MACMILLAN CANCER SUPPORT

Going home from hospital

About this booklet

This booklet is about the support you can get when you go home from hospital. It is for anyone leaving hospital after cancer treatment. It may also be helpful for family members and friends.

The booklet explains:

- the care and support that can be arranged when you leave hospital
- which health and social care professionals may be involved in planning your discharge from hospital, and your care and support at home.

We hope it helps you deal with some of the questions or feelings you may have.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you. It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

If you need practical help, equipment or nursing care at home, there are people who can help you and your family. It can be difficult to remember all the different professionals you meet in hospital and at home. We have included a table on pages 40 to 41 for you to record the names and contact details of the people you may need support from.

On pages 56 to 66, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (page 67).

Quotes

In this booklet, we have included quotes from people who have left hospital after cancer treatment, which you may find helpful. These are from people who have chosen to share their story with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on**18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations.

To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Contents

Preparing to leave hospital

Most people go home when they are discharged from (leave) hospital. You may worry about how you will cope when you get home. But different health and social care professionals can give you information and support.

Each hospital has its own discharge policy. The ward manager or the hospital's Patient Advice and Liaison Service (PALS) should be able to give you a copy.

You and your healthcare team will make a discharge plan together. A family member, friend or carer can also be involved, if you want. Planning is important to make sure you get the support you need. You can talk with your healthcare team about the type of support you think you will need.

You should be fully involved with planning your discharge. But if you find it difficult to talk to professionals, an advocate can talk to them on your behalf. Advocates are independent from your healthcare team and can make sure the team knows about your wishes. The NHS website has more information about NHS advocates. Visit **nhs.uk** and search for 'advocate'.

We have more information about talking to your healthcare team on our website. Visit **macmillan.org.uk/talk-healthcare-team**

When can I go home?

Soon after you are admitted to hospital, the healthcare team will help you plan for your discharge. They will:

- assess what your needs might be when you go home
- involve team members to help meet those needs, such as a physiotherapist, occupational therapist, social worker or community nurse
- arrange for any equipment or services that you might need when you get home.

They will decide when you are likely to go home. This is called your expected date of discharge (EDD). Your EDD may change while you are in hospital.

You should only be discharged when:

- your healthcare team think you are well enough
- you have a written discharge plan describing the support you will get
- the support has been organised so you can safely manage at home.

How is care and support arranged for me?

If you are worried about how you will manage at home, tell the nurses or your keyworker as soon as possible. They can plan for your discharge. A keyworker is your main contact and source of support during your stay in hospital. They are healthcare professionals, and many of them are nurses.

If your stay in hospital was planned, you may have been given information about discharge planning before you went in. If you have a clinic appointment before going into hospital, you can tell the doctor or nurse any worries you have about going home.

You might see lots of different health and social care professionals while your discharge is being planned. You might find it difficult to remember who each person is and what they do. If you forget any details, it is always ok to ask again. We have a table where you can write down their contact details on pages 40 to 41.

Who arranges my discharge?

A hospital discharge team, ward nurse or keyworker will usually make plans for you to go home. Nurses in the ward work as a team, so you may not see the same nurses every day. But they will talk to each other about the support you need when you go home and write it in your hospital notes. They may also involve other health and social care professionals, such as a physiotherapist, occupational therapist or social worker (pages 20 to 32).

When you get home, you may need ongoing care and support from these professionals and from different organisations. A liaison nurse, hospital discharge coordinator or assessment officer will organise this.

It can take a few days or weeks to plan a discharge. This depends on the equipment and services that need to be arranged.

If you are in a private hospital, talk to your healthcare team about what care and support may be available to you when you go home. Social workers are not based in private hospitals. But if you need to discuss your needs, you can contact your local adult social services department. They may do a needs assessment (pages 9 and 10). The NHS website has more information about finding your local adult social services department (page 58).

Planning your care

Planning your care will depend on your needs. It is important that you, your family and carers are involved in these plans. Tell healthcare staff about any worries you have and the help you may need. This makes it easier for them to give you the right support.

Intermediate care (reablement)

Some people need a short period of care when they get home to help them recover and be independent. This is called home-based intermediate care or reablement. This care is paid for by the NHS and can last up to 6 weeks. Health and social care professionals can refer you for an intermediate care assessment if they think it will be helpful.

During this time, professionals support you to do things yourself. This may include goals such as:

- washing
- dressing
- preparing meals
- moving around safely.

This will be described in a care plan. The care plan will suggest a time frame to meet these goals.

They will regularly review how you are getting on. If they think you need more than 6 weeks to recover and be independent, they will refer you to local adult social care services. You will have a needs assessment to determine if you need longer-term care.

