

Getting care and support

A guide for people living with a
terminal illness and those close
to them



**Marie
Curie**

* Calls are free from landlines and mobiles. Your call may be recorded for training and monitoring purposes.

Introduction

If you're living with a terminal illness, good care and support is an important part of getting the most from your life. You should receive high-quality care and be treated with dignity and respect.

You may not know how to access care and support, or who to talk to about getting it. This booklet aims to help you start to explore your care options. It explains what types of care may be available across the UK and who to ask for help. It is written for people living with a terminal illness, as well as the people close to them, including their friends and family.

If you have specific questions about your health and care, it is best to speak to your healthcare team. This might be your GP, or doctors and nurses at a hospital.



There is more information about the topics in this booklet on our website at mariecurie.org.uk/support. You can also call the free Marie Curie Support Line on **0800 090 2309*** or use our online webchat service.

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A quick guide to getting care and support

- Care and support might be physical, emotional or practical, including financial support and help with daily tasks.
- If you are at home or in a care home, your GP is your main contact for questions about getting care and support.
- If you are in a hospital or hospice, your doctors or nurses will be your main contact for questions about care and support.
- Medical and nursing care is free on the NHS. You may also choose to pay for it privately. You may need to pay for personal care, such as help washing and dressing, depending on where you live and your situation.
- The level of care and support that is offered varies in different areas. That might mean that not everything we talk about in this booklet is available.
- It might be unclear who you should talk to about getting care and support. If you feel this way, you could call our free Support Line on **0800 090 2309***. They can help direct you to the right people.

What is palliative care?

Palliative care can be offered at any point after a terminal diagnosis. It may involve:

- managing any symptoms
- offering emotional, spiritual and psychological support
- offering practical support, including things such as planning for the future, financial help or getting equipment
- giving you a good quality of life.

Palliative care is a type of holistic care, which looks after every part of you. It aims to make sure you feel supported and comfortable, rather than cure the illness.



Philip Hardman/Marie Curie

Does having palliative care mean I'll die soon?

Although it includes end of life care, palliative care is much broader and can last for longer. Having palliative care doesn't necessarily mean that you're likely to die soon – some people have palliative care for years.

Who provides palliative care?

The professionals involved in palliative care will depend on:

- what sort of care and support you need
- where you are receiving the care and support.

Some professionals are based in the community – outside of a hospital or hospice. These professionals should be involved as early as possible after your diagnosis. They can assess your needs and wishes, and refer you to specialist care if you need it.

Other professionals are trained in providing palliative care specifically and may help to manage more complex needs. These are sometimes called specialist palliative care professionals. You may need a referral from your GP or district nurse to get support from specialist palliative care professionals.

All of the professionals involved in your care should work together. This is sometimes called your palliative care multi-disciplinary team or MDT.

We describe some of the professionals who may be involved in your care below.

GP

If you are living at home or in a care home, your GP will be your main contact for your care. Your GP may be involved with:

- prescribing your medication
- helping to manage any symptoms
- talking about your wishes and needs
- giving or telling you how you can get information about your terminal illness
- suggesting local and national support services that are available
- working with your district nurse, and the rest of your palliative care team, to make sure you are getting the right care
- telling you about local hospice care.

If you are having problems with your care, even if it's from other health or social care professionals, you can speak to your GP about it.

District nurse or community nurse

A district or community nurse can help if you cannot leave the house for appointments or treatment and need care at home. They may be involved with:

- organising care at home
- giving medical care, such as managing symptoms or changing dressings
- ordering equipment, such as a commode or adjustable bed
- arranging for other services to help with your care, such as a physiotherapist or Marie Curie Nurse.

What is palliative care?

District and community nurses coordinate lots of services, but the availability of these may vary from area to area. These can include healthcare assistants, care workers, Marie Curie Nurses, specialist nurses such as Macmillan nurses, or other care agencies. After discussing it with you, the district or community nurse will prepare a personal care plan and refer you to services which may be helpful.

Speak to your GP about getting a district or community nurse.

Pharmacist

Pharmacists are based in the community. They can support you by:

- giving out (dispensing) medication
- working with the rest of your palliative care team to help you get the right support.

