

A practical guide to living with and after cancer

**WE ARE
MACMILLAN.
CANCER SUPPORT**

WHAT TO DO AFTER CANCER TREATMENT ENDS: 10 TOP TIPS



About this leaflet

After cancer treatment ends, it helps to know what to expect and where you can get further support.

This leaflet may be useful if you're coming to the end of your initial treatment or have recently finished it. The information may also be helpful if you have had cancer treatment in the past.

Here are some suggestions to help you get the best care and support available and to help you lead as healthy and active a life as possible.

Each hospital will provide care and support in a slightly different way.

In this leaflet we've included quotes from people who have finished their cancer treatment, which you might find helpful. Some have chosen to share their story with us through [macmillan.org.uk/cancervoices](https://www.macmillan.org.uk/cancervoices) and some are from our Online Community, which you can visit at [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

'When I got to the end of my treatment, I felt lost. Without Macmillan I don't think I'd be where I am today.'

Megan

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1. Discussing your needs and agreeing a plan of care

As you come to the end of your treatment, someone from your cancer team may talk to you and ask you some questions. The discussion will focus on how you're feeling, what your immediate concerns are and any worries you may have for the future. If this doesn't happen, you can ask your cancer doctor or specialist nurse to have the discussion.

The discussion is sometimes called a Holistic Needs Assessment (HNA) or an end-of-treatment assessment.

Some hospital teams use an electronic assessment tool (pictured opposite). You answer the questions on an electronic device, such as a tablet, and then talk about your answers with your healthcare professional.

The purpose of the discussion is to find out any needs and concerns you may have. This covers your physical health, emotions, spiritual health, work and family life. It can be useful for you, and your healthcare professional, to see where you may need help. It also gives you an opportunity to get information, support and a referral to other services, if appropriate.

If you know in advance when the discussion is likely to be, you could make a list of things you want to talk about. You can have someone with you during the meeting, such as a relative or friend.



An electronic Holistic Needs Assessment

The healthcare professional you talk to will probably be someone you know well from the hospital. It could be your specialist nurse, your doctor or another health professional, such as an occupational therapist, physiotherapist or dietitian. If you don't have the discussion at the end of your treatment, you can request it at a convenient time for you and your healthcare professional.

Care plan

Your healthcare professional may create a care plan with you, based on your discussion. The care plan will help you to identify any care and support that might be helpful to you in the future. It should note any concerns you talked about and any help that was suggested or is already in place. It should also list other services that may be helpful for you. These may be other NHS services, or local services run by other organisations.

Ideally, you should be given a copy of your care plan, which you can keep and update as you need to. You can discuss and develop it further at your follow-up appointments or with your GP.

Our leaflet **Holistic Needs Assessment: planning your care and support** has more information. You can order a free copy by calling **0808 808 00 00** or visiting **be.macmillan.org.uk**

2. Asking about a Treatment Summary

A Treatment Summary is a document that your hospital team may produce at the end of your treatment. It describes the treatment you've had and explains what to expect now treatment has finished. Knowing what happens next can help you adjust to life after your main treatment is over.

Your Treatment Summary will include information about possible side effects or late effects of your treatment. Late effects are side effects that do not go away after a few months, or side effects that develop months or years after treatment.

Your Treatment Summary will also include:

- any symptoms that you need to let your specialist know about.
- dates of follow-up appointments
- details about any tests or investigations you might need in the future
- contact details for your cancer team should you or your GP need to contact them.

Your Treatment Summary should be discussed with you, and you should get a copy. A copy will also be sent to your GP.

If you don't receive a Treatment Summary and would like one, you can contact your hospital team and ask if it is possible to have one.

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You can contact your GP if you have any questions about your Treatment Summary.

Your GP may contact you within six months of your diagnosis for a consultation called a Cancer Care Review. In some practices, you may see a practice nurse who has received specialist training.

If your GP doesn't contact you, you can ring your surgery and ask for an appointment.

There are contact details for support organisations on pages 17 to 19.

Our booklet **Life after cancer treatment** has more information and guidance on what to do when treatment has finished.



3. Finding your main contact

Your hospital team should give you contact details of who to get in touch with if you have any concerns about your health or possible side effects of treatment. This may be a specialist nurse, a doctor or another health professional such as an occupational therapist, physiotherapist, speech therapist or dietitian. This person may be called your key worker.

