

Your Cancer Care in Wales

Helping you understand the care and support you can ask for in Wales, wherever you have your treatment

For more information scan here



MACMILLAN CANCER SUPPORT

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About this leaflet

This leaflet has been written to help you and the people who care for you, such as your spouse, siblings, friends or neighbours, to understand what information and support is available and how you can get it. It is for people who live in Wales, wherever you have your treatment, care or support. Even if you do not have treatment, you can still ask for care and support from your healthcare team.

Please remember that some support may not be available in your area.

This leaflet includes questions you can ask your healthcare team, some tips to help you at appointments, and spaces for you to make notes and write down any other questions you have.

Thanks

This leaflet was originally created by Macmillan's Engagement and Volunteering Team. Our thanks go to the Wales Engagement Steering Group, visitors to the Royal Welsh Show, National Eisteddfod and Pembrokeshire Agricultural Show, Macmillan professionals and people from across Wales living with a cancer diagnosis. Thank you to everybody who has taken the time to share their views and experiences with us and who continue to help us review this leaflet.

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Braille and large print versions of this leaflet are free and available on request by calling the Macmillan Support Line on 0800 808 0000.

What kind of information and support can I ask for?

You can ask your healthcare team (for example your consultant, physiotherapist or clinical nurse specialist) for the following support during and after your treatment:

A Holistic Needs Assessment

You may be asked to answer questions about your needs and what is important to you.

The questions will be about all areas of your life: physical, emotional, practical, financial and spiritual. This is to make sure that your wider needs are met and is an opportunity for you to discuss what matters to you. This may be called a Holistic Needs Assessment (HNA) or an Electronic Holistic Needs Assessment (eHNA).

You should work with the team who care and support you to complete a Holistic Needs Assessment to create a plan for your care. You should be offered a copy of your care plan to take away.

You can discuss your needs with a member of the team supporting you, in a hospital or a community setting, and work together to create a plan for your care. This is called a Care Plan.

A Carer's Assessment

The people who care for you can also ask to speak to someone about their concerns, needs and what is important to them.

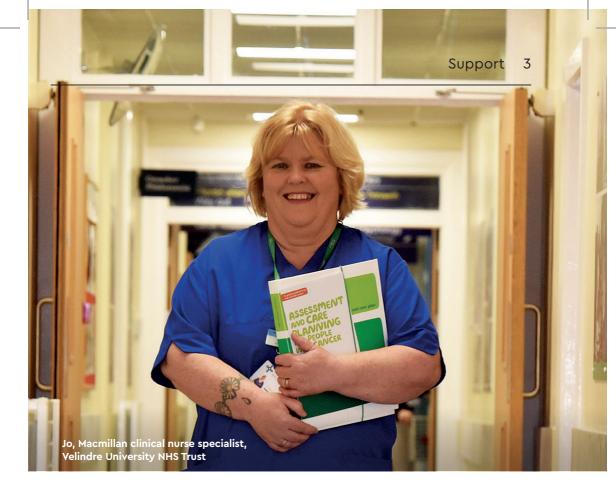
This may be a member of the team supporting you in hospital, or a carers organisation in the community. This may be called a carer's assessment

A Cancer Care Review

You may ask to have a discussion with your Primary Care Team; this could be with your GP or practice nurse after your cancer diagnosis. This is sometimes called a cancer care review. You can ask for an appointment to see your GP at any time during or after your cancer treatment if you have any concerns. You can ask for a cancer care review even if you have not had any treatment.



Cwm Taf Morgannwg Welfare Benefits Advisors Tony and Shirley



A Key Worker

You can ask for the name and contact details of somebody, usually a cancer nurse, who can help you understand what is going to happen and when. This person is often called your key worker.

Health and Wellbeing Event

You may be able to attend an event where you can find out more information about healthy living or support in your local community.

These events are open to both people living with cancer and their families and friends.

Support and information for children

You may ask anyone in your healthcare team about the information and support that is available for children who are affected by the cancer of an adult they care about. You may also want to ask their school for support.

Information about your cancer and treatments

You can ask for information about your cancer and treatment options, to help you understand what is happening, and help you make decisions.

