Living with bladder cancer



Money matters and work

There is more information on bladder cancer and its treatment on our website at www.actionbladdercanceruk.org

Having cancer is likely to affect your finances and your working life. You'll need to take time off for appointments, treatment and recovery, and this may affect your income. You may qualify for benefits and extra help with other costs. While this might seem overwhelming, don't worry (and don't put off applying for benefits) – there are organisations and individuals who can help.

Your rights at work

IF YOU HAVE CANCER:

- If you are diagnosed with cancer, your employment rights are protected by the Equality Act 2010 in England, Scotland and Wales, and the Disability Discrimination Act 1995 in Northern Ireland
- Your employer cannot treat you less well than someone else because you have or have had cancer. Macmillan Cancer Support has an information page on this at www.macmillan.org.uk/informationand-support/organising/work-andcancer/if-youre-an-employer/legislationabout-work-and-cancer.html
- Information about your health is confidential and protected under the Data Protection Act 1998
- If you are having an interview for a new position, your interviewers have to be extremely careful about what they ask in relation to your health, and you must not be discriminated against on the grounds of having or having had cancer

IF YOU ARE A CARER:

- You can request flexible working as long as you have worked for your employer for 26 weeks (for example, working from home, consolidated or reduced hours)
- You may be able to appeal if your employer refuses
- You can take unpaid time off to look after someone in an emergency
- You should not be discriminated against at work because of your caring responsibilities
- You should not be victimised or harassed at work because you are a carer

ACAS, the Advisory, Conciliation and Arbitration Service, has helpful advice on your rights at work at www.acas.org.uk/

if you're in Northern Ireland, the Labour Relations Agency has information at www.lra.org.uk/



If you're working

If you've been diagnosed with cancer, it's wise to tell your manager or your personnel/HR department as soon as possible. This conversation is confidential, and one of the things that should be discussed is how much information you want shared with colleagues. Make sure you also receive information about:

- your options for taking time off for tests, appointments and treatment
- the organisation's policy on flexible working
- any other services that might be helpful

Taking time off Check your contract to see if it specifically says that you will be paid for time off for medical appointments. For many people, this won't be covered – talk to your manager to see if they can help in some way. Your employer should be reasonable about allowing you to have time off for treatment – there are different ways they might approach it. For example, they may treat it as sickness absence, approved unpaid leave or paid or unpaid compassionate leave. Make sure you're completely clear about what is being suggested before you agree.

If you're self-employed Being self-employed can make it easier to adapt working patterns around appointments and treatments, but it can mean that you face additional anxieties over finances and support. You may be able to claim allowances and benefits to help (see later sections). If you want to make large-scale changes to your work, or stop altogether, get some advice from a financial adviser or one of the charities that offers personalised advice (see Box on the back page).

Being self-employed means you miss out on support from your employer or colleagues. Some people find joining a local support group or an online forum can help them avoid feeling isolated.

Carers If you are caring for someone with bladder cancer and you work, talk to your line manager about your situation. Think about whether changing your working arrangements would help. Your employer may have special arrangements in place

for carers, or they may be able to signpost sources of helpful information. Ask if there's a policy on carers. Also check with them about arrangements for time off, sick leave and sick pay.

Keep your manager updated about any changes or likely changes – in that way, they may be able to offer more flexibility. It's also important to know that you have the same rights to fair treatment at work as someone with a disability or chronic illness.

