

WHAT TO DO AFTER CANCER TREATMENT ENDS: 10 TOP TIPS



A woman with brown hair tied back, wearing a blue and white striped long-sleeved shirt, is shown in profile from the waist up. She is reaching her right arm up towards a large green leafy plant. The background is a soft-focus garden with various green plants and a stone wall. The lighting is bright and natural, suggesting an outdoor setting.

● Since being in remission my outlook has completely changed. I'm happiest around plants and nature now. I absolutely love gardening and am now finding a new career in it. ●

Lara, diagnosed with breast cancer

About this leaflet

This leaflet is about what to expect and where to get further support after cancer treatment ends. It is for anyone who is coming to the end of their treatment or has recently finished it.

The information may also be helpful if you have had cancer treatment in the past. It can help you get the best care and support available and make healthy lifestyle choices.

We hope it helps you deal with some of the questions or feelings you may have.

How to use this leaflet

This leaflet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you. It is fine to skip parts of the leaflet. You can always come back to them when you feel ready.

Quotes

In this leaflet, we have included quotes from people who have finished cancer treatment. These are from people who have chosen to share their story with us. This includes Lara, who is on the cover of this leaflet. To share your experience, visit [macmillan.org.uk/shareyourstory](https://www.macmillan.org.uk/shareyourstory)

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit [macmillan.org.uk](https://www.macmillan.org.uk)

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit [macmillan.org.uk/otherformats](https://www.macmillan.org.uk/otherformats) or call **0808 808 00 00**.

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1. Talking about your needs and agreeing a care plan

Towards the end of your treatment, someone from your healthcare team may talk to you and ask you some questions. The discussion will focus on:

- how you are feeling
- what your immediate concerns are and what is most important to you
- any worries you may have for the future.

The aim of the discussion is to find out about any needs and concerns you may have. This includes your physical health, emotions, spiritual health, work, finances and family life. It can help you and your healthcare professional to see where you may need help.

The discussion is sometimes called a Holistic Needs Assessment (HNA). You can have an HNA at different times. You may have had one when you were diagnosed or during treatment. Or you may have one at the end of treatment. We have more information in our booklet **Holistic Needs Assessment: Planning your care and support** (see page 20).

First, you answer a set of simple questions or fill in a checklist about all areas of your life. Next, you discuss your concerns with your healthcare professional. They will give you information and support to help with things you are worried about. Together you can talk about possible solutions and make a plan to help you manage these. They can also refer you to any other services you may need.

The healthcare professional you talk to is usually your key worker. This may be your clinical nurse specialist (CNS). Sometimes you have it with your cancer doctor or another health professional, such as an occupational therapist or dietitian.

If you are not offered the discussion at the end of your treatment, ask your cancer nurse or doctor about it.

Care plan

During the discussion, you and your health professional will agree on the best ways to manage your needs and concerns. They may write down what you have agreed in a care plan. This is sometimes called a personalised care and support plan. It should include the main concerns you have talked about and any help that was suggested or is already in place. It should also list other services that may be able to help. These may be other NHS services, or local services run by other organisations.

Your health professional should give you a copy of your care plan. You can keep this and update it when you need to. You can talk about, and develop, it at your follow-up appointments, or with your GP or practice nurse. If you are not offered a copy of your care plan, ask the healthcare professional you had the HNA with for one.

2. Getting a treatment summary

At the end of treatment, your healthcare team may create a summary of the treatment you have had. This is sometimes called an end of treatment summary. This may be after a certain phase of treatment, or after you finish all your treatment.

It will describe the treatment you have had and help you understand what to expect now your treatment has finished. Knowing what happens next can help you adjust to life after treatment.

Your treatment summary will include information about:

- the cancer diagnosis
- any treatment you have had
- possible side effects of treatment or late effects (side effects that do not go away or happen months or years after treatment ends)
- any symptoms you need to tell your specialist about
- details of any follow-up appointments or tests you might need
- contact details for your cancer team.

Your hospital team will discuss the treatment summary with you. They will give you a copy and also send one to your GP. If you are not given a copy of your treatment summary and would like one, talk to your hospital team.

Your GP may contact you within 6 months of your diagnosis for a consultation called a Cancer Care Review. This is a discussion with your GP or a specially trained practice nurse about any concerns you have and what support is available to you. If your GP does not contact you, you can call your GP practice and ask for an appointment.





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3. Finding out who your main contact is

Your hospital team should give you details of who to contact after your treatment finishes. This may be a specialist nurse, doctor or another health professional such as an occupational therapist, physiotherapist or dietitian. They may be called your key worker. You can contact them if you are worried about your health or any side effects of treatment. Keep their contact details in your phone or somewhere safe.

