

**MACMILLAN**  
CANCER SUPPORT

# QUESTIONS FOR CARERS TO ASK ABOUT WORK AND CANCER

Work and cancer series – for carers



Work was full on and very busy. I was at that point beginning to realise just how bogged down with everything I was getting. And I figured that maybe some help might be useful. 🍷

Prue, who cared for her husband Dave when he was diagnosed with prostate cancer



## The Macmillan work and cancer series

Macmillan produces a range of information about work and cancer.

### For people living with cancer:

- Work and cancer
- Questions to ask about work and cancer

### For employers:

- 10 top tips for line managers
- Managing cancer in the workplace

### For people caring for someone with cancer:

- Working while caring for someone with cancer
- Questions for carers to ask about work and cancer

### For self-employed people with cancer:

- Self-employment and cancer

### More information:

- Your rights at work when you are affected by cancer

## About this leaflet

**This leaflet has questions you may need to ask about work issues if you are a working carer. A working carer is anyone who works while providing unpaid support to a partner, family member or friend with cancer, who could not manage without this support.**

Balancing working and caring responsibilities is not always easy. We hope this leaflet makes you feel more confident about dealing with any workplace issues you might have.

Some of the questions in this leaflet may not be relevant to you. You do not have to read it from start to finish. You can use it to focus on the questions that apply to your situation.

We have split the questions into four sections:

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

If you are self-employed, our booklet **Self-employment and cancer** (see page 18) has more information about dealing with work issues relevant to you. It is written for people with cancer, but you may face some of the same problems.

## How to use this leaflet

The questions you need to ask and when you ask them will depend on your situation. You may need to ask some questions earlier or later than suggested in this leaflet. You can decide what works for you.

Next to each question, there is a list of people or places you can go to 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 26 to 27). You could use these pages to help you remember what questions you need to ask, and write down what you find out.

## Quotes

In this leaflet, we have included a quote from Prue, who is on the cover. She cared for her husband Dave when he was diagnosed with prostate cancer. To share your experience, visit [macmillan.org.uk/shareyourstory](https://www.macmillan.org.uk/shareyourstory)

## Services we mention

There are a lot of services that may be able to help answer your questions. On the next page, we list the services we mention in this leaflet.

- Oncology team – this is the cancer team at the hospital. It may include oncologists, radiologists and cancer nurses. In some services, it may also include a social worker.
- GP services – this is your doctor’s surgery.
- Occupational health professionals – these may include workplace health and safety advisers, nurses, physiotherapists, counsellors, and GPs. They may not be available at every workplace. Your work may offer an external occupational health service. You can find out more from your employer or HR manager.
- Line manager – this is your manager at work.
- HR manager – this is someone in the human resources or recruitment team at your work.
- Advisory services – these are organisations that offer guidance, including help resolving work disputes (see pages 20 to 25).
- Charities and support groups – these may include a Macmillan work support adviser, other cancer support charities (see pages 20 to 25), carers’ organisations (see pages 24 to 25), local support groups and online forums.
- Unions – these are trade or labour unions that you may be a member of.
- Social services – these are services provided by the government to help people in need. They can include help at home, such as shopping or cleaning, care at home or specialist equipment.

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# Questions about caring for someone during treatment

	Oncology team	GP	Occupational health professionals	Line manager	HR	Advisory services	Charities and support groups	Union	Social services
I would like to take time off work to go to hospital appointments with the person I am caring for. Can you tell me how long each appointment is likely to be? Could appointments take longer than expected?	✓								
If the person I am caring for has an appointment, is there anything I might need to do before it? For example, do I need to bring a list of their medication, or ask if they need a repeat prescription?	✓								
If I go to hospital appointments with the person I am caring for, I may need to book time off work in advance. How far in advance can appointments be made?	✓								
If the person I am caring for needs to stay in hospital and visiting hours are only when I am at work, can I visit at different times?	✓								
When am I most likely to need to take time off work or work less 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?		✓							

# Questions about work arrangements

	Oncology team	GP	Occupational health professionals	Line manager	HR	Advisory services	Charities and support groups	Union	Social services
Where can I find out about my legal rights as a working carer?					✓	✓	✓	✓	
I am self-employed. What support can I get to keep my business running while I am caring?						✓			
Being a carer is having an impact on my physical health. How can I make sure I stay physically healthy while working and caring?		✓	✓	✓	✓	✓	✓		
Being a carer is affecting my mental health. How can I look after my mental health while working and caring?		✓	✓	✓	✓	✓	✓		
Are there courses or counselling services that could help me manage my work and caring responsibilities better?		✓	✓	✓	✓		✓		
Does my employer have a policy for supporting carers?				✓	✓			✓	
Can I have flexible working to help me balance my work and caring responsibilities? For example, could I work from home, work flexible hours, or change my working hours?				✓	✓				
Could flexible working affect any employee benefits I have, such as death in service benefit or my pension?				✓	✓	✓			
What types of paid and unpaid leave arrangements are available? For example, could I take carer's leave, emergency leave, a sabbatical, compassionate leave, or use holiday days from next year?				✓	✓				