Charities that provide personal benefits advice

Macmillan Cancer Support has a
 Financial Guidance team who can give information on claiming benefits. If you have a low income, you may be eligible for a one-off grant from the charity, too www.macmillan.org.uk/cancer-information-and-support/get-help/financial-and-work/financial-guidance-help-line

Call: **0808 808 00 00** Monday to Friday 9:00 am to 8:00 pm

 Maggie's has benefits advisors at its Maggie's Centres. You can find your local Centre at: www.maggies.org/ our-centres/

Link to Maggie's page on benefits: www.maggies.org/cancer-support/ managing-practically/money-benefitsand-cancer/

Or you can visit their online centre www.maggies.org/cancer-support/our-support/help-money-worries/

 Age UK have a free advice line that operates 365 days a year, and also have advisers at local Age UKs

Call: **0800 678 1602** 8:00 am to 7:00 pm





Finding out about benefits

Finding out whether you are entitled to benefits can be a complicated business. There is information online at www.gov.uk/browse/benefits/disability. The charity Turn2us at www.turn2us.org.uk has a lot of information on benefits and an online benefits calculator, and the independent organisation Entitled To has online calculators at www.entitledto.co.uk.

Many people need some help to navigate this area. You can get help and advice from a hospital or community social worker, and the hospital may also have a welfare rights adviser. Your local Citizens Advice can also help – you can find details of your local sessions at www.citizensadvice.org.uk/

Jobcentre Plus centres are the local benefits offices. Find your local office at www.gov.uk/contact-jobcentre-plus.

Some charities provide helplines and information too (see Box 2), and many people find getting help from an adviser early on saves a lot of time and frustration.

Main benefits and allowances

The main benefits are described briefly below. You may be entitled to additional help, so speak to an adviser about your personal circumstances.

If you are employed and absent from work because of your cancer, you may be eligible for statutory sick pay – you can check whether you qualify at www.gov.uk/statutory-sick-pay. Your employer may also make a payment – check your contract of employment or contact your human resources department.

If you are self-employed you won't get sick pay, but you may be eligible for tax credits or employment and support allowance (ESA).

Working tax credits are for people who work (employed and self-employed) and have a low income or a disability that would place them at a disadvantage if they tried to get a new job. You may be able to claim working tax credits for up to 28 weeks if you are off work because of illness.

Her Majesty's Revenue & Customs (HMRC) has information here: www.gov.uk/universal-credit/eligibility and a Tax Credits Helpline on 0345 300 3900.

Child tax credits You may be able to claim these if you are responsible for a child aged under 16 or a young person aged 16–19 years who normally lives with you (not university students or young people in training paid by an employer). Use the same helpline as above to find out more.

Personal independence payment (PIP) is an allowance for people aged 16–64 years who are living in England, Wales or Scotland at the time they apply. It's designed to help with extra costs that cancer brings. You'll be assessed by a health professional unless your cancer is terminal (see below). There's information at www.gov.uk/pip.

Employment and support allowance (ESA) provides some financial help if you can't work; you can apply for ESA if you're employed, self-employed or unemployed – see www.gov.uk/employment-support-allowance.

Attendance allowance is paid if you are 65 or over when you first claim and you need someone to look after you. You can find more information here www.gov.uk/attendance-allowance.

Income support may be available if you have a low income, your income falls because of your illness, or statutory sick pay is not enough to live on. In some areas of the UK, you may receive universal credit rather than income support.



Grants, gifts and discounts Some organisations, such as Macmillan Cancer Support, provide one-off grants; you can find more information at www.macmillan.org.uk/cancer-information-and-support/get-help/financial-and-work/macmillan-

grants. The charity Maggies has more information about gifts, treats and discounts for people with cancer at www.maggies.org/cancer-support/managing-practically/gifts-and-experiences/.

