

A practical guide to living
with and after cancer

WHAT TO DO AFTER CANCER TREATMENT ENDS: 10 TOP TIPS

**WE ARE
MACMILLAN.
CANCER SUPPORT**

After 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 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.

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 talk to you about how you're feeling, how you're likely to 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.

The purpose of the discussion is to find out any needs and concerns you may have about your physical health, emotions, work and family life. It can be useful for you, and the healthcare professional doing the assessment, 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.

The person you talk to is likely to 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 could request it at your first follow-up appointment.

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.

Your healthcare professional may create a **care plan** with you, based on your discussion. The care plan will enable you to identify the care and support that might be helpful to you in the future.

The care plan should summarise any concerns you talked about during your discussion, any help that was suggested or is already in place, and possible services that may be appropriate for you. These may be other NHS services, or local services run by other organisations.

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

2. Ask about a Treatment Summary

The **Treatment Summary** is a document produced by your cancer team at the end of treatment. This will describe the treatment you've had and give you a sense of what to expect now that treatment has finished. Knowing what happens next can help you adjust to life after your main treatment is over.

There are contact details for support organisations on pages 14–15.

The Treatment Summary will include information such as the dates of follow-up appointments and details about any tests or investigations you might need in the future. It should also tell you who to contact if you have any concerns or problems.

You should be given a copy of the Treatment Summary and a copy will be sent to your GP.

Your GP is expected to see you within three months of knowing about your diagnosis for a consultation called a **Cancer Care Review**.

3. Find your main contact

Your hospital team should give you the contact details of who to get in touch with if you have any worries or concerns about your health or the possible side effects of treatment. This person can become your **main contact** or **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 post-treatment symptoms

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 your main contact.

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

We have more information about the possible side effects of treatment at macmillan.org.uk

5. Get support with day-to-day concerns

As well as your health, cancer can affect your work, relationships and finances. 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 like Citizens Advice (see page 15).

You may be able to get support from your family and friends. 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 page 12).

'Counselling is a marvellous thing, but I like to talk so talking works for me.'

George

You may find our booklet *How are you feeling? The emotional effects of cancer* helpful.

Many people find social networking a useful way of getting support. You can use our online community at **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 seek additional support for themselves.

7. Try to lead a healthier lifestyle

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

This includes:

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

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

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

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

If you'd 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 the cancer coming back or about possible late effects of treatment that can sometimes 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.

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

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, while others can develop months – and sometimes years – after treatment. It's important to go to your follow-up appointments, so that health checks can be done if needed.

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 contact your hospital, GP or main contact for advice.

10. Share your experiences

Your experience of cancer and cancer treatment may be helpful to other people with the same type of cancer who are about to start their treatment. They may find it useful to hear about how you've 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.

Your main contact can also give you further information.

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**.

'I would like to talk to other people about what they're going through. To be able to exchange ideas is so important.'

Hannah



How Macmillan can help

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

Questions about cancer?

Call free on **0808 808 00 00**

(Mon–Fri, 9am–8pm)

Alternatively, visit **macmillan.org.uk**

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

Non-English speaker?

Interpreters available.

Need more information about cancer?

Our publications about cancer types, treatments, and living with and after cancer are free to everyone affected by cancer. Visit **be.macmillan.org.uk** to order what you need, or call us.

**You can also
find all of our
information
about cancer
on our website**

Our cancer support specialists provide clinical, financial, emotional and practical information and support. Call us on **0808 808 00 00** or email us from **macmillan.org.uk/talktous**

You can also visit one of our information and support centres if you'd like to speak with someone face-to-face. Find your nearest one at **macmillan.org.uk/informationcentres**

Other support services

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

There's also advice online in a range of languages at **adviceguide.org.uk**

You can search for more organisations at macmillan.org.uk, or call our support line on 0808 808 00 00.

Your notes and questions

You can use these pages to write down any questions you want to ask your doctor or nurse, and then to write down the answers you receive.

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 medical editor, Dr Terry Priestman, Consultant Clinical Oncologist.

The Consequences of Cancer Treatment collaborative (CCaT) was created in 2009 by the UK charity 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; Theresa Wiseman, Strategic Lead for Health Service Research;

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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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Shalom M, et al. Do survivorship care plans make a difference? A primary care provider perspective. *Journal of Oncology Practice*. 2011. 7(5): 314–8.

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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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