Some pharmacies have palliative care pharmacists. These pharmacists are trained in palliative care and can offer more specialised support, such as advising on the management of any symptoms and suggesting local palliative care services. You could ask your GP about palliative care pharmacists in your area.

At a hospital or hospice

If you're in hospital or a hospice, the team caring for you provide palliative care. This team can include doctors, nurses, social workers, therapists, counsellors and trained volunteers.

What can you expect from palliative care?

Doctors and nurses follow guidelines about palliative care. Palliative care should be:

- based on a clear care plan that's been agreed with you (this will be made by the professionals involved in your care and should be reviewed regularly)
- kind and compassionate
- high quality and safe
- considerate of all of your needs as a person
- based on what you need and what you want as an individual
- based on honest and timely communication
- provided in the place of your choice where possible
- designed to help you stay as independent as possible
- accessible, so you get the right care whenever you need it, day or night.

Help for family and friends

Your GP, district nurse and other health professionals know it's a difficult time for partners, family and friends when someone has a terminal illness. It's part of palliative care to support the person's loved ones. They may ask your partner or other family carer how they're coping. They may also tell them about what support is available for them, now and in the future.

Talking to health professionals

It's important that you feel able to talk about your wishes and concerns with your healthcare team. Having open, honest conversations can help you get the best care.

It's not always easy to talk about terminal illness, death and dying. You and the people close to you may have a mixture of feelings and concerns. Doctors and nurses might find talking about these things difficult too. And, sometimes, talking to health or social care professionals can seem daunting. Feeling confident about what you want to say can help you to get your views across.



Philip Hardman/Marie Curie

Getting care and support

Here are some tips for having those conversations:

- Think about what you want to say, and how you want to say it, before the conversation. You could even practice in the mirror or with someone close to you.
- Be as clear as possible. It can help to keep what you say short and to the point.
- Do not be afraid to be firm about what you want. You can still be polite while expressing how important something is to you.
- Try to use confident body language, such as sitting up straight and making eye contact.
- Ask someone close to you to come with you to appointments. You might prefer to ask them to speak on your behalf, as long as they know what you want to say.
- Ask for a break if the conversation becomes too emotional for you. It can be difficult to talk about illness and your choices, so it's okay to take a step back.

Remember that you can raise issues that are not medical with your GP, doctors or nurses. It may seem strange, but it's important that they know about your needs. They may also be able to direct you to other organisations and people who can help.



You can find out more about talking to your healthcare team at mariecurie.org.uk/support or by calling our free Support Line on **0800 090 2309***.

Making decisions about your care

If you're living with a terminal illness, you may want to think about where you'd like to be cared for in the future. If you'd like information about how your illness may progress – so you know what's best for you – speak to your GP.

Choosing where you want to be cared for

You might want to think about what's important to you and how the place you'd like to be cared for will affect those things. For example, you may think about things such as being free from pain and discomfort, being near family or friends, and being in familiar surroundings.

Your health and social care professional should try to support your choices about where you want to be cared for. However, it may not always be possible to provide the care you need in the place that you would like.

Depending on your illness, your healthcare professionals may suggest different options, such as staying in your own home or moving to a care home or a family member or friend's home. They may also suggest staying in hospital or a hospice. This is so you can benefit from their specialist skills and equipment.

A hospice is a specialist centre that cares for people who are terminally ill and their families in a welcoming, comfortable environment. They have healthcare professionals on hand as well as people who can support you and your family and friends. They are run by charities and other organisations and you do not have to pay to stay there.

It may be important to you to stay in your care home or your own home with familiar people and surroundings. You can talk to your GP and district nurse and they can help you do this. They can help organise support from nurses and carers from the local council or trust if you need it. They can also give you information about equipment, benefits and local services.

You might be able to be cared for at home but visit a local hospice for appointments during the day. This is so that the hospice staff can help you with pain management, symptoms and other issues. You can also have counselling, complementary therapies and spiritual care. If it's available in your area, your GP or district nurse can tell you about it. Some hospices also have community services, where they can come and visit you in your own home.