Needs assessment

While you are in hospital, the healthcare team will ask you questions to understand your needs before you go home. You will have a needs assessment if you need help with everyday activities. This may include washing, dressing and preparing meals. You will be referred to a hospital social worker for a needs assessment.

A social worker can visit you in hospital to assess the practical, financial, and social help you may need before going home. The local council will then decide if they will provide any services. Each local council has its own rules, so the services that are provided may be different depending on where you live.

It is important that you give as much information as possible. You may want a family member, carer or advocate to be with you for your assessment. It may help to talk about daily tasks and write down a list of things you find difficult. You can do this before the assessment.

An assessor should ask if there is anything that can help you, such as an interpreter. If you have sight problems, you can ask for information in large print. If you find communicating difficult, a family member, carer or advocate can speak on your behalf if you wish. They can take notes during the assessment if you are unable to.

We have more information about talking to your healthcare team at **macmillan.org.uk/talk-healthcare-team**

Questions you might be asked

- Do you live alone?
- Do you have someone who can take you home?
- Do you have family or friends who can help you when you get home?
- How do you manage personal care, such as bathing and washing?
- Do you think you can prepare your own meals at home?
- Can you manage steps or stairs, and is there a bathroom downstairs at home?
- Do you think you will need financial support?
- Do you have any pets that will need looking after?

Your needs assessment should also look at you as a person. The assessor should consider:

- how you identify and how you prefer to be addressed
- your life, family, and friends
- your interests and hobbies
- where you live and who with
- any religious or cultural needs.

Your needs may affect things like treatment decisions and food choices, so you should be involved in any decisions that are made.


NHS
SCOTLAND

Home assessment

If you need changes to your house (adaptations), you will need a home assessment. An occupational therapist (OT) will visit your house and recommend changes to help you. It is important that you are involved in decisions. You may do a home visit with the OT while you are still a hospital patient. It is important that you tell them what you find difficult. Assessments usually take at least 1 hour. Changes might include:

- putting in an outdoor ramp or step rail
- putting in a bath lift or walk-in shower
- adding a rail you can use to pull yourself out of the bath
- lowering kitchen worktops.

If you do not qualify for support, adult social care services must provide a written record of their decision with their reasons. They should provide information about other services that may be able to help you. This might include information about voluntary organisations (page 46) or local care agencies.

Your carers

If you have a carer, they should be included in the needs assessment and discharge planning. A carer gives unpaid help and support to someone with cancer, who could not manage otherwise. They might be a family member or friend.

Before you leave hospital, you and your carer can think about what help you might need at home. If your hospital stay is planned, you can discuss this with your healthcare team at your clinic appointment. You can do this before you go into hospital.

Caring can be hard work, both physically and emotionally. If someone will be looking after you when you go home, they can ask for a carer's assessment to see what support may help. Any adult who cares for another adult can have one. They will need to contact adult social services at their local council and ask for a carer's assessment. The NHS website has more information on finding your local social services team.

You might be worried about being a burden to your family, friends or carers. But support from other services means they will have the help they need to care for you. We have more information in our booklet **Looking after someone with cancer**.

You can order our booklets and leaflets for free. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Discharge plan

After the needs assessment, your healthcare team will plan your discharge. This is often called a discharge plan. It may include:

- 24-hour emergency contact details to use if you become unwell, or the person caring for you needs urgent help
- details of the treatment and support you will get from the community healthcare team when you go home
- names and contact details of who will provide the support
- any equipment and aids you need, such as a raised toilet seat
- changes made to the home, such as rails in the bathroom.

You can ask the ward staff for a copy of your discharge plan before you go home.

Holistic needs assessment

You may also have a holistic needs assessment (HNA) before going home. This is a separate assessment that is only for people with cancer, to find out what help and support they need. It can be done on paper, or online. The online version is called an eHNA.

HNAs are often done at key moments, such as at cancer diagnosis or at the end of treatment. But they can be done at any point you need one.

The questionnaire has a list of concerns. They might be:

- physical
- emotional
- practical
- financial
- spiritual.

You will be asked to give a score out of 10 for how much each concern affects you. You then talk with your key worker or another professional about these concerns.

They will make a personalised care and support plan. This should help address your concerns and provide details of other services that might help. You and your GP should get a copy of the plan.

If you are not offered an HNA, you can ask someone from your healthcare team about it.

We have more information about HNAs on our website.
Visit **macmillan.org.uk/hna**

Care plans

If your needs assessment finds that you need care and support, a care plan will be created for you. This is an agreement between the person who needs care and health and social care professionals.

Your local council must provide you with services to meet your needs. It is important that you are involved with making your care plan, and that you understand the results of any assessment. You will get a copy of the plan and have a named person to contact if there is anything you are unsure about.