	Oncology team	GP	Occupational health professionals	Line manager	HR	Advisory services	Charities and support groups	Union	Social services
Could I have written confirmation of any agreed flexible working or leave arrangements?				✓	✓				
If I 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 am told about changes that have happened at work? For example, changes to technology, team members, targets, client base or policy.				✓					
Can my work be organised so that I can take time off at short notice if I need to? For example, taking time off if there is a problem with care arrangements, or if the person I am caring for needs to go to hospital. Who should I tell at work if I need to take time off at short notice?				✓	✓				
Would it be okay for me to make short personal phone calls or send personal emails during work hours? For example, could I do this if I need to contact the person I care for or let them contact me?				✓					
Can we agree on what to tell people at work about my situation and how it will affect my work? For example, what to tell colleagues, other managers and clients.				✓	✓				
Can we have regular meetings to review my working arrangements?				✓	✓				

## Questions about caring for someone at home

	Oncology team	GP	Occupational health professionals	Line manager	HR	Advisory services	Charities and support groups	Union	Social services
How do I apply for a carer's assessment? (This is done by social services to decide what 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? For example, getting someone to be with them during the day or at night, or help from a care home or day centre.	✓					✓	✓		✓
How can I meet other working carers to share my experiences and learn from others?	✓	✓				✓	✓		✓

# Questions about finances

	Oncology team	GP	Occupational health professionals	Line manager	HR	Advisory services	Charities and support groups	Union	Social services
What benefits can I get if I am 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 go back to work?		✓				✓	✓		✓
Does my employment status affect the benefits I can get? For example, what happens if I am on a short-term contract or employed through an agency?						✓	✓		
If I am 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 the benefits the person I care for can get?						✓	✓		
If I make adjustments like working fewer hours, how will this affect my pay and benefits?				✓	✓	✓			

	Oncology team	GP	Occupational health professionals	Line manager	HR	Advisory services	Charities and support groups	Union	Social services
I need evidence to support my claim for benefits as a carer. Who can help me get this?	✓	✓			✓	✓			✓
When will my benefits be confirmed?						✓	✓		
How long can I claim benefits for?						✓	✓		
How will my company or state pension be affected if I cannot go back to work, or if I work fewer hours to care?					✓	✓	✓	✓	

## Further information and support

Find out about our expert, up-to-date information about cancer and other ways we can help you. All our information is free for everyone.

### Order what you need

To order more booklets or leaflets visit **be.macmillan.org.uk** or call us on **0808 808 00 00**. All our information is also available online at **macmillan.org.uk/information-and-support**

We provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**  
If you would like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call **0808 808 00 00**.

### Other ways we can help

#### Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. We can help with medical questions, benefits, financial guidance and local services, or just be there to listen. Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

#### Information centres

Our centres are based in hospitals, libraries and on mobile buses. You can talk to someone or get more information. Find your nearest centre at **macmillan.org.uk/informationcentres** or call **0808 808 00 00**.

#### Support groups

You can find support groups in your area by calling **0808 808 00 00** or visiting **macmillan.org.uk/selfhelpandsupport**

You may also want to use our Online Community to make friends, blog, and read stories. Visit **macmillan.org.uk/community**

#### Help with money worries

Our financial guidance team can help you with money worries and accessing benefits. Macmillan also offers one-off grants – for anything from heating bills to extra clothing. Call us on **0808 808 00 00** or visit **macmillan.org.uk/financialsupport**

#### Help with work and cancer

Whether you are an employee, a carer, an employer or self-employed, we can help. Visit **macmillan.org.uk/work** or call **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

## Other useful organisations

There are lots of other organisations that can give you information or support.

### Work and employment

#### Access to Work

**Tel** 0800 121 7479

**Textphone** 0800 121 7579 (Mon to Fri, 8am to 7.30pm)

**[www.gov.uk/access-to-work](http://www.gov.uk/access-to-work)**

Provides advice and practical support to people with long-term health conditions and their employers. This helps pay for practical support, so you can do your job.

#### Access to Work (NI)

**[www.nidirect.gov.uk/articles/access-work-practical-help-work](http://www.nidirect.gov.uk/articles/access-work-practical-help-work)**

Gives support and advice to employees with disabilities and their employers. To apply for assistance through this programme, speak to an adviser at your local Jobs and Benefits office.

#### Advisory, Conciliation and Arbitration Service (ACAS)

**Helpline** 0300 123 1100 (Mon to Fri, 8am to 6pm)

**[www.acas.org.uk](http://www.acas.org.uk)**

Gives advice to employees and employers to help improve working life and relations. Offers information, advice and training.

