

A practical guide to living with and after cancer

**WE ARE
MACMILLAN.
CANCER SUPPORT**

WHAT TO DO AFTER CANCER TREATMENT ENDS: 10 TOP TIPS



After cancer treatment, 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.

1. Discuss your needs and agree a plan of care

As you come to the end of your treatment, someone from your hospital team will usually talk to you about how you're feeling, how you might feel over the next few months and about any side effects you've had. This is sometimes called a holistic needs assessment or an end-of-treatment assessment. It's a good time to mention any concerns you have and to talk about any worries about the future.

Some hospital teams use an electronic assessment tool (pictured on the next page). You answer the questions on an electronic device, such as a tablet, and then have a discussion with your healthcare professional.

The purpose of the discussion is to find out any needs and concerns you may have about 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. And it gives you an opportunity to get information, support and a referral to other services, if appropriate.

Before the discussion, you may find it helpful to make a list of things you'd like to talk about. You may also want to have someone with you during the meeting, such as a relative or friend.

You can use the notes pages at the back of this leaflet to write down your questions.

Back MY HOLISTIC NEEDS ASSESSMENT

Physical concerns

(3 of 4)

If any of the problems below have caused you concern in the past week, please touch

Getting around (walking)

Tingling in hands/feet

3 out of 10

Pain

Hot flushes/sweating

Dry, itchy or sore skin

Wound care after surgery

Next

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

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 summarise any concerns you talked about during your discussion 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.

2. Ask about a Treatment Summary

A Treatment Summary is a document that may be produced by your hospital team at the end of your treatment. It will describe the treatment you've had and give you a sense of what to expect now that your 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. It will also describe any symptoms that you need to let your specialist know about. It will include dates of follow-up appointments, details about any tests or investigations you might need in the future, and 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 be given 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.

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 18–19.



3. Find your main contact

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

Whoever your main contact is, they should be able to point you in the right direction whenever you have a concern you'd like some help with. Your GP might be your main contact, but even if they're not, it's still worth telling them about any problems you need help with.

4. Be aware of any symptoms you may experience after treatment

If you have any ongoing symptoms or side effects after your cancer treatment, such as eating difficulties, bowel problems, pain or tiredness, you should speak to your cancer specialist or main contact.

There are many professionals available who can suggest ways to help you manage any symptoms. Your doctor or main contact should be able to refer you to someone, if needed.



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

5. Get 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, hospital social work department, your workplace and organisations such as Citizens Advice (see page 19).

Some hospitals offer Health and Wellbeing events that provide information and support as well as 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.



We can send you information about work and cancer and help with the cost of cancer. You can also speak to our cancer support specialists and benefits advisers on 0808 808 00 00. If you're not sure who to speak to, ask your main contact for suggestions.

6. Talk 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 main contact to suggest somebody to talk to, such as a counsellor or local support group (see pages 18–19).



You may find our booklet *Your feelings after cancer treatment* helpful.

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

You can also encourage your family and friends to get support for themselves.

'We've had a huge, life-changing shock, and it can take time for the full extent of what you've been through to present itself.'

Alison



**'When I got a bit stronger,
I made sure that I went for
a walk every day. A: Just to
get out of the house, and
B: to get a bit of exercise
and feel normal again.'**

Eileen

7. Try to lead a healthy lifestyle

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

- getting some regular exercise
- eating a balanced diet
- cutting down on the amount of alcohol you drink (if you drink it)
- 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.

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



We have more information about the benefits of doing regular exercise and eating a healthy diet at [macmillan.org.uk](https://www.macmillan.org.uk) You can also watch our videos on maintaining a healthy diet at [macmillan.org.uk/dietandlifestyle](https://www.macmillan.org.uk/dietandlifestyle)

If you prefer to read a booklet, you can order a variety of these on [be.macmillan.org.uk](https://www.be.macmillan.org.uk) or call our support line on **0808 808 00 00**.

8. Know what to look out for

You may be worried about your 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 main contact, who can tell you what to look out for. They should also be able to help you look at ways of coping with any worries you may have.



You may find our leaflet *Worrying about cancer coming back* helpful.

You may be given guidance that will help you self-manage. This means looking out for important symptoms, knowing when to get help and where to get help from. Knowing what can happen after treatment ends will help you recognise any symptoms as soon as they develop so that you can get advice.

9. Be aware of your own health

Most side effects of cancer treatment are temporary and will begin to 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 helpful to be aware of your own health and what's normal for you. If new problems or symptoms develop between your appointments, or after you've stopped having regular appointments, you should get in touch with your main contact, hospital or GP for advice.

10. Share your experiences

Your experience of cancer and its treatment may be helpful to other people who are about to start their treatment. They may find it useful to hear about how you coped, what side effects you had and how you managed them.

There are also opportunities to influence future healthcare by sharing your experiences. Ways you can do this include:

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

If you want 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 main contact can also give you further information.

'I know that when I was diagnosed, I would have liked to have talked with somebody who had been through the same experience.'

Erik



Further information and support

We have more information on cancer types, tests, treatments and living with and after cancer. We also have details of other helpful organisations and support groups in your area.

Macmillan

Cancer Support

89 Albert Embankment,
London SE1 7UQ

Tel 0808 808 00 00

(Mon–Fri, 9am–8pm)

Hard of hearing?

Use textphone

0808 808 0121,

or Text Relay.

Non-English speaker?

Interpreters 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.