A care and support plan should include:

- the type of support needed
- how this support will be given
- how much money the council will spend on your care.

Some services are paid for by the NHS or your local council. But you may need to pay for other services. You may have a financial assessment (means test) to decide if you need to pay anything. The NHS website has more information about paying for services.

Help can be provided by adult social care services or arranged with other organisations, such as charities (pages 56 to 66).

Services might include:

- meals at home – such as meals on wheels
- home care – called home-helps and personal care assistants
- someone to sit with you while your carers have some time for themselves – this is called a sitting service
- respite care for carers, to give them a break
- equipment to help with daily activities
- a laundry service for people with bladder or bowel problems (incontinence)
- advice about benefits you could get.

If you are unhappy with your care

Your healthcare team will work closely with you to make sure you have the support you need after leaving hospital. But there may be times you are unhappy about your ongoing care. Talk to your cancer doctor, specialist nurse or key worker first before you go home.

If you still need further help or advice, the hospital Patient Advice and Liaison Service (PALS) can support you.

If you are unhappy about care provided by a care agency, then talk directly with them first. If social services have arranged your ongoing care, you can also talk with a social worker at your local social services department.

Age UK has more information on raising concerns or making a complaint (page 65).

What type of support will I need?

The type of support you will need depends on the reason you have been in hospital. You might have had treatment such as surgery or chemotherapy. Or you might have been in hospital because of problems caused by cancer or its treatment. This is called symptom control.

You may need help with some or all of the following:

- personal care, such as bathing, dressing, and going to the toilet
- domestic tasks such as cooking, cleaning, and shopping
- home adaptations and equipment such as a raised toilet seat, shower seat, handrails, pressure-relieving cushions or a stair lift
- healthcare tasks such as help with dressing wounds, injections, medication or specialist support for controlling symptoms
- emotional care such as company or counselling
- money (page 52).

> “I received a Macmillan grant, which I used for equipment to make life easier when I got home. The grant helped me buy a new mattress, making me a lot more comfortable.”

Krista, diagnosed with myeloma

Which professionals will be involved in my care?

When you are in hospital you will meet different health care professionals. That may include:

- an oncologist – a doctor who treats people who have cancer
- a clinical nurse specialist (CNS) – a nurse who gives information about cancer, and support during treatment
- a surgeon – a doctor who does operations (surgery)
- a support worker – someone who works as part of a cancer care team to provide information and support for people living with cancer.

Before going home from hospital, other healthcare professionals may be involved in your care. It may help to understand what they do and how they may support you.

GP (general practitioner)

A GP is a local doctor who treats general medical conditions. They are responsible for your general healthcare. They may have been the first healthcare professional you had contact with. GPs work closely with other healthcare professionals in the community such as practice nurses, district nurses and social workers.

Your GP can:

- assess if your health has changed and do home visits if needed
- help you manage side effects and symptoms
- prescribe medicines and arrange repeat prescriptions
- give information and support
- organise district nurses, or specialist palliative care nurses, if needed
- refer you to other health professionals, such as a physiotherapist or occupational therapist (OT).

Always tell your GP if you have been in hospital having treatment for cancer. It is important to let them know if you are still having chemotherapy, radiotherapy, or other cancer treatments.

Hospital discharge letter

Before you leave hospital, your hospital doctor will send a letter called a discharge summary to your GP. The letter is usually sent electronically so that your GP gets it within 24 hours of your discharge. You are usually given a copy to take home with you.

The letter will include information about:

- your diagnosis
- the type of treatment you had in hospital
- any medicines you are taking or any changes to your medication
- the follow-up care you may need.

You should also be given telephone numbers for your hospital team in case you need to contact them. We have a table that you could use to write their contact details in (pages 40 to 41).

Your hospital team will tell you what to look out for after you go home, and when to contact them directly. It is important to follow the advice you are given.

District and community nurses

District nurses and community nurses work closely with GPs. They visit people at home to provide advice and support for patients, family members and carers.

Your ward nurse or keyworker may contact your local district nursing service before you go home to arrange a home visit. Not everyone needs this type of help. You may be well enough to go to your GP surgery to see a practice nurse, for example to have stitches taken out. If that happens, you will not need a district nurse visit.

A district nurse or a community nurse will assess your healthcare needs.

The district nurse can:

- give information to you and your carers
- provide support to keep you as independent as possible
- help you manage your medicines at home
- check on your temperature, blood pressure and breathing
- give injections, change wound dressings or remove stitches
- help with managing stomas, catheters, feeding tubes and central lines
- give advice on eating well (nutrition), looking after skin and pressure areas, and bowel or bladder problems
- refer you to other health or social care professionals you may need.