Whoever your main contact is, they should be able to tell you who can help whenever you have a concern you'd like some help with. Your GP might be your main contact. If they aren't your main contact, it's still worth telling them about any problems you need help with.

4. Being aware of any symptoms after treatment

Speak to your key worker if you have any ongoing symptoms or side effects after your cancer treatment. These could include eating difficulties, bowel or bladder problems, pain or tiredness. There are many professionals available who can suggest ways to help you manage any symptoms. Your doctor or key worker should be able to refer you to someone, if needed.

We have more information about the possible side effects of cancer treatment at [macmillan.org.uk/sideeffects](https://www.macmillan.org.uk/sideeffects)



5. Getting support with day-to-day concerns

Cancer can affect your work, relationships and finances as well as your health.

You can get confidential advice and support from a range of people and organisations to help you cope with any changes to your life. For example, you can get help from your local cancer support centre, your hospital social work department, your workplace and organisations such as Citizens Advice (see page 18).

You can contact Macmillan for financial guidance on mortgages, pensions, insurance, borrowing and savings, and for information on benefits, tax credits, grants and loans. Call the Macmillan Support Line on **0808 808 00 00** or visit **[macmillan.org.uk/talktous](https://www.macmillan.org.uk/talktous)**

Some hospitals offer health and well-being events that provide information and support. These events also give you the opportunity to meet with other people in a similar situation. Ask your main contact if there are any events in your area.

You may also be able to get support from your family and friends.

6. Talking about how you feel

It's normal to have mixed feelings at the end of treatment. You may feel relieved that treatment has finished, but anxious about what will happen in the future. It may help both you and your family to talk about your worries and emotions. If you want extra support from outside your family, you could ask your GP or key worker to suggest somebody to talk to. This could be a counsellor, a local support group or a national support organisation (see pages 18 to 19).

Many people find 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 contacts and join online support groups. Go to [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

We have more information in our booklet **Your feelings after cancer treatment** which you might find helpful. You can order a copy by calling **0808 808 00 00** or visiting [be.macmillan.org.uk](https://www.be.macmillan.org.uk)

'I had this strange notion once I finished treatment that my life would suddenly go back to how it was before. I never accounted for my emotions.'

Jules

7. Trying to lead a healthy lifestyle

After treatment, leading a healthy lifestyle can help speed up recovery and improve your well-being.

This includes:

- getting some regular exercise, which you can build up gradually
- eating a healthy balanced diet
- cutting down on the amount of alcohol you drink (if you drink alcohol)
- giving up smoking (if you smoke)
- being safe in the sun.

It's also a good idea to look at reducing stress in your life, relaxing more and having some fun.

Our booklet **Life after cancer treatment** has information on being more physically active, eating well, keeping to or getting to a healthy weight and dealing with stress.

You can get more information from places such as 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 or possible late effects of treatment that can develop months or years later. It's a good idea to discuss these concerns with your healthcare team or key worker. They can help you understand what symptoms to look out for, depending on the type of cancer and treatment you had. They can tell you when to get help and who you should contact.

They can also help you to look at ways of managing any worries you may have.

Knowing what to expect after treatment ends will help you recognise any symptoms as soon as they develop so you can get advice.

You may find our leaflet **Worrying about cancer coming back** helpful. You can order a copy by calling **0808 808 00 00** or visiting **[be.macmillan.org.uk](https://www.be.macmillan.org.uk)**

9. Being aware of your own health

Being aware of your own health and what is normal for you means you are more likely to notice a change.

Most side effects of cancer treatment are temporary and gradually get better once treatment has finished. However, some effects can last longer and may occasionally be permanent. Others can develop months, and sometimes years, after treatment. It's important to go to any hospital appointments and have any tests needed to check your health.

If new problems or symptoms develop between your appointments, or after you've stopped having regular appointments, contact your key worker, hospital or GP for advice.

'If we think about it, it's been one hell of a time and it does take a toll on our bodies physically and mentally. So I've decided to listen to my body and how I'm feeling.'

Jules

10. Sharing your experiences

Your experience of cancer and its treatment may be helpful to other people who are about to start 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're moving on or helping others.