Contacts for carer support in the UK

- Carers Trust has help and advice, including specific information for people living in Scotland, Wales and Northern Ireland www.carers.org
- Money Helper (established by the Government) has advice at www.moneyhelper.org.uk/en/familyand-care/illness-and-disability
- Age UK have an advice line that operates 365 days a year
 Call: 0800 678 1602
 8:00 am to 7:00 pm
- England Your local council may be able to help, but your carer will need to be assessed to see how caring is affecting them. There's more information at www.nhs.uk/conditions/social-care-andsupport-guide/support-and-benefits-forcarers/carer-assessments/. Citizens Advice has comprehensive advice at www.citizensadvice.org.uk/family/lookingafter-people/
- Wales There is information at Carers Wales www.carersuk.org/wales and from NHS Wales at www.nhsdirect.wales.nhs.uk/ livewell/carers/. Citizens Advice Wales has information at www.citizensadvice.org.uk/ wales/family/looking-after-people/carershelp-and-support/

- Scotland There is useful information about support for carers here https://carers.org/ our-work-in-scotland/our-work-in-scotland and Citizens Advice Scotland has some helpful information here at www.citizensadvice.org. uk/scotland/family/help-for-adults-in-thecommunity-s/carers-help-and-support-s/
- Northern Ireland You can call the Benefit Enquiry Line for advice and information on carer's allowance and carer's credit, and also on attendance allowance and disability living allowance (Northern Ireland only). Freephone **0800 220 674** / Make the Call Helpline **0800 232 1271**. Text number: Minicom 028 9031 1092 (for deaf and hard of hearing users only). An answer phone service is available 24 hours a day where a message can be left for a call back during office hours (see www.nidirect.gov.uk/ contacts/disability-and-carers- service), Carers Trust also has information https://carers.org/help-and-info/introduction, as does Citizens Advice Northern Ireland www.citizensadvice.org.uk/nireland/family/ looking- after-people/carers-help-and -support-ni/





If your cancer is terminal you may be entitled to additional benefits, and it may be possible to get your benefits fast tracked. If you have less than 6 months to live, your personal independence payment (PIP) can be fast tracked. Your doctor will need to provide a medical form, but there is less paperwork for you, and your first payment should be made within a couple of weeks. Citizen's Advice has some helpful information at www.citizensadvice.org.uk/benefits/sick-ordisabled-people-and-carers/pip/help-with-your-claim/how-to-claim-if-terminally-ill/.

Getting someone to represent you

If you feel too ill or tired to make calls or have conversations, you can give formal consent so that a family member, friend or a carer can discuss your claims. You will still have control over the claims, though.

You can also go a step further and make someone a legal appointee. You should contact the office that deals with your benefits or tax credits. There's an application form, and someone will visit you and the person you want to appoint. There's more information at https://www.citizensadvice.org.uk/family/looking-after-people/managing-affairs-for-someone-else/.

Help for carers

Carers may be able to apply for some financial support. Carer's Allowance is the main benefit for carers – if your carer qualifies for it they'll also get national insurance credits. If your carer isn't able to get carer's allowance, they may be eligible for carer's credit, which helps to protect their state pension later on.

Local councils and organisations may also be able to help support carers – see Box 3.

Bills and payments

Energy and water bills If you think you may struggle to pay your bills, contact your supplier(s) and tell them that you have cancer. Ask what help they can offer. The Macmillan Support Line has energy advisers who can help you with this (see Box above).

Council tax If your income is low, you may be able to have your council tax reduced. Contact the council that charges you. Your library will have contact details or you can search online at:

- England gov.uk
- Scotland cosla.gov.uk
- Wales wlga.wales

The system is different in Northern Ireland. If you think you're going to have trouble paying your rates bill, phone the Land and Property Services on **0300 200 7801**.

Mortgage payments You may be able to get help with your mortgage repayments or with other housing costs, but this help will be tied to other benefits, such as universal credit. This is a complicated area, so it's best to speak to an adviser who can give you personalised information – see Box 2.

Income tax refund If you have had to reduce or give up work, you may be able to get an income tax refund. The applies to people with cancer and their carers. Contact the HMRC. If you've reduced your hours, it's also worth checking that you are paying the correct amount of tax.

Health-related costs

Prescriptions are free for people with cancer in England. Ask for an FP92A form from your GP surgery or your hospital clinic. In other parts of the UK, prescriptions are free for everyone.

