

Work and cancer series – for carers

**WE ARE
MACMILLAN.
CANCER SUPPORT**

QUESTIONS FOR CARERS TO ASK ABOUT WORK AND CANCER



About this leaflet

This leaflet has questions you may need to ask about work issues if you are a working carer. That's anyone who works while providing unpaid support to a partner, relative or friend with cancer who couldn't manage without this support.

Balancing work and care responsibilities isn't always easy. We hope that using this leaflet will boost your confidence and support you to deal with any workplace issues you might have.

Not all the questions will be relevant to everyone. For example, not all carers will need to take time off work. This leaflet is a flexible guide. You can use it to focus on the questions that apply to your situation.

How to use this leaflet

We have split the questions for carers into four sections:

- caring for someone during treatment
- work arrangements
- caring for someone at home
- finances.

The questions you ask and when you ask them will depend on your situation. You can pick and choose. You may need to ask some questions earlier or later than suggested in the leaflet.

Next to each question, you will find a row of boxes. These show all the places you can go for answers.

- ✓ A large tick shows a service or person who is most likely to be able to answer your question.
- ✓ A small tick shows a service or person who may also be able to help.

At the back of this leaflet, there are blank pages for notes (pages 25–26). You could use these pages to help you remember what questions you need to ask, and record what you find out.

Services we refer to

We refer to a number of services where you may be able to get answers to your questions:

- **Occupational health**

This may include workplace health and safety advisers, nurses, physiotherapists, counsellors, and GPs. It may not be available at every workplace. In some cases, workplaces give employees access to an external occupational health service. You can find out more from your employer or HR department. If you live in England, Wales or Scotland you can also get occupational health support from the **Fit for Work** service. See page 20 for more details.

- **Your line manager**

- **Your HR department**

- **Advisory services**

These are organisations and programmes that can offer guidance and advice, including helping resolve work disputes. See pages 19–21 for examples of the services available and for contact information.

- **Charities and support groups**

These may include Macmillan Cancer Support, other cancer support charities, carers' organisations and local support groups. See page 22 for more details and for contact information.

- **Your union**, if you're a member.

- **Social services**

These are services provided by the state to help people in need. They can include help at home (such as shopping or cleaning), intensive home care and specialist equipment.

- **Oncology team**

This is the team at the hospital. It may include oncologists, radiologists and specialist cancer nurses. In some services, this may also include a social worker.

- **GP services**

If you are self-employed

If you are self-employed and so do not have a line manager, HR department or union, our booklet **Self-employment and cancer** may be helpful. It can give you more information about work issues. It's written for people with cancer, but you may face some of the same problems.

See page 19 for details of our work and cancer resources and our resources for carers, and how to order them.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you is collected in a national database. This is called the cancer registry. It helps the NHS and other organisations plan and improve health and care services. Your hospital will give information about you, your cancer diagnosis and treatment to the registry automatically, unless you ask them not to. As with all medical records, there are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions about the registry. If you do not want your information included in the registry, you can contact the cancer registry in your country. You can find more information at **[macmillan.org.uk/cancerregistry](https://www.macmillan.org.uk/cancerregistry)**. To find details about the cancer registry in your area, see pages 21–22.

Questions about caring for someone during treatment

I'd like to take time off work to go to hospital appointments with the person I care for. Can you tell me how long each appointment will last, including possible delays?

If the person I care for has an appointment, is there anything I might need to do beforehand? For example, check their medication.

So that I can book time off work, how far in advance can appointments be made for the person I care for?

If the person I care for needs to stay in hospital and visiting hours clash with work, can I visit at different times?

When am I most likely to need to take time off work or reduce my hours to provide care?

Does the hospital have free Wi-Fi so that I can access work emails?

Can repeat prescriptions be delivered to my local pharmacy so I can collect them outside working hours?

	Oncology team	GP	Occupational health	Line manager	HR	Advisory services	Charities and support groups	Union	Social services
	✓								
	✓								
	✓								
	✓								
	✓								
	✓								
		✓							

Questions about work arrangements

Where can I find out about my legal rights as a working carer?

I'm self-employed. What support can I get to keep my business running while I'm caring?

Being a carer is having an impact on my physical well-being. How can I work with my employer to reduce the risk of this affecting me, my work and my caring responsibilities?

Being a carer is having an impact on my mental well-being. How can I work with my employer to reduce the risk of this affecting me, my work and my caring responsibilities?

Are there courses or counselling services available to help me better manage my work and caring responsibilities?

Does my company/organisation have a policy for supporting carers?

What flexible working arrangements are available to help me balance my work and caring responsibilities? This could include working from home, flexible hours, or changes to my working hours.