#### Equality Advisory Support Service (EASS)

**Tel** 0808 800 0082

**Textphone** 0808 800 0084 (Mon to Fri, 9am to 7pm, and Sat 10am to 2pm)

**[www.equalityadvisoryservice.com](http://www.equalityadvisoryservice.com)**

Promotes equality and provides information to people about their rights in England, Scotland and Wales.

#### Equality Commission for Northern Ireland (ECNI)

**Tel** 0289 050 0600

**[www.equalityni.org](http://www.equalityni.org)**

Aims to advance equality, promote equality of opportunity, encourage good relations and challenge discrimination through promotion, advice and enforcement.

#### Labour Relations Agency

**Tel** 0330 055 5300

(Mon to Fri, 9am to 5pm)

**Email** [info@lra.org.uk](mailto:info@lra.org.uk)

**[www.lra.org.uk](http://www.lra.org.uk)**

Responsible for promoting the improvement of employment relations in Northern Ireland. Provides advice and support to both employees and employers, and helps resolve disputes.

#### WorkSmart

**[www.worksmart.org.uk](http://www.worksmart.org.uk)**

This website provides information on employment rights, health at work and financial matters. It is part of the Trades Union Congress (TUC).

## Financial support or legal advice and information

### Benefit Enquiry Line Northern Ireland

**Helpline** 0800 022 4250

(Mon, Tue, Wed and Fri, 9am to 5pm, and Thu 10am to 5pm)

**Textphone** 0289 031 1092

**www.nidirects.gov.uk/money-tax-and-benefits**

Provides information and advice about disability benefits and carers' benefits in Northern Ireland. You can also call the Make the Call helpline on **0800 232 1271** to check you are getting all the benefits you are eligible for.

### Carer's Allowance Unit

**Tel** 0800 731 0297

**Textphone** 0800 731 0317 (Mon to Fri, 8am to 6pm)

**www.gov.uk/carers-allowance**

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

### Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office in the phone book or by contacting:

### England

**Helpline** 0344 411 1444

**www.citizensadvice.org.uk**

### Wales

**Helpline** 0344 477 2020

**www.citizensadvice.org.uk/wales**

### Scotland

**Helpline** 0808 800 9060

**www.cas.org.uk**

### Disability and Carers Service

**Tel** 0800 587 0912

**Textphone** 028 9031 1092

(Mon to Fri, 8am to 5pm)

**nidirect.gov.uk/disability-and-carers-service**

Manages Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit in Northern Ireland. You can apply for benefits and find information online or through its helplines.

### GOV.UK

**www.gov.uk**

Has information about social security benefits and public services in England, Scotland and Wales.

### Law Centres Network

**www.lawcentres.org.uk**

Local Law Centres provide advice and legal assistance. They specialise in social welfare issues including disability and discrimination.

### Macmillan Benefits Advice Service (Northern Ireland)

**Tel** 0300 123 3233

### NiDirect

**www.nidirect.gov.uk**

Has information about benefits and public services in Northern Ireland.

## Support for carers

### Carers Direct

**Tel** 0300 123 1053  
(Mon to Fri, 9am to 8pm  
and weekends, 11am  
to 4pm)

**www.nhs.uk/  
carersdirect**

Provides information  
and support for carers,  
including financial help,  
practical tips and home  
adaptations.

### Carers Trust

**Tel** 0300 772 9600  
(Mon to Fri, 9am to 5pm)

**Email** info@carers.org

**www.carers.org**

Provides information  
and support for people  
caring at home for  
a family member or  
friend. You can find  
details for UK offices  
and search for local  
support on the website.

### Carers UK

**Helpline (England,  
Scotland, Wales)** 0808  
808 7777 (Mon and Tue,  
10am to 4pm)

**Helpline (Northern  
Ireland)** 0289 043 9843

**www.carersuk.org**

Offers information and  
support to carers across  
the UK. Has an online  
forum and can put people  
in contact with local  
support groups for carers.

### Crossroads Care Northern Ireland

**Tel** 028 9181 4455

**Email** info@

crossroadscare.co.uk

**www.crossroadscare.  
co.uk**

Provides care to help  
people live independently  
at home, and respite care  
so that carers can have  
a break.

### Crossroads Caring Scotland

**Tel** 0141 226 3793

**Email** info@  
crossroadscotland.co.uk

**www.crossroads-  
scotland.co.uk**

Provides care to help  
people live independently  
at home, and respite  
care so that carers can  
have a break.



## 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 booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by the Working Through Cancer Programme 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.

Thanks to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact us at [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)

## Sources

If you would like information about the sources we use, please contact us at [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)

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**Balancing working and caring responsibilities is not always easy. We hope this leaflet makes you feel more confident about dealing any workplace issues you might have.**

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit [macmillan.org.uk](http://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](http://macmillan.org.uk/otherformats) or call our support line.

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**RIGHT THERE WITH YOU**

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