After treatment ends

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 or explain if there is anything you should do, or not do. You can ask who to contact if you are worried. Remember that your GP will continue to support you throughout your treatment and when you are discharged from the cancer care team and are at home.

Treatment Summary

You should receive a treatment summary from your health care team team at the end of your treatment, describing the treatment you have had.

This is sometimes referred to as a treatment summary. The treatment summary is given to you and a copy is sent to your GP. The summary will also tell you about possible side effects and what to look out for in the longer term.

Side effects of treatment

You can ask for information about the common side effects and long-term consequences of cancer treatments.

Treatable but not curable cancer

Some may hear this term used by their healthcare team to describe a cancer that can be controlled, but cannot be cured. This is a cancer that can very rarely be cured but can be treated to help manage symptoms and slow down the progression of the cancer and extend people's lives.

Some people will have treatable but not curable cancer from the moment they are diagnosed. Others develop it if their cancer progresses or comes back. You may hear of these cancers being described as advanced or incurable.

Welfare Benefits Advisor

You may ask to see a Welfare Benefits Advisor who can support you and your carer to look at any financial concerns you have, including financial concerns over working with cancer, or going back to work.

Physical activity

There is evidence that keeping physically active can benefit people affected by cancer in many ways. You can start slowly at a level that's right for you, in an activity that you enjoy, and build up gradually. For more information, talk to your healthcare team.

What Macmillan Support can I ask for?

Benefits and financial information

Financial issues can cause worry when you or someone you care for becomes ill. You may be able to claim benefits, or get financial assistance from other organisations. You can ask to speak to a Macmillan welfare benefits advisor about benefits and financial information. If there isn't an advisor in your area, you can contact the Macmillan Support Line free on 0808 808 00 00. You may also speak with your healthcare team about a Macmillan grant, which is a one-off payment towards your unmet financial needs.

Cancer and work

There are Macmillan advisors in many areas who can provide advice, advocacy and information on welfare benefits and entitlements to people affected by cancer who are working, or want to get back to work.

The confidential Work Support Service is available to anyone who calls the Macmillan Support Line. The members of the Work Support Service work Mon-Fri 8am-6pm

For more information contact the Macmillan Support Line on 0808 808 00 00

Macmillan BUPA Counselling

If living with cancer gets too much and you are struggling with how you are feeling, you may be able to access our FREE specialist counselling sessions provided by BUPA. Up to six remote, specialist, one-on-one counselling sessions, are offered over the phone, or online, and are designed to help you understand, manage and overcome difficult feelings.



www.macmillan.org.uk/cancer-informationand-support/get-help/emotional-help/bupacounselling-and-emotional-well-being-support

To access BUPA counselling, you can:

- call the Macmillan Support Line on 0808 808 00 00
- enquire about the service via
 Macmillan online chat
- Refer yourself online by going to macmillan.org.uk and search for BUPA

Boots Macmillan Beauty Advisors

These are specially trained by Macmillan to give face to face advice and tips to help you cope with the visible side effects of cancer and it's treatment. They can offer lots of tips to help you look and feel more like yourself.



https://www.macmillan.org.uk/cancerinformation-and-support/get-help/macmillanservices/boots-macmillan-beauty-advisors

For more information go to www.macmillan. org.uk and search Boots, or www.boots.com/store-locator

Boots Macmillan Information Pharmacists

These pharmacists have been specially trained to understand different types of cancer and treatment, answer your questions about medication, listen to your concerns and provide emotional support, guide you to other sources of information and support, and connect you to to Macmillan services in your local area.



Visit

www.macmillan.org.uk/cancer-informationand-support/get-help/macmillan-services/ boots-macmillan-information-pharmacists

Macmillan Buddies Support

If you need to talk, we're here to listen.

Subject to an initial assessment call, we'll match you with someone who understands what you're going through, and they'll give you a weekly telephone call, video call or home visit. They can also let you know about our services, and all the ways Macmillan can help, to make sure you don't face cancer alone



www.macmillan.org.uk/cancer-informationand-support/get-help/emotional-help/ macmillan-buddies

To access Macmillan Buddies, you can:

- refer yourself online by going to www.macmillan.org.uk, and search for Macmillan Buddies
- call the Macmillan Support Line on 0808 808 00 00

HOPE and iHOPE

You may want to attend Macmillan's HOPE or iHOPE programme. HOPE stands for Help Overcome Problems Effectively. It helps people living with cancer and carers live more fulfilled lives with and beyond cancer, gain confidence in their ability to self-manage and live their lives as well as possible.