The district nurse can also arrange for equipment to be delivered. They will show you how to use it safely. This includes a:

- commode, if you have difficulty moving to the bathroom to use the toilet
- special mattress, if you have difficulty moving, or you need to spend a lot of time in bed
- bedpan, for going to the toilet in bed
- hoist or sling, if you are unable to move to and from your bed, chair or commode
- hospital bed.

Pharmacist

Pharmacists can give you information and advice about medicines. You may meet them when you are in hospital, or in your local pharmacy after you go home.

They know how medicines work, which drugs can be taken together safely and possible side effects. A pharmacist can:

- suggest other ways to take your medication, if you are finding it difficult
- suggest other things to help, like organising medicines into boxes for different times of the day
- deliver medicines to you at home
- get rid of medication you no longer need.

We have more information about taking your medicines (pages 36 to 39).


PM
AM

Occupational therapist (OT)

You may have symptoms or side effects from your cancer or treatment. Symptoms such as fatigue or numb or tingling hands or feet (peripheral neuropathy) can make everyday tasks more difficult.

We have more information in our booklet **Coping with fatigue** (page 50) and at **macmillan.org.uk/peripheral-neuropathy**

An occupational therapist (OT) can look at how you manage day-to-day activities. They may check if you need help with activities such as dressing, washing and cooking. They can suggest ways to help you. They can also arrange practical changes to make your home safe, comfortable and easy to live in.

Sometimes they need to visit your home to assess your needs. If this happens, it can be done with you, a family member or carer. Sometimes the hospital OT will ask a community OT to do this assessment when you go home.

After the assessment, the OT will give you information about adaptations, aids or equipment that might be right for you. If you agree, they can arrange any equipment you need. Adaptations to your home can sometimes take a while. You may be discharged before these are done, but only if it is safe for you.

The OT may think it would help for carers to come and help you with your personal care or preparing meals. They will refer you to a social worker who will organise this.

"We assess patients so we can see what they have trouble doing. Some may be focused on gaining strength and regaining mobility. Others may be focused on washing and dressing themselves, or returning to their hobby. „

Tara, occupational therapist

Physiotherapist

If you have problems walking or moving around (mobility) while you are in hospital, you will be referred to a physiotherapist. The physiotherapist can assess your needs. They can work with you to improve your mobility before you go home. The physiotherapist can also talk to you about moving around safely. They can give you information about how to prevent falls. They can help with exercises to:

- manage breathlessness
- manage stiffness in joints
- improve muscle strength and mobility.

If you need mobility aids such as a walking frame, they can also arrange this. Or they can give you advice about where to get them. If you need physiotherapy after going home, the physiotherapist can arrange an outpatient clinic appointment for you.

> **"I had to eat a high-calorie diet to increase my weight. I needed to build up my strength and stamina. The physios, doctors and I set realistic goals and targets."**
>
> Paul, diagnosed with tongue cancer

Your GP, or nurses in the community can arrange a referral to a physiotherapist. Some physiotherapists visit people at home.

We have more information at **macmillan.org.uk/mobility**

Social services

A social worker is responsible for assessing what practical, financial and social help you need. They are also trained in offering emotional support. A social worker may sometimes be called a care manager. While you are in hospital, you may be referred to a hospital social worker, care manager or assessment officer if you need help with:

- preparing meals
- personal care such as washing and dressing
- money.

If you are at home, you can request help yourself by contacting your local social services department. Find your local council on **gov.uk**

Dietitian

Cancer and its treatment can cause eating problems. If you have problems with your diet, your healthcare team can refer you to a dietitian. Qualified dietitians give information and advice about food and food supplements. They can provide advice on eating well when you have cancer or are having treatment. Some problems that dietitians may be able to help with include:

- loss of appetite
- weight loss
- nausea and vomiting
- taste changes.

A dietitian can:

- review your diet, taking into account any cultural, religious or special dietary requirements
- talk to you, your family, or a carer about the food you may need when you go home
- give you advice on which foods are best to help your recovery
- provide food supplements if you need them, or ask your doctor to prescribe them
- refer you to a community dietitian, who can visit you at home.

We have more information about how cancer and its treatment can cause problems with eating in our booklet **Eating problems and cancer**.

You can order our booklets and leaflets for free. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Preparing meals

If you need help to prepare meals, your family or carers may be able to help. Or you can talk to your local adult social care department. A social worker may arrange for meals to be provided to you at home. This is sometimes called meals on wheels.

This service usually has to be paid for. It may be provided by a private company or the local council. They can offer different meals to suit your cultural and religious needs, and any special dietary needs.

Continence adviser

If you are having problems with leakage (incontinence) from your bladder or bowel, it can be difficult to manage. It can also be upsetting for you.

