

What you can do to help yourself

This fact sheet is about things you can do to help yourself when you have cancer. Doing things for yourself and becoming involved in your care and health is known as self-management. You may also hear it called supported self-management, as your healthcare team will be there to support you.

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.

You can also discuss this information with our cancer support specialists. Interpreters are available for non-English speakers. Call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you're hard of hearing you can use textphone 0808 808 0121, or Text Relay. Alternatively, visit macmillan.org.uk

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What is self-management?

Self-management is about being involved in the day-to-day management of your health. It can help you live better and can be useful when you have an illness like cancer that can affect your life for many years. Conditions like this are sometimes called chronic or long-term conditions.

Lots of people with cancer are cured or live for many years after treatment. These people are often called cancer survivors. Some people may need further treatment for the cancer at some point. Others may be living with treatment side effects or symptoms.

Your healthcare team are your doctors, nurses and other health professionals. They have experience in supporting people with cancer and can give you advice. They don't know you well as a person. So you need to tell them about your problems, concerns and needs. This way they can give you the best advice and help. And you need to let them know if things are improving for you or not.

Self-management allows you to form a partnership with your healthcare team. You can work together to make a plan of care that meets your needs. The plan will help you manage your health.

How can self-management help me?

Being involved in your care can help improve your quality of life. It can help you:

- understand your condition and how it affects your life
- make changes to your life that will help you
- know when you need help and who to get it from
- feel more in control of your life.

Self-management can help you at all stages: at diagnosis, during and after treatment, and when you're getting on with life again.

Self-management before treatment

When you are first told you have cancer, you will be given information about the cancer and the different treatment options. This will help you:

- understand what is going on
- make decisions
- plan ahead and set goals for the future.

Understanding

Your healthcare team will tell you about the cancer and what it means for you. They will explain how it affects you and the treatment options they think are best for you. Ask as many questions as you need to help you understand. You may want to write down the answers – or get someone else to write them down – so you can refer back to them later. Your healthcare team may give you some written information. If they don't, you can ask for it.

You can also get information from cancer charities like Macmillan (see pages 8–9). Many charities have helplines and websites. There is a lot of information available on the internet. Be careful to look for websites that produce reliable information. You can look for information that has the Information Standard logo on it. This means it is based on evidence and is produced according to strict guidelines.

Decision making and care planning

Being involved in decisions about your cancer, its treatment and how it affects you can give you some control. Your healthcare team will make a plan for your care and treatment. They will talk to you about your treatment options and find out how you feel about them. They can also help you with any decisions you need to make. This means that together you can make a plan that's right for you.

Having the information you need will help you make decisions. You can ask questions to help you understand what your healthcare team are offering you. You may find it helpful to read our booklet about making decisions.

Planning ahead – setting goals

Some people find it useful to think about what they want to achieve – their goals. Goals can be small and easy to achieve, or bigger and more complex. Set goals you think you can achieve and not things you'll find too difficult. As you succeed with small goals, you can set more challenging ones.

Think about something you want to change or improve as you start treatment. For example, you may want to:

- improve your diet and eat more fresh fruit and vegetables
- find someone to help you at home during treatment
- cut down or stop smoking.

Once you've decided on your goal, you can plan how best to achieve it. Ask yourself what you are going to do, when you are going to do it and what reward you will get once you have achieved it.

Think about how confident you are that you will achieve your goal. You might find it helpful to use a scale of 0–10, with 0 being not confident at all and 10 being very confident. Aim for a confidence level of around 7. If your confidence level is under 7, think about what will help, for example getting help and support from family and friends.

Not all our goals go to plan. It's a good idea to think about what to do and how to cope if things don't go as planned.

Check how you are doing with your plan regularly. If you've achieved your goals, think about setting some more. If you've had setbacks or trouble following your plan, you may need to think about changing the goals or replanning how you can achieve them.

You can set goals for the appointments you have with your healthcare team. Before you meet, think about what you'd like to talk about and what you want to get from the meeting. This can help you get the most from the appointment. Writing down some notes can help you remember what it is you want to know.

You can talk about your goals with your family and friends, who can give you support and encouragement. You can also talk to your doctor or specialist nurse so they can advise and support you.