Wigs and fabric supports are free in Wales and Northern Ireland. In England and Scotland, you can get a free NHS wig or fabric support if you qualify



for certain benefits or allowances, you are a hospital inpatient when you receive the wig or fabric support or you are entitled to a valid NHS tax exemption certificate. Some hospitals also supply them free of charge — ask your medical team. If you don't get a free wig or want to use a private supplier, you can claim back the VAT. The supplier may be able to provide a VAT refund form, which they will submit for you. www.nhs.uk/nhs-services/help-with-health-costs/wigs-and-fabric-supports-on-the-nhs/.

Equipment and home adaptations If your medical team agrees that you need specialised equipment, they can refer you to a social worker who will help organise it, or you can contact your local social services or social work department directly for an assessment (search online for the details or ask your library to help). The equipment or adaptations may be free, depending on your circumstances.

The Disabled Living Foundation has advice and information about the different types of equipment that are available at www.dlf.org.uk.

Nursing home costs You may be eligible for some help if you are in a nursing home. Ask your medical team for advice or call one of the support lines shown in the Box on the back page.

Travel and transport

Help with hospital transport If you receive certain benefits, you may also be able to claim a refund on transport costs for hospital appointments. And the British Red Cross may be able to provide help if you're returning home from hospital – see www.redcross.org.uk/get-help/get-supportat-home.

You may also be able to use some local community transport schemes or have reduced fares. There are a number of different schemes that might be helpful. Macmillan Cancer Support has a good overview of what's on offer at www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/benefits-and-financial-support/help-with-transport-and-parking

Road tax You may be able to get free or reduced road tax if you meet the requirements. There's more information at www.gov.uk/financial-help-disabled/vehicles-and-transport.

Blue badge scheme Having a blue badge allows you to park closer to your destination if you have mobility problems. See www.gov.uk/get-blue-badge for more information.

Insurance

Claiming Being diagnosed with cancer may mean you can claim under an existing insurance scheme, such as mortgage payment protection or income protection. Find out whether you are eligible for a pay out and claim as soon as possible.

Buying Insurance that's unconnected to your cancer shouldn't be affected (car insurance, for example). But any policy linked to your health will be affected – you may not be able to buy insurance, you may have higher premiums or there may be special conditions.

Pensions

State pension The age at which the state pension starts has changed in recent years. To find out when you will reach the state pension age, visit GOV. UK. You can find out about your entitlement to state pension at GOV.UK (search for 'pension') or by phoning the Future Pensions Centre on 0800 731 0175.

Telephone from outside the UK: +44 (0)191 218 3600 Welsh language telephone: 0800 731 0175 Textphone: 0800 731 0176

If you're on a low income, you may qualify for pension credit – see www.gov.uk/pension-credit for more information.

Your workplace or private pension may be affected if you have had to stop work or reduce your hours. Speak to your human resources department at work or someone at the pension scheme.



If you've had several pensions over the years and want to put them together, the free Pension Tracing Service can help you locate them all – phone them on 0800 731 0193 or www.gov.uk/find-pension-contact-details It's a good idea to get some personal financial advice before making any changes, though, so you may want to contact an independent adviser.

Accessing your pension You may be able to have some benefit from your pension earlier than you planned.

If you are thinking of retiring early and claiming your pension, check your pension rules. If your cancer is terminal, you may be able to claim a lump sum.

The age at which you can access your pension depends on the type of pension you have. There is some helpful information from Macmillan Cancer Support at www.macmillan.org.uk/information-and-support/organising/your-finances/pensions/accessing-your-pension.html. It's a good idea to speak to a financial adviser before making any decisions.

Going back to work

You may feel able to go back to working as normal after you've had some time away, but it's quite likely that you'll have long-lasting treatment effects that need to be considered. You might feel tired or sore, for example, or you may need to use the toilet more often. Your employer should be able to make reasonable adjustments to help (see Box 4). These can be set out in a return-to-work plan.