By sharing your experiences you may also be able to influence future healthcare for people affected by cancer. Ways you can do this include:

- joining a patient group or forum
- volunteering with a cancer charity
- taking part in research or filling in 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 would like to get more actively 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 further information.



Further information and support

Cancer is the toughest fight most of us will ever face. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

Macmillan

Cancer Support

89 Albert Embankment,
London SE1 7UQ

Tel 0808 808 00 00

(Mon to Fri, 9am to 8pm)

Hard of hearing?

Use textphone

0808 808 0121,

or Text Relay.

Non-English speaker?

Interpreters are available.

Alternatively, visit

macmillan.org.uk

To order any of our
booklets, visit

be.macmillan.org.uk

or call us on

0808 808 00 00.

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Cancer Voices

www.macmillan.org.

uk/cancervoices

A UK-wide network that enables people who have or have had cancer, and those close to them, to speak out about their experience of cancer.

Other useful organisations

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300

Email bacp@bacp.co.uk

www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

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 on one of these websites:

England

Helpline 03444 111 444

Email debt.advice@citizensadvice.co.uk

www.citizensadvice.org.uk

Wales

Helpline

03444 77 2020

www.citizensadvice.org.uk/wales

Scotland

www.citizensadvice.org.uk/scotland

Northern Ireland

Helpline 0800 028 1181

Email debt.advice@citizensadvice.co.uk

www.citizensadvice.org.uk/nireland

GOV.UK

www.gov.uk

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

Healthtalk

Email

info@healthtalk.org
www.healthtalk.org
www.healthtalk.org/young-peoples-experiences
(site for young people)

Has information about cancer, and videos and audio clips of people's experiences. Also provides advice on topics such as making decisions about health and treatment.

NHS Choices (England)

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 (Scotland)

Helpline

0800 22 44 88
(Daily, 8am to 10pm)
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.



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 has been written by the Consequences of Cancer Treatment collaborative (CCaT), and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Chief Medical Editor, Dr Timothy Iveson, Macmillan Consultant Medical Oncologist. The Consequences of Cancer Treatment collaborative (CCaT) was created in 2009 by Macmillan Cancer Support and the Department of Health for England. Its purpose is to influence and improve care for cancer survivors experiencing side effects of treatment, whether shortly after treatment or in the longer-term.

CCaT members are: Jo Armes, Research Fellow Specialist Care; Natalie Doyle, Nurse Consultant for Living With and Beyond Cancer; Sara Faithfull, Professor and Director of Health Science Innovation and Enterprise; Professor Deborah Fenlon, Professor of Nursing; Diana Greenfield, Macmillan Consultant Nurse and Honorary Professor; Gillian Knowles, Nurse Consultant; Karen Robb, Macmillan Rehabilitation Clinical Lead; Karen Roberts, Chief of Nursing and Allied Health Professionals; Claire Taylor, Macmillan Nurse Consultant, Colorectal Cancer; Mary Wells, Professor of Cancer Nursing Research and Practice; Isabel White, Clinical Research Fellow in Psychosexual Practice; and Professor Theresa Wiseman, Professor of Supportive Cancer Care/Strategic Lead for Applied Health Research.

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Sources

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

Jacobs and Shulman. Follow-up care of cancer survivors: challenges and solutions. *Lancet Oncology*. 2017. 18.

Macmillan Cancer Support. University of the West of Scotland.

Assessment and care planning for cancer survivors: a concise evidence review. 2014.

Macmillan Cancer Support. Managing heart health during and after cancer treatment – a guide for professionals. 2015.

Murchie et al. Determining cancer survivors' preferences to inform new models of follow-up care. *British Journal of Cancer*. 2016. 115.

NHS Improvement. National Cancer Survivorship Initiative (NCSI).

National Cancer Survivorship Initiative (NCSI) consensus statement.

Innovation to implementation: Stratified pathways of care for people living with or beyond cancer – A 'how to guide' innovation.

Shneerson et al. A survey investigating the associations between self-management practices and quality of life in cancer survivors.

Support Care Cancer. 2015. 23.

Thomas et al. Physical activity after cancer: an evidence review of international literature. *British Journal of Medical Practitioners*. 2014. 7(1) 708.

This leaflet is for anyone who is coming to the end of their cancer treatment or has recently finished it.

It gives suggestions to help you get the best care and support available. It also gives ideas to help you lead as healthy and active a life as possible.

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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