

A practical guide to living with and after cancer

WE ARE  
MACMILLAN.  
CANCER SUPPORT

# YOUR SUPPORT AND FOLLOW-UP CARE

Helping you take an active  
role in your cancer care



## About this leaflet

This leaflet is about how you can take an active role in your care. It describes types of support that your healthcare team may call the Recovery Package.

Cancer can affect many areas of your life, and not just your physical health. During and after your cancer treatment, you may have questions about emotional, practical or financial concerns.


To make sure that you get the help you need, you can have meetings with your healthcare team to talk about any concerns you may have. Together, you can make plans about how you can get the right support.

This leaflet looks at:

- some of the support you can ask for after a cancer diagnosis
- what options may be available to you for your follow-up care, and what information you need
- ways you can look after yourself.

### Using the glossary

Some of the words used to talk about support and follow-up care can be difficult to understand. In this leaflet we have put some of these words in **bold** and explained them in the glossary on pages 20–21.



**'I'm quite an independent person and it was very important to me that I try to retain that as much as possible.'**

Shola

## Notes and questions

You can use the notes page at the back of this leaflet to write down any questions you may have for your healthcare team. You can also use this page to make notes during any appointments. This may help you to remember the discussions.

## Quotes

In this leaflet we have included quotes from people affected by cancer who have chosen to share their story with us. If you would like to share your story, visit [macmillan.org.uk/shareyourstory](https://www.macmillan.org.uk/shareyourstory)

## If you need more help

You can also discuss the information in this leaflet with our cancer support specialists:

- Call our support line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm. If you would prefer to speak to us in another language, interpreters are available.
- If you are hard of hearing, you can use textphone **0808 808 0121**, or Text Relay.

Our Online Community is a place where you can talk to others for help and support. You can also join groups related to your experiences, for example about a particular cancer type or life after cancer. Visit [community.macmillan.org.uk](https://www.community.macmillan.org.uk)

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## What types of support can I ask for?

You can always ask your healthcare team for support during and after your cancer treatment.

More and more healthcare teams are offering to arrange the steps below for people who have had a cancer diagnosis:



An assessment where you answer questions about your needs and what is important to you. The questions will be about all areas of your life. This is known as a **Holistic Needs Assessment (HNA)** (see page 8). You talk about your answers with a member of your healthcare team and work together to create an action plan of your care.



A written summary of your treatment for you to take away. This is sometimes called a **Treatment Summary** (see page 9). This summary is also sent to your GP, so you both know what has happened and what to expect after treatment.



An event where you can find out more information about healthy living or support in your local community. This is sometimes called a **Health and Wellbeing Event** (see page 10).



A discussion with your GP or practice nurse about six months after your cancer diagnosis. This is sometimes called a **Cancer Care Review** (see page 12). You can ask for an appointment to see your GP at any time during or after your cancer treatment, if you have any concerns.

Together, these conversations and plans are sometimes called the **Recovery Package**. They are aimed at improving your quality of life during and after treatment for cancer.

If you are not offered these types of support but feel any of them would be useful, you could ask your healthcare team if they can arrange them.

**Different healthcare teams may have different names for these steps. You can use the glossary on pages 20–21 to read about some terms that might be used.**

The Holistic Needs Assessment took the burden of having to remember everything, every single time. The checklist normalised everything, so any area of your life that is affected by the treatment is highlighted and can be discussed with your healthcare team.

**Adrienne**



## Holistic Needs Assessment (HNA)

A **Holistic Needs Assessment (HNA)** gives you the chance to think about your concerns and discuss possible solutions. This assessment can be useful at any time after your diagnosis. The assessment usually has three parts:

- 1** You answer a simple set of questions or checklist about all areas of your life, to see whether there are any concerns you may have. The questions may be answered on paper or electronically. It usually takes under ten minutes to complete. You are often asked to rate how mild or severe your concerns are, to help work out what needs to be dealt with first.
- 2** You have a discussion with a member of your healthcare team, to talk about the issues you have and think of possible solutions. Together, you will agree on how to deal with your concerns. This is sometimes referred to as a **care plan**. A care plan may include things like giving you information leaflets or contact details for organisations that could help with your concerns.
- 3** The member of your healthcare team writes down the plan you agreed. You will be offered a copy of this plan to take away with you. It may also be shared with other members of your healthcare team.

Our leaflet **Planning your care and support: having a holistic needs assessment** has more information.







## Treatment Summary

At the end of your treatment, your healthcare team should create a summary describing the treatment you have had. This is sometimes referred to as a **Treatment Summary**. The summary will also tell you what to expect now that your treatment has finished.

The summary should include details about:

- the cancer treatment you have had
- any tests or investigations you might need
- side effects or potential signs and symptoms you should be aware of
- contact details for your healthcare team, in case you or your GP need to contact them.

Knowing what might happen next can help you adjust to life after your main treatment is over.