What types of paid and unpaid leave arrangements are available? This could include carer's leave, emergency leave, sabbaticals, compassionate leave, borrowing holiday days from next year or buying additional days.

	Oncology team	GP	Occupational health	Line manager	HR	Advisory services	Charities and support groups	Union	Social services
					✓	✓	✓	✓	
						✓			
		✓	✓	✓	✓	✓	✓		
		✓	✓	✓	✓	✓	✓		
		✓	✓	✓	✓		✓		
				✓	✓				
				✓	✓			✓	
				✓	✓				

Could I have written confirmation of any agreed flexible working arrangements or leave arrangements?

If I can take a large amount of time off work to care, how much notice do I have to give before I go back?

If I take time off work to care, how can I make sure I'm updated about changes that happen at work while I am off?

Can my work be organised so that I can take leave at short notice if I need to? For example, this could be if there's a problem with care arrangements, or if the person I care for needs urgent medical attention or needs to go to hospital. If so, who should I tell at work?

Would it be okay to make brief personal phone calls or send personal emails during work hours so that I can get in touch with the person I care for and they can contact me?

Can we talk about how to tell my colleagues and other managers about my situation?

Can we have regular reviews to check my working arrangements?

Oncology team	GP	Occupational health	Line manager	HR	Advisory services	Charities and support groups	Union	Social services
			✓	✓				
			✓	✓				
			✓					
			✓	✓				
			✓	✓				
			✓	✓				
			✓	✓				

Questions about caring for someone at home

How do I apply for a carer's assessment? (This is done by social services to decide the support you need to be able to care for someone.)

How can I organise extra support at home to help me manage my work and caring responsibilities? This might include day-sitting, night-sitting, care homes or day centres.

How can I meet other working carers to share my experiences and learn from others?

	Oncology team	GP	Occupational health	Line manager	HR	Advisory services	Charities and support groups	Union	Social services
	✓	✓				✓	✓		✓
	✓					✓	✓		✓
	✓	✓				✓	✓		✓

Questions about finances

What benefits can I get if I'm self-employed?
For example, can I get Carer's Allowance, Universal Credit or Employment and Support Allowance?

What benefits could I get if I continue working, stop working or return to work?

Does my employment status affect the benefits I can get?
For example, what happens if I'm on a short-term contract or employed through an agency?

If I'm already getting benefits like Income Support, how will this affect the benefits I can get as a carer?

The person I care for is getting benefits. Will this affect the benefits I can get as a carer?

If I get benefits as a carer, will this affect any benefits for the person I care for?

If I make adjustments like reducing my working hours, how would this affect my pay and benefits?

I need evidence to support my claim for benefits as a carer. Who can help me get this?

	Oncology team	GP	Occupational health	Line manager	HR	Advisory services	Charities and support groups	Union	Social services
		✓				✓	✓		✓
		✓				✓	✓		✓
						✓	✓		
						✓	✓		
						✓	✓		
				✓	✓	✓			
	✓	✓			✓	✓			✓

When will my benefits be confirmed?

How long can I claim benefits for?

How will my company or state pension be affected if I can't go back to work, or if I reduce my working hours to care?

Oncology team	GP	Occupational health	Line manager	HR	Advisory services	Charities and support groups	Union	Social services
					✓	✓		
					✓	✓		
				✓	✓	✓	✓	



Further information and support

How we can help

You can call our support line on **0808 808 00 00** (Mon–Fri, 9am–8pm).

Our cancer support specialists can help with medical questions, money worries or just be there to listen if you need someone to talk to. You can speak to:

Welfare rights advisers

You can speak to our welfare rights advisers or search online for a Macmillan benefits adviser near you at **[macmillan.org.uk/benefitsadvisers](https://www.macmillan.org.uk/benefitsadvisers)**

Financial guides

You can speak to our financial guides about your pension, insurance or any other financial planning matter. You can also contact them online at **[macmillan.org.uk/financialguidance](https://www.macmillan.org.uk/financialguidance)**

If you live in Northern Ireland, you can also call the Macmillan Northern Ireland Macmillan Welfare Benefits Service on **0300 123 3233**.

Want to find out more?

For more information and practical advice about work and cancer visit **[macmillan.org.uk/work](https://www.macmillan.org.uk/work)**

Related resources

We have more information about work and cancer for working carers and for employees affected by cancer:

- **Working while caring for someone with cancer**
- **Your rights at work when you are affected by cancer**
- **Work and cancer: a guide for people living with cancer**
- **Questions to ask about work and cancer**
- **Self-employment and cancer.**

You can order these resources and more copies of this leaflet by visiting **be.macmillan.org.uk/work** or calling **0808 808 00 00**.

Advisory services

Advisory, Conciliation and Arbitration Service (ACAS)

Tel 0300 123 1100

www.acas.org.uk

An organisation that helps to resolve work disputes and offers advice to employees and employers.