Help Overcome Problems Effectively, For more information on HOPE courses in your area, please email

ServiceOpsSupport@macmillan.org.uk



What questions can I ask my healthcare team?

You can ask your healthcare team questions about the support and information available to you. You may want to have someone with you during your appointments with your healthcare team, such as a relative or friend. You may also find it helpful to make notes during your appointments.

There is a section in the back of this booklet to help you with the questions you may want to ask and a section where you can make notes.



Glossary

You may come across some of the terms below. Your healthcare team may also have different terms for some of these things.

Holistic Needs Assessment (HNA) / Electronic Holistic Needs Assessment (eHNA)

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 plan of your care.

Care Plan

This is a plan of your care, created for you by the team who care and support you after a Holistic Needs Assessment (HNA or eHNA). It explains how you will be supported now and in the future.

Cancer Care Review

This is a chance for you to have a discussion with your GP or practice nurse to check you have the support you need. You can get advice about looking after yourself, or find out where to get support.

Carer's Assessment

This is where the people who care for you can ask to speak to someone about their needs and what is important to them. This could be a member of the team caring and supporting you in hospital, or in the community

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.

Key Worker

You can ask for the name and contact details of a key worker. You can contact this person if you have any questions or want something explained. This person is often your cancer nurse.

Macmillan Welfare Benefits Advisor

There are Macmillan advisors in many areas who can provide advice, advocacy and information on welfare benefits and entitlements to people affected by cancer.

Macmillan Support Line

Our cancer support specialists can help with medical questions, money worries, carer support, emotional support, energy advice, support with challenges you may have at work, or just be there to listen if you need someone to talk to. Call our free, confidential phone line on **0808 808 00 00**, available 8am-8pm, 7 days a week.

Treatment Summary

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

If you need more help



Macmillan Support Line

For information and support, our Macmillan Support Line cancer support specialists can help with medical questions, money worries, carer support, emotional support, energy advice, support with challenges you may have at work or just be there to listen if you need someone to talk to.

Call our Macmillan Support Line free on 0808 808 00 00, 8am-8pm, 7 days a week.



Online Community

Our Online Community is a place where you can talk to others, join groups related to your experiences and discuss the things that matter to you. Visit macmillan.org.uk/community for more information and to sign up.



For Local Information and Support in Wales

Macmillan Cancer Information and Support Centre

There may be a Macmillan Cancer Information and Support Centre at the hospital, or in the community near where you live. You, or anyone supporting you, can telephone or call in to any of our Macmillan Cancer Information and Support Centres. Call our Macmillan Support Line on 0808 800 00 00 for contact details.



Support groups

To find out about support groups, where to get information and how to get involved with Macmillan where you live, please visit macmillan.org.uk/inyourarea

Because cancer can affect your life in so many ways, we do whatever it takes to give people the support they need.

For more information and support, visit macmillan.org.uk

Questions about my care and support

Who is my key worker?
Name:
How can I contact them?
Contact details:
Who can I talk to about what matters to me and the support I need?
Name:
Contact details:
Who can the people who care for me talk to?
Name:
Contact details:
Who can I speak to about welfare benefits advice?
Name:
Contact details:

Questions about my cancer and treatment

Can I have a copy of my Care Plan?
Can I have information about my cancer diagnosis?
Can I have information about my treatment options, to help me make decisions?
Are there any common side effects, and how long will they last?
Are there any long-term side effects of treatment?

Questions about my cancer and treatment	
Can I have someone with me at appointments?	
	_
	_
Where can I park?	
	_
	_

Who can I talk to if I am worried?

What will happen after my treatment ends? Can I have information about the treatment I have been given? Is there anything I should do, or not do? Are there things I should look out for?

Questions about what happens after my treatment ends

My notes

Before your appointments you may find it helpful to make a list of things you'd like to talk about. You can also use this space to write down things like dates and times for appointments, or anything else you need to keep handy.