If you have a partner, friend or family member helping care for you, they may be affected by where you choose to be cared for. If your wish is to be cared for at home, you may both want to have a chat with your GP or district nurse about what's involved.

Changing your mind about where to be cared for

Some people change their mind about where and how they'd like to be cared for if their needs change, and that's fine. For example, you might want to be cared for at home, but then decide you would be better off in a hospice or hospital.

If you change your mind, let your doctor or nurse know. They'll do their best to support you, but it may take time to make arrangements for this.

NHS continuing healthcare

NHS continuing healthcare pays for all of your care, including carers or care home fees, if:

- you're very ill **and**
- living at home or in a hospice or care home **and**
- live in England or Wales.

You must be assessed to get NHS continuing healthcare. Your doctor or nurse can organise the application process. If you think you might be eligible, speak to them. If your health is getting worse quickly and you may be nearing the end of your life, you can get it organised more quickly ('fast tracked').



Find out more about NHS continuing healthcare at mariecurie.org.uk/continuinghealthcare or call the free Marie Curie Support Line on **0800 090 2309***.

If you live in Scotland

Scotland has a different system called ‘hospital-based complex clinical care’. You can get more information about it from Care Information Scotland (see page 29).

If you're not able to make decisions

The ability to make a decision is called ‘mental capacity’. If you lose mental capacity, other people can make decisions for you. There are rules in place to make sure they act in your best interests.

It can be useful to plan what you want to happen if you lose capacity to make your own decisions in the future. Here are a few things you could consider:

- Setting up a lasting health or welfare Power of Attorney (LPA). This is a way of choosing someone who you want to make decisions about your health and social care on your behalf. This could be a friend, relative or a professional. It's currently available in England, Wales and Scotland.
- Making an advance care plan (or anticipatory care plan). This allows you to tell people how you want to be cared for in the future. It's a good idea to discuss your plans with your family or friends, and your doctor or nurse.

If you lose mental capacity and you haven't given anyone Power of Attorney, there are other options for people to make decisions on your behalf. This might include setting up a deputy in England or Wales, a controller in Northern Ireland, or a guardianship order in Scotland.

Making decisions about your care

If someone doesn't have a friend or family member to represent them, the NHS or local council or trust can appoint an independent mental capacity advocate:

 Find out more about mental capacity and planning ahead on our website at mariecurie.org.uk/planningahead. You can also order our free booklet, **Planning ahead**, from the website or through the Marie Curie Support Line on **0800 090 2309***.



Philip Hardman/Marie Curie

Care at weekends and at night

If you're living at home with a terminal illness, it can be reassuring to know what to do if you need a doctor or nurse when your GP surgery is closed.

You may have been given a specific number to call if you need support – for example, to get hold of your district nurse or community nursing team. Keep this to hand and share it with people close to you if needed.

In England, Scotland and Wales

If you live in England, Scotland or Wales and your GP surgery is closed, call **111**.

The 111 helpline is open 24 hours a day, seven days a week. They can suggest local services to support you, and connect you to a GP, nurse or pharmacist if you need it.

In Northern Ireland

If you live in Northern Ireland, call your GP surgery. If your GP surgery is closed, you'll be directed to an out-of-hours service.

You can also find the number for your local out-of-hours service at nidirect.gov.uk.

If you need emergency care

If you have a medical emergency at any time, call **999** for an ambulance.

Personal and social care

If you need help with everyday activities, such as getting washed and dressed, you may be able to get social care and support from the local council or trust. You can get this type of support even if someone close to you is taking care of you.

The local council or trust can arrange for paid carers to come to your home. This can take time and may be for set hours – for example, paid carers may only be able to visit between one to four times a day.

Arranging a needs assessment

You must have a needs assessment to find out what support can be offered. You can:

- contact your council or trust directly and ask for one
- ask your GP or district nurse to help arrange it.

The assessment can also cover adjustments to your home to make things easier for you. For example, you may need grab rails or an adapted shower.

If you're assessed as needing social care, the council or trust can organise it for you.

How much does personal and social care cost?

Whether you pay some of the cost depends on what services are available in your area. It can sometimes depend on how much money or savings you have.