You can discuss the summary with your healthcare team and they should offer you a copy to keep. A separate copy should also be sent to your GP. You may find the treatment summary useful if you want to tell others about your care. For example, you may want to use your treatment summary when applying for travel insurance.



## Health and Wellbeing Events

You may be invited to an event, where you and other people affected by cancer can find out more about healthy living and getting local support. These are sometimes called **Health and Wellbeing Events**.

These events either take place in a hospital or somewhere in the community. They usually last a few hours or half a day, and include a variety of workshops, stalls and talks.

The events can be a really good opportunity to meet other people in a similar situation. You can learn about support in your local area, and who to contact for help in the future, if you need to.

They are a chance to get information about:

- claiming benefits and other financial support
- getting back to work or education
- eating well and leading a healthy lifestyle
- the possible long-term consequences of treatment
- the emotional effects that cancer and its treatment may have, and where to seek help if you need it
- being aware of signs and symptoms that may mean the cancer has come back, and who to contact
- local services and opportunities – for example, support groups or local physical activity groups.

We have more information on the topics mentioned on this page. Call us free on **0808 808 00 00** to order the information you need.



## Cancer Care Review

This is a discussion with your GP or practice nurse. It usually happens about six months after your cancer diagnosis. This is sometimes called a **Cancer Care Review**.

The aims of the discussion are to check whether:

- you have any concerns
- you need any more information or support.

It is a chance to talk about how you are feeling, if your concerns have changed and any new worries that you may have.

You can also ask your GP about:

- the information and support available in your area
- work and benefits
- prescriptions
- getting more active.

They will either be able to help you themselves or they can find someone who can.

Your GP will discuss your cancer and the treatment you have had. They will help you understand what to look out for, what to do and when you might need to contact your healthcare team for advice.

If you and your healthcare team created a **care plan**, or have a summary of your treatment (see page 9), it is worth bringing these to your appointment with your GP.

# Supported self-management and follow-up

## What is self-management?

Self-management involves taking a more active role in your healthcare. To help you achieve this, you will have support from your healthcare team.

Self-management can include:

- learning more about your condition and how it affects your life
- eating well and keeping active
- letting your healthcare team know how you are
- knowing when you need support or information, and who or where to get it from
- being aware of possible side effects of treatment
- knowing the possible symptoms of any effects of treatment that may develop later (late effects)
- knowing the possible signs that the cancer may have come back
- planning ahead and setting goals for the future
- feeling more in control of what is happening to you.





## Help with self-management

Some people feel they don't have the confidence to be involved in managing their health. Others simply don't want to do this on their own. However, you can get training and support to help you get more involved.

Your healthcare team will be able to support you with self-management. They may know of training courses you could do. Training courses are often free. They aim to show you ways to manage your health better.

We offer courses and workshops that can support you. HOPE (Helping to Overcome Problems Effectively) is a free short course that looks at ways to manage the impact of living with and beyond cancer. We also offer a range of online courses. To find out more about HOPE and sign up for our online courses, visit [learnzone.macmillan.org.uk](https://learnzone.macmillan.org.uk)

You could also visit your local Macmillan information and support centre, if there is one near you. They can tell you whether there are local courses that could help you look after yourself. Find your nearest centre by visiting [macmillan.org.uk/inyourarea](https://macmillan.org.uk/inyourarea)

Some other organisations and support groups may also run training courses (see page 23).

'Treatment finishes but there is always a contact available. Life starts to move toward some sense of semi-normality.'

Graham

## Follow-up care

Self-management can help you at all stages of your cancer treatment. It may also mean you continue to get support and information from your healthcare team in a different way, once your treatment has finished. For example, instead of having standard follow-up appointments, you could contact your healthcare team when you need to for support.

Whether you have regular follow-up appointments or not, you will still be able to contact your healthcare team directly if you need help. For example, you might want to talk about any worries you may have about the cancer coming back. If you do not have routine appointments, you will still have any tests (such as scans or blood tests) that are needed. These tests check how you are and may help show possible problems.

### Types of follow-up care

There are three main types of follow-up care you may have. You may move between them at different times after treatment. The three types are:

- **Supported self-management** – This is where you are given information to help you self-manage. You can contact your healthcare team for help, if you need it.
- **Shared care** – This is where you continue having scheduled face-to-face, phone or email contact with your healthcare team.
- **Active management** – This is when you need more support or different care than supported self-management and shared care can provide.

## Which type of care is best for me?

The best type of follow-up care for you will depend on:

- how severely the cancer and its treatments are expected to affect you after treatment
- how well you and your healthcare team expect you to manage after treatment – this could depend on things like your personal situation and how you feel about self-management.

You will be involved in any decisions about what type of follow-up care you have. Your healthcare team can answer any questions you have. Together, you can decide what would be best for your situation.

