

Care and support during coronavirus (covid-19)

Information for people living with a terminal illness, and their family and friends

Summer 2020



**Marie
Curie**

Care and support
through terminal illness



Philip Hardman/Marie Curie

This booklet is for people living with a terminal or life-limiting illness, and their family and friends. You might be thinking about what care and support is available during the coronavirus situation. You may also be thinking about how to protect yourself from coronavirus.

If you have any questions about your care or local services, speak to your GP or another health or social care professional. You can also contact the Marie Curie Support Line to speak to a nurse or trained staff member on **0800 090 2309*** or webchat at **mariecurie.org.uk/support**. This service is free for everyone across the UK – you don't need to have accessed Marie Curie's nursing or hospice services to contact us.

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

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Palliative and end of life care

If you have a terminal illness, you might have lots of questions or worries about what kind of support you can get. During the coronavirus situation, some services may be working differently but there is still help available to get the care you need.

What care might I need?

When you have a terminal or life-limiting illness, you might benefit from **palliative care**. This can involve:

- managing physical symptoms such as pain or breathlessness
- emotional, spiritual and psychological support
- social care, including help with things like washing, dressing or eating
- support for your family and friends.

Palliative care includes caring for people who are nearing the end of life – this is sometimes called **end of life care**. But palliative care can also be helpful at any time in your illness, including alongside other treatments.

Where can I receive care?

There might be different options for where you can receive care. Hospices, care homes and hospitals may have restrictions on visiting because of the coronavirus situation. And some of their usual services might not be available. You might want to check this before you make a decision.

Health and social care professionals should try to support your preferences about where you want to be cared for. But it's not always possible to provide the care you need in the place that you would like.

Care at home

If you're living at home, your GP is responsible for your healthcare. If you're not able to leave your home, the GP may organise for district or community nurses to visit and help with things like taking medication and managing symptoms.

If you need more support to manage your symptoms, the GP or district nurse may organise for a specialist palliative care team to help. This may include support from hospices or charity organisations.

If you need help with day-to-day tasks, such as eating, washing or dressing, this is sometimes called **social or personal care**. Your district or community nurse may be able to help organise this. You can also contact your local council or trust directly to ask for support from social services.

In some areas of the UK, Marie Curie nurses and healthcare assistants can help with your care at home, usually in the last weeks of life. Speak to your GP to see if this is available.

Hospice care

Hospices provide specialist nursing and medical care and can help to manage symptoms that are difficult to control. Hospices also offer social, practical, emotional and spiritual support. Some people stay in the hospice. But hospices also give support to people staying at home – this may be face-to-face or on the phone.

Hospital care

If you become unwell or need tests or treatment, your GP or other healthcare professional may advise you to go into hospital.

Care homes and nursing homes (residential care)

In a care home, the staff are professional carers, but they're not nurses. They provide help with washing, dressing and providing meals. A nursing home is similar to a care home, but there are also trained nurses on duty.

Not sure who to ask for help?

Speak to your GP about getting help with your healthcare needs. If you need help with day-to-day life or social care, your GP or district nurse may help organise this. You can also contact social services through your local council or, in Northern Ireland, your health and social care trust.

Paying for care

Medical and nursing care is free in the UK – this includes all care provided by the GP, district or community nurses, and hospices.

Personal care or social care is sometimes free, but you may have to pay for some or all of it. This may include paying for care home or nursing home fees. Check with your health or social care professional or contact your local council or trust. You may want to pay for additional care on top of what you can get for free, if this is an option for you.

How is care affected by coronavirus?

The care that's available may be different from normal. However, support is still available, and you should still ask for help if you need it.

It may feel unsettling or worrying if your care is different from what you're used to or what you were expecting. It may help to talk about any concerns or feelings you have about this. You could speak to a family member or friend. Or you can talk things through with a nurse or trained officer on our free Support Line – call **0800 090 2309***.

If you have any questions or worries about your care, you can ask your GP or another healthcare professional.

We're still here to support people affected by terminal illness. Please don't be afraid to ask for help.

Maria, Marie Curie Nurse

Less face-to-face contact

Health and social care services are reducing face-to-face contact to avoid spreading coronavirus. They may organise appointments on the phone or by video call, rather than seeing you in person. But they should still see you if you need face-to-face care or support.

Hygiene and personal protective equipment (PPE)

If you see a health or social care professional, they should follow current government guidance about what precautions need to be taken. What they do might depend on whether you or someone in your household has coronavirus symptoms and what care they need to provide.