Citizens Advice

www.citizensadvice.org.uk

Provides advice on a variety of issues including financial, legal, housing and employment issues.

England and Wales
www.citizensadvice.org.uk

Scotland
www.cas.org.uk

Northern Ireland
www.citizensadvice.co.uk

You can also find advice online in a range of languages at **www.citizensadvice.org.uk/resources-and-tools/languages**

Employee assistance programmes

Your company might have an employee assistance programme offering advice, information and sometimes counselling. You should check with your HR department to see if your employer offers this.

The Fit for Work service

The Fit for Work service is a government-sponsored service introduced in 2015 in England, Wales and Scotland. It is free and confidential.

Fit for Work provides the services of occupational health professionals to working people if they:

- have been off work for four weeks or more
- are likely to be off work for four weeks or more.

The service is available to everyone. It is particularly suitable for people whose employers don't have their own occupational health services.

GPs or employers can refer you to the service. You will then have an assessment, followed by support for your situation.

You can contact the Fit for Work helpline or visit the website to get advice and support:

England and Wales

Tel 0800 032 6235

www.fitforwork.org

Scotland

Tel 0800 019 2211

www.fitforwork.scotland.scot

Northern Ireland

The Fit for Work service is not available in Northern Ireland.

If you live in Northern Ireland, you should contact your workplace occupational health service, if you have one.

Jobcentre Plus

**[www.gov.uk/
contact-jobcentre-plus](http://www.gov.uk/contact-jobcentre-plus)**

Run by the Department for Work and Pensions (DWP). Aims to help people of working age find jobs and help those unable to work in making claims.

Labour Relations Agency –

Northern Ireland

Tel 028 9032 1442

www.lra.org.uk

In Northern Ireland, the Labour Relations Agency helps to resolve work disputes and offers advice to employees and employers.

Cancer registries

The cancer registry

A national database that collects information on cancer diagnoses and treatment.

This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration Service

Public Health England,
Wellington House,
London SE1 8UG

Tel 020 7654 8000

**Email [enquiries@
phe.gov.uk](mailto:enquiries@phe.gov.uk)**

www.ncr.nhs.uk

Scottish Cancer Registry

NHS Information Services,
Gyle Square,

1 South Gyle Crescent,
Edinburgh EH12 9EB

Tel 0131 275 7777

Email nss.csd@nhs.net

**[www.isdscotland.org/
Health-Topics/Cancer/
Scottish-Cancer-Registry](http://www.isdscotland.org/Health-Topics/Cancer/Scottish-Cancer-Registry)**

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Public Health Wales
NHS Trust,

3rd Floor,
16 Cathedral Road,
Cardiff CF11 9LJ

Tel 02920 373500

**Email [general.enquiries@
wales.nhs.uk](mailto:general.enquiries@wales.nhs.uk)**

**[www.wcisu.wales.
nhs.uk](http://www.wcisu.wales.nhs.uk)**

Northern Ireland Cancer Registry

Centre for Public Health,
School of Medicine,
Dentistry &
Biomedical Sciences,
Queen's University Belfast,
Mulhouse Building,
Grosvenor Road,
Belfast BT12 6DP
Tel 028 9097 6028
Email nicr@qub.ac.uk
www.qub.ac.uk/nicr

Charities and support groups

The Carers' Trust

www.carers.org

Provides access to breaks, information and advice and education, training and employment opportunities for carers. They also have information about carers' organisations in your local area, such as carers' centres.

Carers UK

www.carersuk.org

A charity that helps millions of people who look after an older, disabled or seriously ill family member or friend.

Employers for Carers

www.

employersforcarers.org

Part of Carers UK, this service for employers aims to help them retain the one in seven employees in their workforce caring for a family member.

MIND

Infoline 0300 123 3393
(Mon–Fri, 9am–6pm)

Email info@mind.org.uk

www.mind.org.uk

Provides advice and support to anyone experiencing a mental health problem.



You can search for more organisations on our website at macmillan.org.uk/organisations or call us on 0808 808 00 00.

Disclaimer

We make every effort to ensure that the information we provide is accurate and up-to-date, but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This leaflet was written, revised and edited by Macmillan Cancer Support's Cancer Information Development team with support and approval from the Working Through Cancer team at Macmillan. It is based on content originally produced in partnership with Loughborough University and Affinity Health at Work as part of the National Cancer Survivorship Initiative.

With thanks to: Charlotte Argyle, Macmillan Carers Support Programme Manager; Jacqui Bailie, Macmillan HR Manager, Operations; Mary Edwards, Operations Manager, Employers for Carers, Carers UK; Katherine Wilson, Strategic Manager, Employers for Carers, Carers UK; Dr Philip Wynn, Senior Occupational Health Physician, Durham County Council; and the people affected by cancer who reviewed this edition.