Self-management during treatment

There are lots of ways to get involved during your treatment, such as:

- attending appointments and taking your medicines
- being aware of possible side effects of treatment and letting your healthcare team know how you are
- following the advice from your healthcare team.

Attending appointments and taking medicines

Your healthcare team will probably give you a plan of when you will have your treatment. For example, if you're having radiotherapy, your treatment may be booked at a certain time every day, Monday to Friday. Or if you're having chemotherapy you may be booked in once every couple of weeks. It's important to keep these appointments, as your treatment is planned to be as effective as possible.

If you have trouble getting to appointments on certain days, talk to your doctor or specialist nurse to make other arrangements. You may be able to have a phone appointment with the specialist nurse.

Always take any medicines you are given exactly as you have been told. This way you can make sure they work as well as possible for you.

Ask questions if you don't understand about your treatment or want more details.

Side effects of treatment

You may get side effects from your treatment. It is important to let your doctors and nurses know about any side effects you have. They can't help you unless you tell them what's going on.

You can write down any side effects as they occur, to help remind you at your next appointment. Try keeping a diary or making a note of how side effects interfere with your day-to-day life. You can use your diary to help you when you are talking to your doctor.

Your doctors and nurses can give you advice on the best way to manage any side effects. They can often prescribe drugs to help control them. You should take medicines exactly as they have been explained.

You may want to find things you can do yourself to help you manage side effects. You can ask other people who have been through similar treatment how they coped. They may have practical tips that could help you. You could speak to members of a support group or use an online forum. Macmillan has an online community at macmillan.org.uk/community

You may also like to look for different ways of managing side effects online, at your local library or cancer information centre, or by calling the Macmillan Support Line on **0808 808 00 00**.

Before trying new ways of managing side effects, talk it over with your doctor or key worker.

Following advice

Different members of the healthcare team will give you advice during your treatment. For example, you may be:

- told to avoid certain foods because they interact with your treatment
- advised on how to manage side effects if you get them
- advised to stop smoking
- given exercises to do following surgery.

When members of the healthcare team give you advice, they should explain how it will help you. If you're unsure why they have suggested something, ask them to explain it again.

It's up to you whether you follow the advice your healthcare team give you. But they are experienced in caring for people with cancer and won't suggest things that aren't likely to be helpful. If for some reason you can't follow the advice, or you need help, talk to the person who gave you the advice. You can work together to look at different possible solutions.

Self-management after treatment

Adjusting to life after treatment is sometimes difficult. You may feel happy that treatment has finished. But you may feel uncertain about the future when you won't have the support and contact with the hospital that you're used to.

During this time, becoming involved in your own care can help you feel more in control of your health. It can help you:

- adjust to life after treatment
- make positive lifestyle changes
- improve your health in mind and body
- manage any ongoing side effects of treatment
- know the possible symptoms of any late effects (consequences) of treatment
- know possible signs that the cancer has come back.

Adjusting to life after treatment

As you come to the end of treatment, your nurse or doctor will ask you how you're feeling. They will explain how you are likely to feel over the next few months and

about any side effects that may affect you. This is sometimes called a holistic needs assessment. It's a good time to mention any worries you have for the future.

You may be offered a summary of the treatment you have had and what to expect now. This tells you about any tests you may need in the future. It may also give you the dates of follow-up appointments.

Some hospitals run education and support days or health and well-being clinics to promote recovery after cancer. People are given information to help them begin to manage their health and live better after treatment. If you think this would be useful for you, ask if your hospital runs one of these days.

It's important to know who to contact if you have any concerns about your health. Your healthcare team should give you contact details of someone who will be your main contact or key worker. This is often the clinical nurse specialist.

You may find setting goals for the future helps you adjust to life after treatment. This is discussed on pages 3–4. Remember to be realistic about what you can achieve.

People recover from treatment at different speeds, so don't feel guilty if you're taking a bit longer than you thought.

You may find it useful to get some emotional support to help you adjust to life after cancer. Ask your key worker if there is someone you can talk to, such as a counsellor.