Your district nurse will help with:

- providing information on managing problems with leakage
- supplying pads, urinary catheters or other equipment or aids
- referring you to a continence adviser if you need it.

A continence adviser is a specialist nurse or physiotherapist who gives advice and support to people with continence problems. They can assess the problem and give you advice and information about aids to manage it.

Age UK has information on how you can get free incontinence products (page 65). You may also be able to get help with laundry services. You can get more information from Bladder and Bowel UK and the Bladder and Bowel Community (page 57).

National Key Scheme for toilets

The National Key Scheme (NKS) offers disabled people access to locked public toilets across the UK. You can buy a Radar key for £5 (including postage and packaging) from Disability Rights UK – page 63. The website also has a list of NKS toilets in different regions.

Just Can't Wait toilet card

This card allows you to use toilets in shops, pubs and other places, without difficult or embarrassing questions. You can download the card to your mobile phone. The Bladder and Bowel Community has more information (page 57).

Macmillan toilet card

We have a free toilet card to help you get urgent access to a toilet. Download it from **macmillan.org.uk/toilet-card**

If I need specialist help with symptoms

Other teams can help manage your symptoms and make you more comfortable at home.

Palliative care team

A community palliative care team can provide specialist help with cancer symptoms such as pain or shortness of breath. Your GP, hospital doctor, nurse or key worker can refer you.

These teams include specialist nurses and doctors who are experts in controlling symptoms and giving emotional support. The team can also include other specialist palliative care professionals such as:

- an occupational therapist (OT)
- a physiotherapist
- a dietitian
- a social worker.

The team is usually based in a hospice, and will visit people who are being cared for at home. The team works closely with GPs, district nurses and other hospital services. Palliative care nurses help with symptom control and end-of-life care.

As well as managing symptoms, palliative care teams also care for people who are close to the end of their life.

We have more information in our booklets **Coping with advanced cancer** and **A guide for the end of life** (page 50).

Macmillan nurses

Macmillan nurses are specialist cancer nurses. They can help you to understand your cancer diagnosis and treatment options. And they can support you through your cancer experience. They can also support the people close to you. They can be based in a hospital, in a hospice or in the community.

In hospital, they might specialise in a specific cancer. These nurses are called clinical nurse specialists (CNS).

In a hospice or in the community, they help to manage symptoms and give emotional support. These specialist nurses are called palliative care nurses. Macmillan nurses do not usually give physical (hands-on) care.

Marie Curie nurse

Marie Curie nurses provide free nursing care, usually during the last weeks of someone's life. They can be specialist cancer nurses or palliative care nurses. They also provide support for carers and family.

They can stay in your home overnight or part of the day, to give the person looking after you a break. They are usually arranged by the district nurse or palliative care team. Marie Curie nurses are not available in all areas. It may also depend on the local trust or health board.

Private care nurse

Some people can get help at home from a private nurse. But this can be expensive. There are many private nursing agencies. You can ask the GP, district nurse or your local social services for advice. Check your local phone book under 'nursing agencies' or search online. The Care Quality Commission can check the standards of care in nursing agencies (page 58).

My medicines

If you need medicines when you go home, you will usually be given enough for 7 days. The discharge letter to your GP will include information about your medication (page 22).

If you carry on taking medicines after this, you will need a repeat prescription. You can usually get this from your GP. But some drugs, such as chemotherapy or other cancer drugs, can only be prescribed by your hospital doctor and collected from the hospital pharmacy.

Make sure you ask your GP surgery for your repeat prescription before your medicine runs out. This is because it can take up to 48 hours for your prescription to be ready to collect. You can also ask the GP surgery to send it straight to your local pharmacy. Some pharmacies can request regular prescriptions for you.

Prescriptions are free in Scotland, Wales and Northern Ireland. In England, prescriptions are free for people with cancer. If you need prescriptions for anything related to cancer or its effects, you can apply for an exemption certificate. You need to fill in a form called an FP92A, and get it signed by your GP.

You can collect one of these from your GP surgery or hospital clinic. Find out more by visiting **nhs.uk** and searching for 'exemption'.

If you are registered for patient online services with your GP, you can order your repeat prescription through the NHS website.

Taking your medicines

Always take your medicines exactly as they have been prescribed. This is important to make sure they work as well as possible for you.

If there is anything you are not sure about, always ask your cancer doctor, specialist nurse or pharmacist.

You should take any unused medicines back to the pharmacy.

If you find it difficult to remember when to take your different medicines, a pharmacist might organise them for you. This can also help you see if you miss a dose. The pharmacist can use one of the following:

- Dosette boxes are plastic boxes with small compartments that clearly show which tablet needs to be taken at what time of day.
- Calendar blister packs have the day and time when the medicine should be taken printed on the pack.