If your employer has an occupational health adviser, they will be the best person to talk to about adjustments. If there isn't an occupational health service, your GP should be able to help or refer you to someone who can.

Talking to colleagues When you go back to work, it will be your decision whether or not you tell people about your cancer. If it would make you feel more confident, try to think how you're going to answer some of the most likely questions. Some people find the easiest way is to plan a straightforward and positive

explanation. But if you don't want to talk about it, just tell people that. You may find that some people are affected by your experience – it may remind them of a difficult time in their own life.

Getting through the day You may find it quite difficult to get back into the routine of work. Be easy on yourself. Accept help if it's offered, and don't try to do too much straight away. It's natural to have some self-doubt. But if you're finding it very difficult, or the feelings aren't subsiding, it might help to get some advice and support. Your GP surgery may have details of counselling, or you could contact a charity such as Macmillan Cancer Support

Possibilities to consider when returning to work

WHAT YOU WILL DO

- A gradual return to normal hours
- More flexibility part-time working, working from home or flexible start or finish times or working from home
- Reviewing your job description if you think some tasks may be more difficult now
- Starting back with fewer responsibilities or with lighter tasks allowing you to do 'light duties' for a time
- Changing your role

PRACTICALITIES

- Will you need extra breaks and a place where you can rest?
- Will the walk from the car park be difficult?
- Is the location of your office suitable for you?
- Can you get to a toilet easily?







More information

As well as information about bladder cancer and treatments, our website has other information sheets that you might find helpful. It also has listings of regional support groups for bladder cancer patients.

Your specialist or GP may be able to provide letters of support if necessary for your employer if you require absence from work or altered working practices, or to support benefit applications etc.

Other charities have information on work that may be helpful, too.

- Cancer Research UK at www.cancerresearchuk.org/about-cancer/ coping/practically
- Citizens Advice has information on discrimination at www.citizensadvice.org.uk/ law-and-courts/discrimination/protectedcharacteristics/disability-discrimination/ and on benefits at www.citizensadvice.org.uk/ benefits/sick-or-disabled-people-and-carers/
- Macmillan Cancer Support has information on work, and also offers training and consultancy for employers – www.macmillan.org.uk/ information-and-support/organising/workand-cancer. There's information on finances at www.macmillan.org.uk/information-andsupport/organising/your-finances/planningyour-finances, and for carers at www.macmillan.org.uk/information-andsupport/organising/benefits-and-financialsupport/looking-after-someone-with-cancer/
- Maggies has information at www.maggies. org/cancer-support/our-support/help-money-worries/, with information for carers at www.maggies.org/cancer-support/managing-practically/money-benefits-and-cancer/benefits-and-carers/supporting-someone/financial-help-carers/

 StepChange at www.stepchange.org/ is a charity which provides a free debt advice service

Other information sources

- The Government's site with information on benefits and allowances is at www.gov.uk/ financial-help-disabled
- Working with Cancer is a social enterprise that aims to help people affected by cancer get back to work – they offer coaching and advice, and there are useful links on their website at www.workingwithcancer.co.uk
- Unum, an employee benefits provider, has worked with Maggies to produce a simple guide to help employers support employees with cancer – it's available at www.unum.co.uk/ docs/UP3313.pdf
- This Is Money financial website has a blog on cancer and benefits at www.thisismoney.co.uk/ money/howmoneyworks/article-4670712/ Cancer-finances-Benefits-entitled-to.html (written in 2017)
- Access to Work is a government programme for people with long-term health conditions in England, Scotland and Wales. The programme aims to help you stay at work and work more easily by providing advice and practical support; there's information at www.gov.uk/access-towork
- If you live in Northern Ireland, there's information about help and support at www.nidirect.gov.uk/ information-and-services/people-disabilities
- There's a helpful article on finding an independent financial adviser here www.moneysavingexpert.com/savings/bestfinancial-advisers