Payment even if you are working.

If you have an insurance policy, such as critical illness cover, income protection or mortgage payment protection, you may be able to make a claim when you're diagnosed with cancer. You can find out more about this by reading **Macmillan Cancer Support's** booklet on insurance from their Financial guidance series of information.

People supporting someone with bowel cancer, such as family members, can also be affected financially. They might earn less money if they have to take time out of work to help look after you. In some cases, they may be able to get benefits, allowances or grants to help them manage if they're worried about money.

You can find information and advice about money worries on our website, or by talking to financial advisors at Maggie's or Macmillan Cancer Support.

If you're worried about affording essential items, like food and toiletries, you may be able to get help from a local food bank. Your healthcare team or **Citizen's Advice** can provide information and a referral if needed. **Trussell** offers more information, including a list of food banks around the UK.

Applying for benefits can feel overwhelming. If you're struggling, ask a friend or family member to help contact organisations.

Prescriptions

NHS prescriptions are free in Scotland, Wales and Northern Ireland. If you live in England, you can apply for a medical exemption certificate. This means you can get free NHS prescriptions if you're receiving treatment for cancer, its side effects or the side effects of treatment.

To get your certificate, you'll need to fill in a form called an FP92A form that you can get from your GP or specialist nurse. A medical exemption certificate allows you to get free NHS prescriptions for five years. This also includes medicines that aren't related to your cancer. You'll be able to renew your certificate if you're still having treatment.

You may be able to get free prescriptions even if you're having private treatment.

If you have a permanent stoma you'll have free prescriptions for life. You'll need to apply for a medical exemption certificate. Ask your GP, hospital doctor or specialist nurse for more information.

Transport

Bills

If you claim certain benefits, you may be able to get a discount or money back for council tax or utility bills. Contact your local council or utility supplier for more information.

If you're receiving palliative care or caring for someone who is, you might be able to receive financial support to cover your energy bills. **Marie Curie** can give you expert information on things like supplier-specific support, grants, and energy efficiency updates. To find out more, call the **Marie Curie** helpline on 0800 090 2309 and ask to speak to an Energy Support Officer.

You can ask your energy provider to join the Priority Services Register. This is a service that means vulnerable people, including people with long-term medical conditions, are listed as a priority in a power cut.

More information

If you have family, friends or carers that help look after you, they may also be able to get financial support.



You can find more information at bowelcanceruk.org.uk/family-and-friends

Transport to and from appointments

Travelling to hospital often for treatment, tests and appointments can be expensive.

If you receive certain benefits, you may be able to get help or a refund for some of your travel costs through the NHS Healthcare Travel Costs Scheme. This includes travel to or from hospital or specialist appointments. You can find more information on the **NHS website**.

Macmillan Cancer Support also offer useful advice and information. If you're in Northern Ireland, you can find out about getting help with health costs on the nidirect website.

Many hospitals and local councils offer transport to and from hospital for appointments. Contact your local hospital to find out about services they provide.

Some local volunteer groups and charities also help with hospital transport. You can find more information about support available in your area through your GP, local council or social services.

Driving

If you're a driver, you'll need to notify the DVLA if you have any side effects that could affect your driving, such as peripheral neuropathy or side effects of your medication. The **government** website has more information about when and how to get in touch.

Getting a blue badge

If you have problems moving around, or if you've been told your cancer can't be cured, you may be able to get a blue badge. A blue badge allows you to park closer to where you need to go. It also means you don't pay for hospital parking.

The badge is registered to you, so you can use it if you're driving, or if you're a passenger in a car.

If you have specific medical conditions or get certain benefits, you may already qualify for a blue badge. You can apply for a blue badge at **gov.uk** A blue badge lasts 3 years. You'll need to reapply for a new one before it expires.

10 Practical tips Practical tips Practical tips

Travel

Speak to your healthcare team if you're planning to travel during your treatment. They can tell you how your treatment might affect your plans.

They can also give you a letter to take with you, listing the medicines you're taking and what they're for. This can be helpful if you're travelling abroad.

If you're travelling abroad, you should find out about healthcare in the country you're visiting.
Write down emergency services contact numbers before you travel.
You can find these for each country at gov.uk.

If you become unwell while travelling, contact the local emergency services or ask your hotel or holiday representative to call a doctor. In some countries you can use a Global Health Insurance card (GHIC). This may reduce the cost of some emergency or pre-arranged treatment, so that you pay the same as a local resident in that country. You can get more information and a free card from the **NHS website**.

Travel tips:

- Download a smartphone app such as Flush and Toilet Finder, which can be useful for finding nearby toilets
- Contact music venues and sports stadiums in advance to ask about access to toilets and other assistance
- Get a Radar key, which allows you to open locked most public toilets around the country.
 This is part of the National Key Scheme. You can get a Radar key from different organisations including
 Disability Rights UK and Bladder & Bowel Community.
 There may be a cost involved.

Travelling with a stoma

If you have a stoma, your stoma care nurse specialist can give you a travel certificate. A travel certificate is a document that you can show to travel authorities and their staff. It tells them important information about your stoma and any supplies you carry when travelling. This helps them to know what to expect without you having to explain what the items are.