If you live in England, Wales or Northern Ireland

In England, Wales and Northern Ireland, personal care is means-tested. This means that whether you pay towards your care depends on how much you have in savings.



Layton Thompson/Marie Curie

You may have an assessment that shows you need adaptations to your home. Some of these might be paid for:

- by your local council or trust
- by a grant – this is called a Disabled Facilities Grant in England, Wales and Northern Ireland.

If you live in Scotland

In Scotland, personal care is free. This free care covers things like help with washing or going to the toilet, and preparing and eating food.

If you have an assessment that shows you need adaptations to your home, some of these might be paid for:

- by your local council
- by a grant – this is called a Mandatory Grant in Scotland.



We have more information about care assessments and financial help for equipment and adaptations on our website at mariecurie.org.uk/support. Or you can call the Marie Curie Support Line on **0800 090 2309***.

Private care options

If you're able to pay for care, you can arrange different types of care privately, including a nurse or a carer.

The UK Homecare Association (see page 32) is the professional association for homecare providers and offers information about using agencies. You can contact them to find a local homecare agency.

You can also employ a carer directly rather than through an agency. If you do this, you pay their National Insurance and pension contributions. Age UK (see page 29) has factsheets on employing and paying for home carers.

Questions to ask private carers

You may want to compare several agencies. When you speak to them, you might ask questions such as:

- Have you cared for someone with similar needs to mine?
- What sort of training do your carers receive?
- What happens if my regular carer is sick or on holiday?

Benefits and finances

We know that the cost of having a terminal illness can be worrying. But there is a lot of financial support available to help you deal with any costs. These are the main benefits you might be able to claim:

- Attendance Allowance is for people who are over State Pension age, have a disability and need help caring for themselves.
- Personal Independence Payment (PIP) is for people who are aged 16 or over and have not reached State Pension age, have a disability or health condition and need help with daily living and getting around.
- If you're under State Pension age and not able to work, you may be able to claim Employment Support Allowance (ESA) or Universal Credit.
- Carer's Allowance is for people who regularly spend at least 35 unpaid hours a week caring for someone with substantial needs.

If you're living with a terminal illness, you may be able to get your claim fast-tracked and paid at the highest rate. This is usually if you're not expected to live more than six months. It doesn't apply to all benefits. Your doctor will need to fill in a report called a DS1500 form.



There are other benefits available. For more information about benefits, visit our website at mariecurie.org.uk/benefits. You can also contact Citizens' Advice and other organisations (see page 30).

Who to contact about benefits

If you live in England, Scotland or Wales

The Department for Work and Pensions (DWP) deals with most benefits. For help and to apply for specific benefits, use the telephone numbers below or visit [GOV.UK](https://www.gov.uk).

- Attendance Allowance: **0800 731 0122**
(textphone **0800 731 0317**).
- Carer's Allowance: **0800 731 0297**
(textphone **0800 731 0317**).
- Personal Independence Payment: **0800 121 4433**
(textphone **0800 121 4493**).
- Employment and Support Allowance: Contact the Jobcentre Plus on **0800 169 0310**
(textphone **0800 169 0314**).
- Universal Credit: **0800 328 5644**
(textphone **0800 328 1344**).

If you live in Northern Ireland

For help and to apply for specific benefits, use the telephone numbers below or visit nidirect.gov.uk.

- Attendance Allowance and Carer's Allowance: **0800 587 0912** (textphone **0800 012 1574**).
- Personal Independence Payment: **0800 012 1573** (textphone **0800 587 0937**).
- Employment Support Allowance Centre: **0800 085 6318** (textphone **0800 328 3419**).
- Universal Credit: **0800 012 1331** (textphone **0800 012 1441**).

Changes to benefits

The benefits that are available and who is eligible for them may change. For the most up-to-date information, please visit mariecurie.org.uk/benefits or call our Support Line on **0800 090 2309***.

Making a complaint about your care

If you are unhappy about your care, it's your right to make a complaint. Some people are reluctant to complain because they think it might affect their care. This shouldn't happen and the organisation that's providing care needs to hear when things aren't going well so it can improve its services.

If you're a family member, friend or someone else complaining on behalf of someone with a terminal illness, talk to them first to check they agree with your complaint.