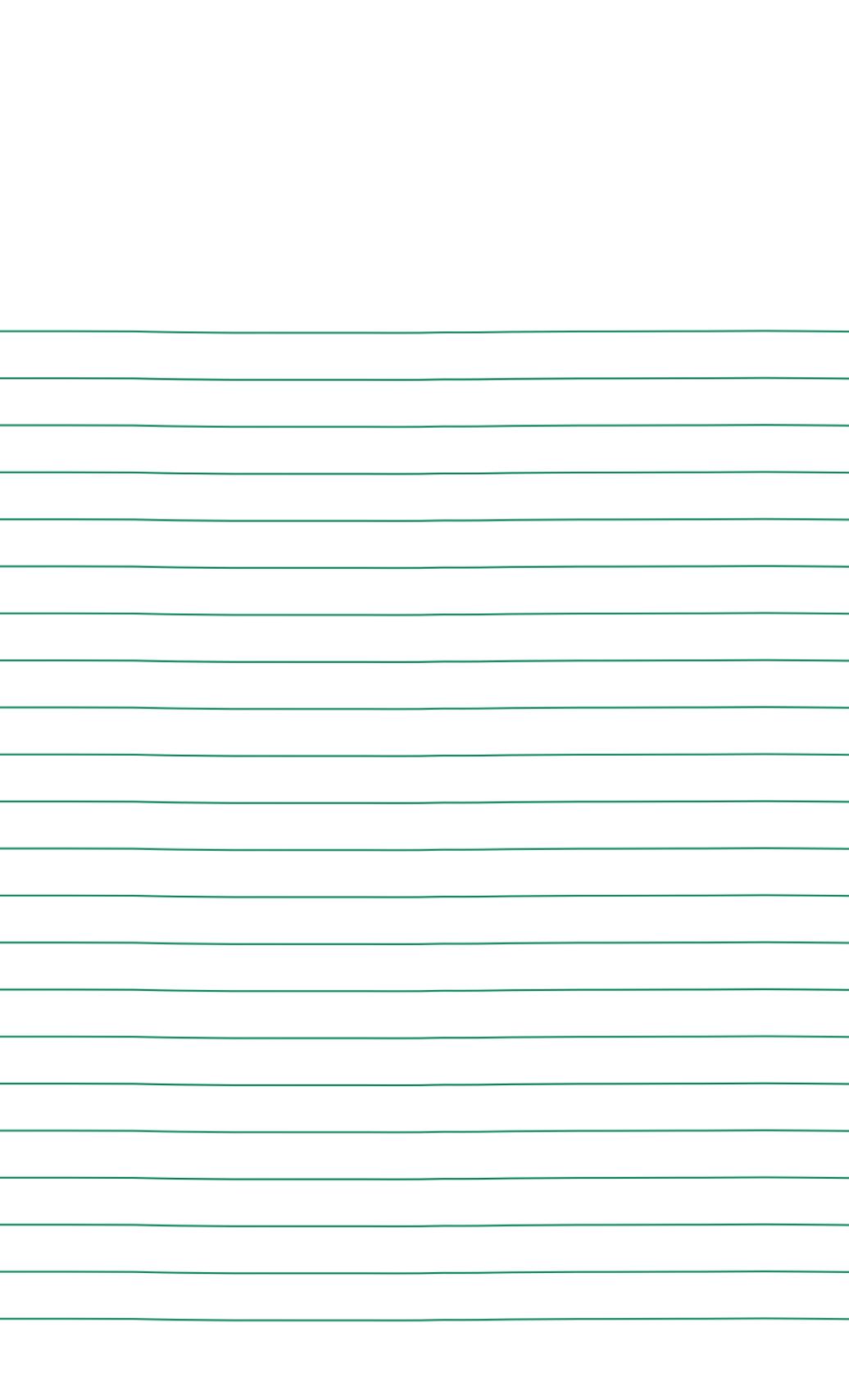
Sources

We've listed a sample of the sources used in this publication below. If you'd like further information about the sources we use, please contact us at bookletfeedback@macmillan.org.uk

Carers UK website. www.carersuk.org (accessed July 2016).

Gov.uk website. www.gov.uk (accessed July 2016).





This leaflet has questions you may need to ask about work issues if you are a working carer. It is for anyone who works while providing unpaid support to a partner, relative or friend with cancer who couldn't manage without this support.

Balancing work and care responsibilities isn't always easy. We hope that using this leaflet will boost your confidence and support you to deal with any workplace issues you might have.

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these visit **macmillan.org.uk/otherformats** or call our support line.

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