

# YOUR CANCER CARE IN WALES



Helping you understand  
the care and support you  
can ask for in Wales

**MACMILLAN**  
CANCER SUPPORT

# Contents

## About this leaflet

## What type of support can I ask for?

## What type of information can I ask for?

## What questions can I ask my healthcare team?

- Questions about my care and support
- Questions about my cancer and treatment
- Questions about what happens after my treatment ends
- My notes

## Glossary

Some of the words used to talk about care and support in this leaflet may be unfamiliar to you. We've put some of these words in **bold** and explained them in the back pages.

## If you need more help

Front cover: Sharon, Macmillan Gynaecology Clinical Nurse Specialist, Betsi Cadwaladr University Health Board

Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Also operating in Northern Ireland.

**MAC16988\_0319**

## About this leaflet

This leaflet has been written to help you, and the people who care for you, 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.

Please remember that some support may not be available in your area. This leaflet includes questions you can ask your healthcare team, and spaces for you to make notes and write down any other questions you have.

**Thanks** This leaflet has been 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.

First produced in 2017. Reviewed 2018.

**Braille and large print versions of this leaflet are available on request.**

# What type of support can I ask for?

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

**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**.

**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 can discuss your needs with a member of your healthcare team and work together to create a plan for your care.

**Carer's Assessment** The people who care for you can also ask to speak to someone about their needs and what is important to them. This may be called a **carer's assessment**.

**Health and Wellbeing Event** You may ask to attend 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. These events are open to both people living with cancer and their families and friends.

**Cancer Care Review** You may have a discussion with your GP or practice nurse about 6 months 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.

**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.



**Sarah, Macmillan information and support specialist,  
Cardiff and Vale University Health Board**

## What type of information can I ask for?

**Care plan** You may work with your healthcare team to create a plan for your care. This will be based on your needs and the things that matter most to you. It will include actions to support you. You can ask for a copy of your care plan to take away with you.

**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 or 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.

### **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.

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



**Jo, Macmillan clinical nurse specialist,  
Velindre University NHS Trust**



**Treatment Summary** At the end of your treatment, your healthcare team should produce a summary describing the treatment you have had. They will send this to your GP, and you can ask for a copy to be sent to you too.

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

**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. You may also want to attend a self-management programme, such as Macmillan's HOPE programme, to help you feel more informed and confident about how to live well.

**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.

**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.



## 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.



**Rhian, cancer nurse specialist with Catherine, Macmillan cancer navigator**

# 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: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

### **Can I have a copy of my Care Plan?**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# Questions about my cancer and treatment

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 what happens after my treatment ends**

**What will happen after my treatment ends?**

---

---

---

---

---

---

# Questions about what happens after my treatment ends

Can I have information about the treatment I have been given?

---

---

---

---

---

Are there things I should look out for?

---

---

---

Who can I talk to if I am worried?

---

---

---

## 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:

A large, empty white rectangular box with a thin black border, intended for the user to write their notes. It occupies the lower two-thirds of the page.



# Glossary

You may come across some of the terms below.  
Your healthcare team may also have different terms 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's a chance for you to check you have the support you need. You can get advice about looking after yourself or find out where to get support.

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

**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.

**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) / 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.

**Key Worker** You can be given 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 or just be there to listen if you need someone to talk to. Call our free, confidential phone line on **0808 808 00 00**.

**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 some of the things described in this glossary.

**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.



**Rhian, Macmillan mobile cancer information specialist and John, diagnosed with myeloid leukaemia.**

## **Right there with you**

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** or visit **[macmillan.org.uk](http://macmillan.org.uk)**

To find out about support groups, where to get information and how to get involved with Macmillan where you live, please visit **[www.macmillan.org.uk/inyourarea](http://www.macmillan.org.uk/inyourarea)**

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](http://macmillan.org.uk/community)** for more information, and to sign up.