Talking about the problem as soon as possible may give people a chance to set things right quickly. Speak to a member of staff where the problem happened. If they're not the right person to talk to, ask who you should be talking to.

If informally talking about a problem doesn't address your concerns, ask for a copy of the organisation's formal complaints procedure. Every NHS service, local council or trust, care home or other care provider should have one.

If you're not satisfied after making a formal complaint you can take the matter further. There are different procedures for this, depending on where you live in the UK. It also depends on whether your complaint is about health or social care.

If you want support to make a complaint, there are organisations that can help you (see pages 30–31).

Support for carers

If you have a partner, friend or family member who is looking after you, they can get a carer's assessment from the local council or trust. In Scotland, this is called an Adult Carer Support Plan. As a minimum, they will be given information about local services for carers including benefits, respite care (to care for you while they have a break from caring) and support groups.

At the assessment, the council or trust will ask questions to find out what effect caring is having on the person's health and wellbeing. If the assessment finds they need support, the council or trust will provide it. For example, they might give the person training in how to care for you, or provide help with housework and transport.

Carers UK (see page 30) has further information about carer's assessments.

Support for carers at work

If they're working as well as caring for you, they're protected from discrimination at work. They can also ask for flexible working if they've been working continuously for the same employer for 26 weeks.

They can get more information about their rights as a carer from Citizens Advice and Carers UK (see page 30).

Benefits and financial support for carers

They may be entitled to the benefit Carer's Allowance (see page 21).



Find out more at mariecurie.org.uk/carers or call the Marie Curie Support Line on **0800 090 2309***.



Philip Hardman/Marie Curie

How Marie Curie can help

Marie Curie is here for anyone with an illness they're likely to die from, and those close to them. Whatever the illness, wherever you are, we're with you to the end.

Marie Curie Support Line

0800 090 2309*

Our free Support Line is for anyone with an illness they're likely to die from and those close to them. Our team, including nurses and specialist Energy Support Officers, offers practical and emotional support on everything from symptom management and day-to-day care to financial information and bereavement support. Our Support Line is available in over 200 languages, or via webchat at mariecurie.org.uk/support. Open between 8am to 6pm from Monday to Friday, and 11am to 5pm on Saturday.

Marie Curie Companions

Companion volunteers focus on what's important to you and those close to you. It might be accompanying you to appointments, being there to listen to how you're feeling without judgment, or stepping in so family or carers can take a break. Companions provide the emotional and practical support you want - at home, in hospital or over the phone.

mariecurie.org.uk/companions

Marie Curie Telephone Bereavement Service

Get ongoing bereavement support over the phone from the same volunteer. You can access up to six sessions of 45 minutes. We can help if your bereavement was expected, happened recently or was some time ago.

mariecurie.org.uk/bereavement

* Your call may be recorded for training and monitoring purposes.

Marie Curie Online Community

Our Online Community is a space for you to share thoughts, feelings and experiences. It's moderated by the Marie Curie Support Line team, who can also help answer your questions.

community.mariecurie.org.uk

Marie Curie Hospice care where it's needed

Our hospices

Our hospices help people with any illness they're likely to die from, and the people close to them, receive the support they need. From medical and physical support to psychological and emotional care, whatever your illness, at whatever stage of the journey, we help you to live the best life possible, right to the end.

mariecurie.org.uk/hospices

Hospice care at home

Our nurses, healthcare assistants and other healthcare professionals bring the clinical, practical and emotional help you need to you, in the comfort of your own home. And we offer support to the people close to you too - from reassurance and practical information to letting them take a break.

mariecurie.org.uk/nurses

Looking for more information?

If you found this booklet useful, we have free information available online at mariecurie.org.uk/support or to order at mariecurie.org.uk/publications

Useful organisations

Age UK

0800 678 1602

ageuk.org.uk

Has a network of local branches that aims to help older people make the most out of life. Offers a befriending service and sometimes loans out wheelchairs.

Age Scotland

0800 12 44 222

ageuk.org.uk/scotland

The national branch of Age UK for Scotland.