These are not suitable for all medicines and may not be free. They are usually prescribed by a GP following a needs assessment (pages 9 and 10). If you think dosette boxes or calendar blister packs would be helpful, talk to your hospital team.

You can also buy pill organisers without an assessment or a prescription. These are plastic boxes with compartments for different days and times of the day. If you think this would help, you, a family member, or carer can put your medicines into these.

You may take your medicines on a regular basis. Or you may have medicines to help stop or treat side effects. These medicines might be taken at a set time, or only when you need them.

We have information about different cancer treatments at **macmillan.org.uk/treatments-and-drugs**

Things you can do

You might find it helpful to use a medication app on your phone and set reminders to take your medicines.

It might help to write down the details of each of your medications, like in the example below. This can help when you need to remember the details.

Medication record

Medication (name)
Reason for taking (for example, for pain)
Instructions on how to take it (for example, with food or on an empty stomach)
When to take it (for example, morning, evening, daily or when needed)
How much to take (dose)

The Macmillan Organiser has more information and tools for recording key contacts, appointments, medication, and symptoms (page 50).

Boots Macmillan Information Pharmacist

After you have been discharged, you may have questions about your medication. Boots Macmillan Information Pharmacists are specially trained to:

- understand the different types of cancer and treatment
- answer your questions about medication
- listen to your concerns and provide emotional support.

We have more information about finding a Boots Macmillan Information Pharmacist near you. Visit **macmillan.org.uk/boots-info-pharmacists**

Oxygen treatment

Oxygen is used to help people whose oxygen levels are low all the time. It is not a treatment for breathlessness, and it is only suitable for some people. If your doctor thinks you need oxygen at home, they will refer you to a specialist. Oxygen can be given in different ways:

- If you only need oxygen for short periods of time, your doctor may recommend oxygen that is stored in a cylinder.
- If you need it for longer periods, the hospital may supply an oxygen concentrator. This is a machine that filters oxygen from the air around you.

You have the oxygen using a face mask or through small tubes that sit under the nostrils (nasal cannula).

If you want to go out once you are back at home, you can get a small moveable (portable) cylinder. If you use a wheelchair, you can have it fitted to this. If you want to travel with oxygen, there are a few things to consider. Asthma and Lung UK has more information. Search **blf.org.uk** for 'travelling with oxygen'.

Oxygen can be a fire hazard, so it is important to use it safely at home. No one should smoke or use flammable products near oxygen. E-cigarettes or vapes can also be a fire risk. Always keep the oxygen at least 3 metres away from flames and heat sources.

Key contacts

Before you are discharged from hospital, you will get a list of names and contact details to use if you are worried once you get home. Keep these somewhere safe, so you or a family member, friend or carer can use them.

It is normal to feel worried about being discharged from hospital. Making a list of the contact details of people involved in your care at home can make you feel less nervous.

You can use this table to write down the contact details of the different people who may be involved in your care at home. You may not need contact details for all of them. There are blank spaces so you can add other people's details.

Support service	What they can help with or provide	Name and contact details
Key worker (may be clinical nurse specialist)	Information, advice, and support.	Name: Tel:
GP practice	Ongoing medical care, support and prescriptions.	Name: Tel:
District nurses	Nursing care, information, advice, and support.	Name: Tel:
Occupational therapist (OT)	Practical help and equipment to make your home safe and daily tasks easier.	Name: Tel:
Physiotherapist	Help with mobility. Provide aids such as a walking frame.	Name: Tel:

Support service	What they can help with or provide	Name and contact details
Social services – care manager	An assessment of practical and social needs. Arrange services such as home care and respite care.	Name: Tel:
Dietitian	Information about eating, diet, nutrition and supplements.	Name: Tel:
Community palliative care team	Specialist care and support with symptom control, emotional support and end of life care.	Name: Tel:
Continence adviser	Specialist advice and information about aids and equipment to help you with any continence problems.	Name: Tel:

My hospital discharge checklist

You may find it helpful to use this checklist before you go home from hospital. You can tick off the things you know have been done.

☐ Do your family, friends, or carers know when you are going home?

☐ Do you have someone to take you home? Or has your hospital transport been arranged?

☐ Do you have suitable clothes to go home in?

☐ Will there be someone to meet you when you get home? Do you have keys to get in?

☐ Will there be food in the house? Will the heating be on (if needed)?

☐ Have you got your medicines?

☐ Do you know how to take your medicines or dietary supplements?

☐ Do you know when your follow-up appointment is?

☐ Do you know what care has been arranged for you when you go home?

☐ Do you have contact details for all the people who will be providing care and support?

☐ Do you know what to do if you feel unwell, or have an urgent problem or emergency?