## Tips to help you look after yourself

### Leading a healthy lifestyle

Many people affected by cancer want to make positive changes to their lives. The steps you can take to lead a healthier lifestyle can include:

- giving up smoking
- being physically active at a level that is right for you (check with your doctor if you have any concerns)
- eating a well-balanced diet
- keeping to a healthy weight
- limiting how much alcohol you drink
- learning how to reduce stress and relax more.

We have more information about making changes to your lifestyle. Your GP, hospital team, pharmacy and community or leisure centre can also help you.

## Worries about cancer coming back

You may worry about the cancer coming back or about effects of treatment that may happen later. It is a good idea to talk about these concerns with your healthcare team. They can tell you what to look out for and help you find ways of coping with your worries.

Knowing what to look out for means you can ask your doctor or healthcare team for advice early. It can also stop you from unnecessary worry.

Our booklet **Worrying about cancer coming back** has suggestions to help you manage uncertainties, worries or fears.

## Getting help and support

Cancer can affect other parts of your life, such as work, relationships and finances. You may need advice and support to help you cope. There are different people you can ask for help.

A good place to start is your GP, hospital healthcare team or a social worker. They may be able to help you directly, or refer you to someone else.

We have information and support centres all over the UK. They often have access to a benefits adviser, who can help with financial concerns. You can also speak to our cancer support specialists, financial guides and benefits advisers. Call them free on **0808 808 00 00**.

Other organisations can also provide confidential advice and support in person, such as your local Citizens Advice office (see page 23).

## Glossary

You may come across some of the terms below. Your hospital may also have its own name for some of these things.

### Cancer Care Review

A discussion with your GP or practice nurse, which takes place within six months after your cancer diagnosis. It is a chance for you both to check that you have the support you need. You can get advice about looking after yourself or find out where to get support.

### Care plan

An action plan created by you and your healthcare team after a Holistic Needs Assessment (HNA). It sets out how you will be supported now and in the future.

### Health and Wellbeing Event

This is the name sometimes given to local events for people affected by cancer. At these events, you can find out about healthy living and local support.

### Holistic Needs Assessment (HNA)

This is where you complete a questionnaire about your concerns and needs, either on paper or electronically. You then discuss your answers with your healthcare team and create a care plan.

### Recovery Package

You may hear your healthcare team use this term. It describes some conversations you may have and plans you may make with your healthcare team. It includes all of the other things described in this glossary.



**'Just knowing there are support services like Macmillan that you can access is the key.'**

Shola

### Supported self-management

This is where, after your cancer treatment, you do not have regular follow-up appointments with your healthcare team. Instead, you are given information and support to help you look after yourself.

You can still contact your healthcare team and arrange appointments whenever you need them. The idea is that you have more control. This type of follow-up care is not suitable for everyone (see pages 13–18).

### Treatment Summary

Your healthcare team creates this summary after you have finished treatment. You and your GP will both get a copy. It should be shared with other health and social care professionals in the future, to help them understand the treatment you have had.

'My consultant gave me the option of having a letter sent to me with my results, instead of going to follow-up appointments every six months. However, I think regular appointments can be useful. It's a good opportunity to discuss any problems you may have.'

**Alan**

## Further information and support

### Talk to us

You can call the Macmillan Support Line on **0808 808 00 00**. Our cancer support specialists can help with medical questions, money worries or just be there to listen if you need someone to talk to. Our free, confidential phone line is open Monday–Friday, 9am–8pm.

You can order this information for free at **be.macmillan.org.uk**. Alternatively, you can call us to order the information you need.

If you have any further questions, you can ask your GP, key worker or the doctor and nurse at the hospital where you are having your treatment.

### Related resources

We have more information about:

- leading a more healthier lifestyle
- managing the symptoms of cancer
- emotional and practical issues you may face after cancer treatment
- having a Holistic Needs Assessment (HNA).

### Cancer Voices

Cancer Voices is a UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Visit **www.macmillan.org.uk/cancervoices** for more details.



## Other useful organisations

### 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](http://www.citizensadvice.org.uk)

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

**Northern Ireland**  
[www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)  
You can also find advice in a range of languages at [www.citizensadvice.org.uk/resources-and-tools/languages](http://www.citizensadvice.org.uk/resources-and-tools/languages)

### Health and Social Care Alliance Scotland

Venlaw Building,  
349 Bath Street,  
Glasgow G2 4AA  
**Tel** 0141 404 0231  
**www.alliance-scotland.org.uk/what-we-do/self-management**  
Helps people living with long-term conditions in Scotland.

**Self Management UK**  
1A Trident Business Park,  
Dalton Avenue,  
Warrington WA3 6AX  
**Tel** 0333 3445 840  
**Email** [hello@selfmanagementuk.org](mailto:hello@selfmanagementuk.org)  
**www.selfmanagementuk.org**  
Provides and delivers free courses aimed at helping people who are living with a long-term health condition, so they can manage their condition better on a daily basis.



You can search for more organisations on our website at [macmillan.org.uk/organisations](http://macmillan.org.uk/organisations) or call us on 0808 808 00 00.





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](http://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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