If you are worried about something, your main contact can advise you who to speak to if you need help. Your GP might be your main contact. If they are not your main contact, you should still tell them about any problems you need help with.

4. Knowing about symptoms or side effects after treatment

Tell your key worker if you have any new or ongoing symptoms or side effects after treatment. These are different for everyone and could include problems with eating, bowel or bladder problems, pain, hot flushes or tiredness.

It can also include sexual health problems, such as vaginal dryness or difficulty getting an erection. Make sure you talk about what is important to you.

There are many professionals who can help you manage any symptoms you have. Your doctor or key worker can refer you to someone, if needed.

5. Getting support with day-to-day worries

Cancer can affect your work, relationships and finances.

You can get confidential advice and support from different places to help you cope with any changes to your life.

These may include:

- your local cancer support centre
- your hospital social work department
- your workplace
- organisations such as Citizens Advice (see page 24).

You can also contact us for financial guidance on mortgages, pensions, insurance, borrowing and savings, and for information on benefits, tax credits, grants and loans (see page 22).

Some hospitals offer health and well-being events for people affected by cancer. These provide information and support and the opportunity to meet other people in a similar situation. Ask your key worker if there are any events in your area.

It's hard to finish treatment and move on. But you learn to, and it gets easier with time and wonderful friends, family and support.

Amy

6. Talking about how you feel

It is normal to have mixed feelings at the end of treatment. You may feel relieved that treatment has finished, but worried about what will happen in the future. It may help you and your family to talk about your worries and emotions. If you would like extra support from someone outside your family, ask your GP or key worker to suggest somebody for you to talk to. This could be a counsellor, a local support group or a national support organisation (see pages 23 to 26).

Many people find online social networking a useful way of getting support. You can use our Online Community to talk to people in our forums, start your own blog, make friends and join online support groups. Visit [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

7. Trying to have a healthy lifestyle

After treatment, having a healthy lifestyle can help speed up your recovery and also improve your well-being. This includes:

- doing some gentle exercise 2 to 3 times a week, which you can build up slowly
- eating a healthy, balanced diet and keeping to a healthy weight
- stopping smoking (if you smoke)
- keeping to sensible drinking guidelines (if you drink alcohol)
- staying safe in the sun.

It is also a good idea to try and reduce the amount of stress in your life. You could try relaxation techniques and doing hobbies that you enjoy.

You can get more information from your GP practice, hospital team, local pharmacy or community or leisure centre.

8. Knowing what to look out for

You may be worried about the cancer coming back. You might also be worried about any possible late effects of your treatment. It is a good idea to talk about these concerns with your someone from your healthcare team. They can explain what signs or symptoms to look out for and who you should contact. This will depend on the type of cancer and treatment you had.

Knowing what to look out for may help you to feel more in control. It means you get the right help if you need it. Your healthcare team can also help you find ways of coping with any worries you have.





9. Being aware of your own health

Being aware of your own health and learning what is now normal for you means you are more likely to notice any changes.

Most treatment side effects start to get better when treatment finishes. But sometimes side effects may not go away, or happen months or years later (late effects). It is important to tell your cancer team if side effects do not improve or develop after treatment has ended. If you notice new symptoms or problems between appointments, contact your key worker, hospital or GP practice for advice.

You should always go to your hospital appointments and have any tests needed to check your health.

10. Sharing your experiences

Other people starting treatment may find it helpful to hear about your experience of cancer and its treatment. They may find it useful to hear how you coped, what side effects you had and how you managed them. It may also help you to feel that you are moving on by helping others.

By sharing your experience, you may also be able to improve future healthcare for people affected by cancer. This includes:

- joining a patient group or forum
- volunteering with a cancer charity
- taking part in research or answering a satisfaction questionnaire
- telling NHS staff what you think about the care you received, or the care you would like to have received.

If you want to become more involved, most hospitals have a department to help you. These are usually called Patient and Public Involvement Departments or Patient Participation Groups. Your key worker can also give you more information.

Services provided outside of treatment were crucial to my recovery. These included counselling and fitness classes and courses with other patients who understood what I was going through.

Alison

Further information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more booklets or leaflets like this one. Visit be.macmillan.org.uk or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at macmillan.org.uk/information-and-support You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also 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 us on **0808 808 00 00**.

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you would like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting [macmillan.org.uk/selfhelpandsupport](https://www.macmillan.org.uk/selfhelpandsupport)

Online Community

Thousands of people use our Online Community to meet other people going through the same things. Share your experiences, ask questions, or just read through people's posts at [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

Help with money worries

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area.