☐ If you are having cancer treatment, do you have a 24-hour telephone number?

☐ Do you have a contact number for your hospital team or key worker?

☐ Do you have all the equipment or items you need to use at home, such as incontinence pads, stoma bags or catheter bags?

☐ Has a discharge letter been sent to your GP?

☐ Have you been given a fit note (Statement of Fitness for Work) if you need one? A fit note can help you go back to work when you are able to. You can find more information at **gov.uk**

☐ Do you know when you can return to everyday tasks, work, or exercise?

> **"When I was getting ready to leave the hospital, I was prescribed lots of painkillers and told not to lift anything heavy for 2 weeks."**
>
> Danielle, diagnosed with cervical cancer

When I get home

Your cancer doctor or specialist nurse will usually give you advice before you go home. If you had surgery, they will give you advice on looking after your wound and looking out for signs of infection. They will also give you advice on activities you should not do, such as lifting or driving.

We have more information about what happens after surgery at **macmillan.org.uk/after-surgery**

If you have had chemotherapy, radiotherapy or targeted therapy drugs, your cancer doctor or specialist nurse will explain the possible side effects.

We have more information in our booklets **Understanding chemotherapy** and **Understanding radiotherapy**, and at **macmillan.org.uk/targeted-therapy**

It is very important to follow the advice you are given by your hospital team. This includes who you should contact about any concerns. You should also know what emergency number to use if you feel unwell or have an urgent problem.

We have more information about avoiding infection and sepsis at **macmillan.org.uk/infection** and in our booklet **Cancer treatment and sepsis**. It includes how to protect yourself and when to contact your hospital team.

You can order our booklets and leaflets for free.
Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

> **“I now have time to think about what has happened. You get used to being in hospital and under care, and then suddenly all that will slow down, and appointments won't be as regular. You have time to realise: ‘Hang on... I had cancer.’ „**

Danielle, diagnosed with cervical cancer

What other support is available?

Other organisations can provide emotional and practical support when you get home from hospital.

Voluntary organisations and charities

Voluntary organisations and charities can provide support to people at home. They can also help the people close to you. The help they offer includes:

- information and support
- lending aids and equipment
- grants and other financial help and advice
- respite care for carers, so they can take a break
- counselling and support groups
- transport services
- befriending and practical help.

Your specialist nurse or keyworker should be able to tell you about local voluntary organisations and charities. You can also speak to our cancer support specialists on **0808 808 00 00**.

Counselling

You may need emotional support as well as practical help when you go home. You might feel worried or scared. It is natural to feel like this when you are not sure what is going to happen.

You might get support from family members or friends. But you may find that certain feelings are hard to share with them. It can sometimes be useful to talk to someone who has been trained to listen. Counsellors and psychologists can help you explore your feelings and talk through confusing or upsetting emotions.

If you would like to be referred to a counsellor, speak to your specialist nurse, cancer doctor or GP about this before you go home. They can refer you to a doctor, counsellor or social worker who specialises in the emotional problems that affect people with cancer.

> **"We get asked for practical information about how to support cancer patients, their family, friends, colleagues, employers, teachers and health professionals."**
>
> Karen, Macmillan Cancer Information
> and Support Officer

Support groups

After you come home from hospital, you might find it helpful to talk to others who have been through similar situations. You might find it useful to join a support group or online community. This can be a good option when you find it hard to talk to family members or friends.

Joining a support group for people affected by cancer can give you and the people close to you the chance to talk to others who understand. The nurses in the hospital may be able to give you information about local support groups. We have more information about the different types of help available. Visit **macmillan.org.uk/emotions**

You may want to join an online support group or chat room for people affected by cancer. On our Online Community, you can speak to people in our chat rooms, talk about your experiences, share your thoughts and feelings, make friends and join support groups. Visit **macmillan.org.uk/community**

A support group meeting

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

If you would like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **macmillan.org.uk/ourinfo**

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. We can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Our trained cancer information advisers can listen and signpost you to further support. Call us on **0808 808 00 00**. We are open 7 days a week, 8am to 8pm.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to **macmillan.org.uk/talktous**

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call **0808 808 00 00** and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to find out more about Macmillan Grants.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

You can also use our Ask an Expert service on the Online Community. You can ask a financial guide, cancer information nurse, work support advisor or an information and support advisor any questions you have.

Macmillan healthcare professionals

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

General cancer support organisations

Cancer Focus Northern Ireland

Helpline **0800 783 3339**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Support Scotland

Tel **0800 652 4531**
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
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.

Penny Brohn UK

Helpline **0303 300 0118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

General health information

Asthma and Lung UK

Helpline **0300 003 0555**
www.asthmaandlung.org.uk
Supports people affected by any type of lung disease.