Age Cymru (Wales)

029 2043 1555

ageuk.org.uk/cymru

The national branch of Age UK for Wales.

Age NI

0808 808 7575

ageuk.org.uk/northern-ireland

The national branch of Age UK for Northern Ireland.

Care Information Scotland

0808 011 3200

careinfoscotland.scot

Can help you find care, get care services, and get support for carers.

Carers UK

0808 808 7777 (England, Wales and Scotland)

028 9043 9843 (Northern Ireland – you can also use the number above)

carersuk.org

Provides information and support to carers, including benefits advice.

Citizens Advice

0800 144 8848 (England)

0800 702 2020 (Wales)

0800 028 1456 (Scotland)

03454 04 05 06 (Consumer rights helpline)

citizensadvice.org.uk

Citizens Advice provides information about benefits, housing and employment, debt, consumer and legal issues. Search the site for your nearest bureau in England, Wales, Scotland and Northern Ireland, or call one of the helplines.

Court of Protection

GOV.UK/court-of-protection

Makes decisions on financial and welfare matters for people who lack mental capacity.

NHS Complaints Advocacy

nhscomplaintsadvocacy.org

0300 303 1660

This is a free and independent service that can help you make a complaint about the NHS. The website has information about the complaints process and you can get further support by calling the helpline.

Office of the Public Guardian

[GOV.UK/office-of-the-public-guardian](https://www.gov.uk/office-of-the-public-guardian)

0300 456 0300

Protects people in England and Wales who may not have mental capacity to make decisions.

Patient Advice and Liaison Service (PALS) (England and Wales)

Offers free confidential advice, information and support on any health-related matter. You can access PALS through your local hospital in England and Wales, or by calling **111**.

Patient Advice and Support Service (PASS) (Scotland)

cas.org.uk/patientadvice

0800 917 2127

A free, independent service that provides confidential information, advice and support to anyone who uses the NHS in Scotland.

Patient and Client Council (Northern Ireland)

patientclientcouncil.hscni.net

0800 917 0222

An independent organisation that can help you make a complaint about health or care services in Northern Ireland.

Scottish Independent Advocacy Alliance (SIAA)

siaa.org.uk/find-an-advocate

0131 510 9410

Can help you find an independent or non-independent advocate. The website also has some useful leaflets and videos about how independent advocacy can help.

Turn2Us

turn2Us.org.uk

0808 802 2000

A national charity that provides information on finances, services and grants.

UK Homecare Association

ukhca.co.uk

020 6881 8188

The professional association for homecare providers.

About this information

This booklet was produced by Marie Curie's Information and Support team. It has been developed with people affected by terminal illness, and health and social care professionals.

If you'd like the list of sources used to create this information, please email review@mariecurie.org.uk or call the free Marie Curie Support Line on **0800 090 2309***.

Notice

The information in this publication is provided for the benefit and personal use of people with a terminal illness, their families and carers.

This information is provided as general guidance for information purposes only. It should not be considered as medical or clinical advice, or used as a substitute for personalised or specific advice from a qualified medical practitioner. In respect of legal, financial or other matters covered by this information, you should also consider seeking specific professional advice about your personal circumstances.

While we try to ensure that this information is accurate, we do not accept any liability arising from its use. Please refer to our website for our full terms and conditions.

Did you find this information useful?

If you have feedback about this booklet, please email us at review@mariecurie.org.uk or call the free Marie Curie Support Line on **0800 090 2309***.

Marie Curie

Marie Curie is the UK's leading end of life charity. Whatever the illness, wherever you are, we're with you to the end.

0800 090 2309*

Marie Curie provides free support over the phone in over 200 languages, and via webchat, to anyone with an illness they're likely to die from and those close to them.

Our team, including nurses and specialist Energy Support Officers, offers practical and emotional support on everything from symptom management and day-to-day care to financial information and bereavement support. Visit mariecurie.org.uk/support

We also have an Online Community where you can share thoughts, feelings and experiences at community.mariecurie.org.uk

We can't do it without you

Our free information and support services are entirely funded by your generous donations. Thanks to you, we can continue to offer people what they need, when they need it.

To donate, visit mariecurie.org.uk/donate

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