Ongoing side effects

Most side effects begin to go away after treatment ends. Some side effects can last longer and can occasionally be permanent. Potential long-term effects will be included in your treatment summary. Always let your cancer specialist or key worker know if you have side effects that are not getting better. These can include tiredness, eating difficulties, bladder and bowel problems, or pain. Together you can talk about the best way of managing your side effects. Your doctor can refer you to other specialists for further help, if needed.

We have information about managing different side effects that you may find helpful.

Lifestyle changes

A healthy lifestyle can help speed up recovery and improve your well-being. You could make changes to your lifestyle such as:

- giving up smoking
- being physically active
- eating a well-balanced diet
- keeping to a healthy weight
- sticking to sensible drinking limits
- learning how to reduce stress and relax more.

We have more information about stopping smoking, physical activity and cancer treatment, and healthy eating.

Your GP practice, hospital team, pharmacy and community or leisure centre can also provide information.

Knowing what to look out for

You may worry about the cancer coming back or about getting late effects of treatment. It's 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 for advice early. It can also stop you from unnecessary worry.

Recurrence and advanced cancer

In some situations, cancer may not completely respond to treatment. It may come back again later on (called a recurrence) or spread to a different part of the body (called secondary or advanced cancer). If this happens, you will need more information about how it may affect you. You will also need information about your options for further treatment.

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, depending on the problem. 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. You can also ask your family and friends for support. They often want to help but might not know how.

You can get confidential advice and support from a range of people and organisations. These include your local cancer support centre, your hospital social work department, your workplace and organisations like Citizens Advice (see page 8).

You can also speak to Macmillan's cancer support specialists and benefits advisers on **0808 808 00 00**.

Learning how to support yourself

Not everyone has the confidence or wants to be involved in managing their own health. But you can get training and support to help you get more involved.

Your doctor, nurse or key worker may be able to help you start self-managing. They may know of training courses you could do, such as the Expert Patients Programme (see below). Training courses are often free. They aim to show you ways to manage your health better. Some cancer organisations and support groups may also run training courses (see below).

Macmillan offers a range of courses and workshops that can support you. The HOPE course (Helping to Overcome Problems Effectively) is a free short course that looks at ways to manage the impact of living with and beyond cancer. You can read more at learnzone.macmillan.org.uk

Contact details of 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

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

Expert Patients Programme

Rutherford House, Warrington Road, Birchwood Park, Warrington WA3 6HZ
Tel 0800 988 5550

www.expertpatients.co.uk

Provides and delivers free courses aimed at helping people who are living with a long-term health condition to manage their condition better on a daily basis.

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 develop self-management policies and good practice for people living with long-term conditions in Scotland. This includes the campaign *My condition, my terms, my life*.

Self-management Support Resource Centre

90 Long Acre, London WC2E 9RA

Tel 020 7257 8000

Email info@health.org.uk

<http://selfmanagementsupport.health.org.uk>

Offers information on self-management for people living with a variety of long-term conditions.

Self Management UK

Tel 03333 445 840

Email hello@selfmanagementuk.org

www.selfmanagementuk.org

Delivers a range of self-management programmes for people with long-term conditions.

Related Macmillan information

- Controlling the symptoms of cancer
- Eating problems and cancer
- Giving up smoking
- Healthy eating and cancer
- Help with the cost of cancer
- How are you feeling? The emotional effects of cancer
- Life after cancer treatment
- Making treatment decisions
- Physical activity and cancer treatment
- What to do after cancer treatment ends: 10 top tips

For copies of this information call free on **0808 808 00 00** or visit **macmillan.org.uk**

This fact sheet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Chief Medical Editor Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to Dany Bell, Cancer Manager and Head of Operations; Natalie Doyle, Nurse Consultant; Anna Lynall, Project Co-ordinator; and the people affected by cancer who reviewed this edition.

This fact sheet has been compiled using information from a number of reliable sources, including:

- McCorkle et al. Self-management: enabling and empowering patients living with cancer as a chronic illness. *CA: A Cancer Journal for Clinicians*. 2011. 61(1).
- National Cancer Survivorship Initiative (NCSI) - Self Care/Self Management Workgroup. *Survivorship: living with and beyond cancer*. 2008.
- Scottish Government. *"Gaun Yersel!" The Self Management Strategy for Long Term Conditions in Scotland*. 2008.

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