Visit [macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport) to find out more about how we can help you with your finances.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit [macmillan.org.uk/work](https://www.macmillan.org.uk/work)

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **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.

General cancer support organisations

Maggie's Centres

Tel **0300 123 1801**

Email **enquiries@maggiescentres.org**

www.maggiescentres.org

Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300** (Mon to Fri, 9am to 5pm)

Email **bacp@bacp.co.uk**

www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their 'How to find a therapist' page.

Financial support or legal advice and information

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 by contacting:

England

Helpline **03444 111 444**

www.citizensadvice.org.uk

Wales

Helpline **03444 77 2020**

www.citizensadvice.org.uk/wales

Scotland

Helpline **0808 800 9060**

www.cas.org.uk

Northern Ireland

Helpline **0800 028 1881**

www.citizensadvice.co.uk

General health information

Health and Social Care in Northern Ireland

online.hscni.net

Provides information about health and social care services in Northern Ireland.

NHS.UK

www.nhs.uk

The UK's biggest health information website. Has service information for England.

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88** (Mon to Fri, 8am to 10pm, Sat and Sun, 9am to 5pm)

www.nhsinform.scot

NHS health information site for Scotland.

Patient UK

www.patient.info

Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

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 and Analysis Service

Tel 020 7654 8000

Email enquiries@phe.gov.uk

www.ncras.nhs.uk

Tel (Ireland) 021 4318 014

www.ncri.ie

Scottish Cancer Registry

Tel 0131 275 7050

Email nss.csd@nhs.net

www.isdscotland.org/health-topics/cancer/scottishcancer-registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 029 2037 3500

Email general.enquiries@wales.nhs.uk

www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Tel 028 9097 6028

Email nicr@qub.ac.uk

www.qub.ac.uk/nicr



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 is based on content originally developed by the Consequences of Cancer Treatment collaborative (CCaT). It has been written and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Chief Medical Editor, Prof Tim Iveson, Macmillan Chief Medical Editor.

The Consequences of Cancer Treatment collaborative (CCaT) was created in 2009 by Macmillan Cancer Support and the Department of Health for England. Its purpose was to influence and improve care for cancer survivors experiencing side effects of treatment, whether shortly after treatment or in the longer term. CCaT members: Dr Jo Armes, Reader in Cancer Care and Lead for Digital Health; Dr Natalie Doyle, Nurse Consultant, Living with and Beyond Cancer; Professor Sara Faithfull, Professor of Cancer Nursing Practice, Lead for Clinical Innovation; Professor Deborah Fenlon, Professor of Nursing; Dr Diana Greenfield, Macmillan Consultant Nurse and Honorary Professor; Gillian Knowles, Cancer Nurse Consultant; Dr Karen Robb, Macmillan Rehabilitation Clinical Lead; Dr Karen Roberts; Dr Claire Taylor MBE, Macmillan Nurse Consultant in Colorectal Cancer; Dr Mary Wells, Lead Nurse for Research; Dr Isabel White, Psychosexual Therapist; and Professor Theresa Wiseman, Clinical Professor of Applied Health Research in Cancer Care.

With thanks to: Deborah Fenlon, Professor of Nursing; Louise Smith, Macmillan Cancer Information Specialist and Survivorship Lead; and Jane Wraight, Clinical Nurse Specialist.

Thanks also 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 **cancerinformationteam@macmillan.org.uk**

Sources

We have listed a sample of the sources used in the booklet below. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

European Society for Medical Oncology. Supporting self-management of patients and family members. 2019.

Macmillan Cancer Support. Providing personalised care for people living with cancer: a guide for professionals providing holistic needs assessments, care and support planning. 2019.

Maher, J et al. Implementation of nationwide cancer survivorship plans: Experience from the UK. *Journal of Cancer Policy*. 2018. Vol 15, pp 76-81.

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

Share your cancer experience

Support people living with cancer by telling your story, online, in the media or face to face.

Campaign for change

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

Help someone in your community

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

Raise money

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

Give money

Big or small, every penny helps. To make a one-off donation see over.

Call us to find out more 0300 1000 200
macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order /
Charity Voucher made payable to
Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity
Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Do not let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box.

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online
go to macmillan.org.uk/donate



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Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

This leaflet is about what to expect and where to get further support after cancer treatment ends.

The leaflet gives suggestions to help you get the best care and support available and make healthy lifestyle choices.

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**

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.

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CANCER SUPPORT**

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Patient Information Forum