Macmillan 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)

BACP House,

15 St John's Business Park,
Lutterworth LE17 4HB

Tel 01455 883 300

Email bacp@bacp.co.uk

www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services. 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. Find details for your local office in the phone book or on one of the following websites:

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 adviceguide.org.uk

GOV.UK

www.gov.uk

Has comprehensive information about social security benefits and public services.

Healthtalkonline

www.healthtalkonline.org

www.youthhealthtalk.org

www.healthtalk.org

Both websites contain information about some cancers and have video and audio clips of people talking about their experiences of cancer and its treatments.

NHS Choices

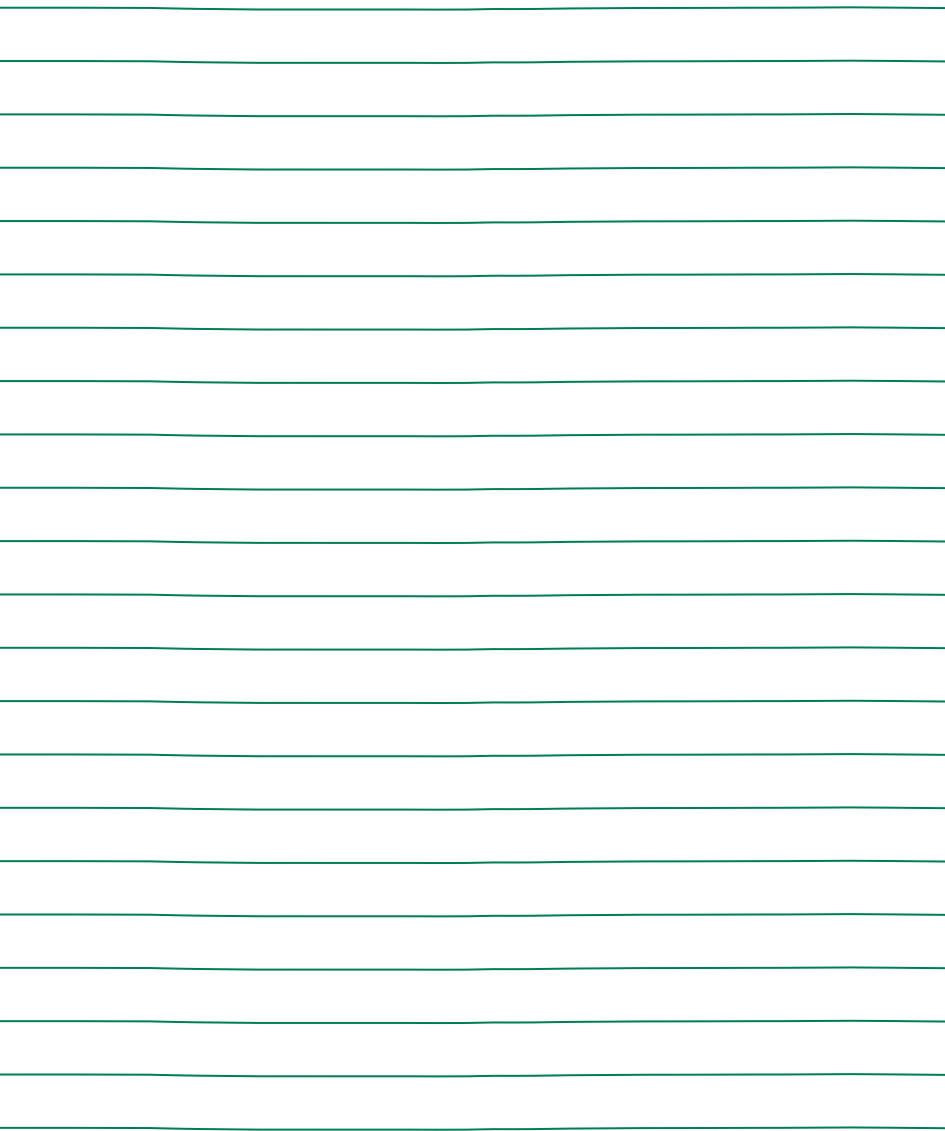
www.nhs.uk

The online 'front door' to the NHS. It's the country's biggest health website and gives all the information you need to make decisions about your health.

Patient UK

www.patient.co.uk

Provides information about health and illnesses.



Disclaimer

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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, 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 of Cancer Nursing Practice; Debbie Fenlon, Senior Lecturer; Diana Greenfield, Macmillan Nurse Consultant; Gillian Knowles, Nurse Consultant; Karen Robb, Consultant Physiotherapist for Cancer Services; Karen Roberts, Macmillan Reader and Nurse Consultant in Gynaecological Oncology; Claire Taylor, Macmillan Lead Nurse for Colorectal cancer; Mary Wells, Professor of Cancer Nursing Research and Practice; Isabel White, Clinical Research Fellow in Psychosexual Practice; and Theresa Wiseman, Strategic Lead for Health Service Research.

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Throughout this booklet we've included quotes from people who have finished their cancer treatment. They have chosen to share their experience with us by becoming a Cancer Voice.

To find out more, visit macmillan.org.uk/cancervoices

We've also used quotes from healthtalkonline.org

Some names have been changed.

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

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More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on **0808 808 00 00** (Mon–Fri, 9am–8pm) or visit **macmillan.org.uk**

Hard of hearing? Use textphone **0808 808 0121**, or Text Relay.

Non-English speaker? Interpreters available.

Braille and large print versions on request.

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