Bladder and Bowel Community

www.bladderandbowel.org
Home Delivery Service **0800 031 5406**
Information and support for anyone affected by bladder and bowel control problems as well as their families, carers and healthcare professionals.

Bladder and Bowel UK

www.bbuk.org.uk
Helpline **0161 214 4591**
Information and support with bladder and bowel health, for anyone affected by bladder or bowel control problems.

Health and Social Care in Northern Ireland

www.northerntrust.hscni.net
Provides information about health and social care services in Northern Ireland.

NHS.UK

www.nhs.uk
The UK's biggest health information website. Has service information for England.

NHS 111 Wales

111.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline **0800 224 488**
www.nhsinform.scot
NHS health information site for Scotland.

Care Quality Commission

www.cqc.org.uk
Tel **0300 061 6161**
Independent regulator of health and adult social care in England.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

UK Council for Psychotherapy (UKCP)

Tel **0207 014 9955**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline **0300 123 3393**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**
Textphone **028 9031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Carer's Allowance Unit

Tel **0800 731 0297**
Textphone **0800 731 0317**
www.gov.uk/carers-allowance
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use the online webchat or find details for your local office by contacting:

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

Disability and Carers Service

Tel **0800 587 0912**
Textphone **0800 012 1574**
nidirect.gov.uk/contacts/disability-and-carers-service
Manages Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit in Northern Ireland. You can apply for these benefits and find information online or through its helplines.

GOV.UK

www.gov.uk
Has information about social security benefits and public services in England, Scotland and Wales.

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details online by visiting:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

https://gov.wales/find-your-local-authority

Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 1233 233**

Money Advice Scotland

Tel **0141 572 0237**
www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland.

NiDirect

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

Equipment and advice on living with a disability

British Red Cross

Tel **0344 871 1111**
www.redcross.org.uk
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK

Tel **0330 995 0400** (not an advice line)
www.disabilityrightsuk.org

Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

Living Made Easy

Helpline **0300 999 0004**
www.livingmadeeasy.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

Motability Scheme

Tel **0300 456 4566**
www.motability.co.uk
The scheme enables disabled people to exchange mobility allowances they have as part of benefits (including the enhanced rate mobility component of Personal Independence Payment) to lease a new car, scooter or powered wheelchair.

Scope

Helpline **0808 800 3333**
Textphone Use Type Talk by dialling **18001** from a textphone followed by **0808 800 3333**.
www.scope.org.uk
Offers advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

Support for older people

Age UK

Helpline **0800 678 1602**
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Live Through This

www.livethroughthis.co.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBTIQ+ cancer experiences. LTT runs a peer support group with Maggie's Barts.

Support for carers

Carers Trust

Tel **0300 772 9600**
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline (England, Scotland, Wales) **0808 808 7777**
Helpline (Northern Ireland) **028 9043 9843**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Your notes and questions

Your notes and questions

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

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

With thanks to: Diana Borthwick, Clinical Nurse Specialist; Ben Bowers, Community Palliative Care Nurse/Community Research Nurse Consultant; Karen Clayton, Clinical Nurse Specialist; Dr Denis Colligan, GP; Dr Anthony Cunliffe, GP; Jennifer Fulton, Physiotherapist; Nikki Hunter, Clinical Nurse Specialist; Diane Jones, Physiotherapist; Dr Pauline Love, GP; and Hannah Wylie, Occupational Therapist.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

Below is a sample of the sources used in our information about going home from hospital. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

National Institute for Health and Care Excellence Transition between inpatient hospital settings and community or care home settings for adults with social care needs committee. Transition between inpatient hospital settings and community or care home settings for adults with social care needs: NICE guideline [NG27]. 2015. Available from www.nice.org.uk/guidance/ng27 [accessed May 2022].

National Institute for Health and Care Excellence Intermediate care including reablement committee. Intermediate care including reablement: NICE guideline [NG74]. 2017. Available from www.nice.org.uk/guidance/ng74/chapter/recommendations [accessed May 2022].

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

1. **Share your cancer experience**
   Support people living with cancer by telling your story, online, in the media or face to face.

2. **Campaign for change**
   We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

3. **Help someone in your community**
   A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

4. **Raise money**
   Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

5. **Give money**
   Big or small, every penny helps. To make a one-off donation see over.

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Do not let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online go to **macmillan.org.uk/donate**

Registered with
FUNDRAISING
REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

MACMILLAN
CANCER SUPPORT

This booklet is for anyone who is going home from hospital after cancer treatment.

The booklet explains the support that can be arranged for you when you go home. It also has information about the healthcare professionals who may be involved in your care.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

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Creator
Patient Information Forum

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