You can ask your stoma care specialist nurse for a travel certificate which is translated into several languages. You can also download and print a travel certificate from **Colostomy UK**. Some airports and their staff may not be aware of travel certificates or understand the content. Wearing a sunflower lanyard may help to let staff know that you need assistance.

Most airports have a Special Assistance team who can help you have a smooth experience. Contact them before your trip to see what services they offer.

Some airlines offer extra luggage allowance for people with a stoma. Contact the airline's Special Assistance team to find out more. You can find contact details for them on the airline's website.

Your stoma care nurse specialist can offer helpful tips for travelling with a stoma. **Colostomy UK** offers more information about travelling with a stoma.

Remember

Always carry some spare stoma supplies in your hand luggage in case of baggage delays.





I generally felt well prepared before flying with my ileostomy (stoma), still there was a touch of apprehension. I was concerned I'd be challenged about my stoma supplies when going through security, even with the travel leaflet my stoma nurse had given me. But as it happened, I sailed through. I also avoided eating for a few hours before my flight to minimise the output into the stoma bag while I was travelling.

Jamie

Travel insurance

It can sometimes be more expensive and difficult to get travel insurance after a diagnosis but a letter from your hospital team can help.

Some high street companies offer insurance to people with cancer but there may be some limits to what they'll cover you for. There are specialist companies that insure people with illnesses such as cancer. Some of these can be more expensive so you might need to shop around.

Your Cancer Support Worker or Cancer Care Coordinator may be able to give advice on travel insurance.

If you already have travel insurance, check that it covers all your medical conditions. If you don't have travel insurance, get quotes from different companies that cover all your medical conditions. Money Helper has a list of companies that offer travel insurance policies to people with serious medical conditions or disabilities.

It's important to tell your insurer about any medical conditions and answer all their questions accurately. If you don't mention something, then need to make a claim, they may refuse to pay out. Always tell your insurer if your health or medication changes in the time between buying the policy and travelling.

More information

Macmillan Cancer Support has more information about finding travel insurance when you have cancer. They also have a travel insurance blog and forum where you can find out about recommended travel insurers for people with cancer.

Other useful organisations

Bladder and Bowel Community

w bladderandbowel.org

An organisation providing support and products for people with bladder and bowel control problems.

Bladder and Bowel UK

w bbuk.org.uk

Signposts to local continence services and provides 'Just can't wait' toilet cards.

Citizens Advice

w citizensadvice.org.uk

Provides free, confidential advice on money, work and housing. You can find details of your local Citizens Advice on their website or in your phone directory.

Colostomy UK

w colostomyuk.org

T 0800 328 4257

Offers support, reassurance and practical information to anyone who has, or is about to have, a colostomy.

Disability Rights UK

w disabilityrightsuk.org

T 0330 995 0400

Sells Radar Keys and provides information on work and benefits.

GOV.UK

w gov.uk

The Government website for the UK provides information about travel abroad, access to benefits, including applying for a blue badge, and the Equality Act.

Macmillan Cancer Support

w macmillan.org.uk

T 0808 808 0000

Provides support and information on cancer, money, benefits and work.

Maggie's

w maggiescentres.org

T 0300 123 1801

Provides free practical, emotional and social support to people with cancer and their family and friends. Maggie's has centres at some NHS hospitals as well as an online centre.

Marie Curie

w mariecurie.org.uk

Provides palliative and end of life care, information and support for people living with any illness.

Money Helper

w moneyhelper.org.uk

Provides free and impartial advice on all financial topics, including insurance policies.

NHS

w nhs.uk

Provides health and lifestyle information, as well as information on practical aspects, including travel costs and GHIC cards when travelling abroad.

nidirect

w nidirect.gov.uk

Government website for Northern Ireland citizens. Includes information on help with health costs.

Tenovus Cancer Care

w tenovuscancercare.org.uk

T 029 2076 8850

Support for people with cancer in Wales, including practical advice and a helpline.

Trussell

w trussell.org.uk

Provides practical support and advice for people who may need to access a food bank.

Social Security Scotland's Local Delivery service

w mygov.scot

T 0800 182 2222

Provide personal support for people in Scotland with applying for benefits applications.

Working With Cancer

w workingwithcancer.co.uk

Provides employment support and career advice to people affected by cancer and their partners.

More support



Online Communities

Our online communities are welcoming places for everyone affected by bowel cancer to ask questions, read about people's experiences and support each other. Join us at bowelcanceruk.org.uk/online-communities



Website

Visit our website for a range of information about bowel cancer including symptoms, risk factors, screening, diagnosis, treatment and living with and beyond the disease. Visit bowelcanceruk.org.uk



Publications

We produce a range of expert information to support anyone affected by bowel cancer. Order or download our free publications at bowelcanceruk.org.uk/our-publications



Ask the Nurse

If you have any questions about bowel cancer, contact our nurses at bowelcanceruk.org.uk/nurse

Notes

Bowel Cancer UK is the UK's leading bowel cancer charity. We're determined to save lives and improve the quality of life of everyone affected by the disease.

We support and fund targeted research, provide expert information and support to patients and their families, educate the public and professionals about bowel cancer and campaign for early diagnosis and access to best treatment and care.

To donate or find out more visit bowelcanceruk.org.uk



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Patient Information Forum

Please contact us if you have any comments about the information in this booklet: feedback@bowelcanceruk.org.uk

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