They should wash their hands thoroughly before and after they provide care. They might wear a plastic apron, facemask and gloves. You can ask them what their current policy is. It's OK to ask them to make sure that they are following this – it can help you feel more comfortable with the care you're getting.

Social care

Some of the processes for getting social or personal care have changed because of the coronavirus situation, so that care can be put in place more quickly for those who need it the most. Speak to your local council or trust about how to get support if you're not sure.

Possibly less care available

Some services may not be available because of more people needing help or staff being off sick. But this will vary across the UK. You should still ask for support if you need it or if you're worried.

Having visitors

If you're staying in a hospice, care home or hospital, there may be restrictions on visitors. There may be a limit on the number of visitors and visiting times, or they may not be able to allow visitors. The restrictions on visitors might change at different times. Check with the staff to see what the current policy is.

When to ask for help

You should still ask for help if you need it – health and social care professionals are there to support you. Getting the right care for you means that you can have a better quality of life and be as comfortable as possible in the time you have left. It can also mean that your family or friends feel more supported.

You should ask for help if:

- you have concerns or questions
- your symptoms get worse or change
- your symptoms aren't being managed
- you develop new symptoms
- you feel worried or upset and need emotional support.

You can contact your GP, district nurse or care team.
If there is a medical emergency, call **999** immediately.

Protecting yourself from coronavirus

When you're living with a terminal or life-limiting illness, you may be at risk of serious complications if you get coronavirus. You might have lots of different feelings about this – you may feel anxious, confused, frustrated or upset. This is very understandable – it can be a worrying time. It may help to talk about how you're feeling with family or friends, or contact our Support Line on **0800 090 2309***.

Government rules

There may be government rules about what you can or can't do. Some of these rules are about reducing physical contact with other people (called “social distancing”) to limit the spread of coronavirus. These are likely to change, so we haven't included specific information in this booklet. It's important to be aware of these so that you can make sure you're following any rules.

The rules might be different depending on where you live in the UK.

Advice from the government or healthcare professionals

Some people with a terminal illness are considered “extremely vulnerable” and may be given advice from the government on protecting themselves or “shielding”. Other people may be considered “vulnerable” and might be advised to be extra careful to follow government rules. It might help to check the latest advice on the government websites.

It can help to ask for advice from your health or social care professionals on your individual situation. You may be able to get advice from charities who support people with the condition or illness that you have. It might also help to talk to your family or friends about what they think. You may decide how you want to manage your risk and decisions yourself. Some people will decide not to follow all the advice they've been given, while others will decide to take extra precautions to protect themselves. It is a personal decision.

Whatever you decide, it's important to do what feels right for you. Try not to feel pressured into a decision that you don't feel comfortable with.

You may be thinking about your risk and what might happen if you get coronavirus. If you feel upset or worried about this, you may find it helpful to talk about how you're feeling. It might also help to make plans for what care you would want if you did get coronavirus. You could speak to a family member or friend, or get advice from a healthcare professional. You can also contact our Support Line on **0800 090 2309***.

Reducing your risk of getting coronavirus

If you do want to reduce your risk of getting coronavirus, there are some general things you might want to think about:

- Wash your hands with soap and water for at least 20 seconds on a regular basis. If soap and water aren't available, you can use hand sanitiser.
- Try not to be in close contact with other people – if you're meeting people, it's best to meet outside and keep your distance if possible.
- Try not to share food or drink with other people.
- Avoid contact with people who have coronavirus symptoms.

These are general things to think about, as the guidance and rules do change quite quickly. It can help to make sure you're aware of any guidance from the NHS or government.

If you're in contact with family and friends, you can ask them to follow any guidance as well. If they are coming into your home, they should wash their hands or use hand sanitiser when they arrive.

If you're seeing health or social care professionals, you can ask them about the precautions they are taking.

You can find out more about the current government rules and advice on the government websites, at **mariecurie.org.uk/coronavirus** or by calling our Support Line on **0800 090 2309***.

Getting more information

You might have questions about other things that may be affecting your life. These include:

- how symptoms can be managed
- how you can make decisions about your future care
- benefits and financial support
- making plans for your finances
- how family and friends can help with your care
- support for your family and friends
- how your loved ones can prepare for the future.

We have more information about all of these things in our booklets and on our website at **mariecurie.org.uk/support**. You can order free booklets on the website or by calling our Support Line. You can also contact the Marie Curie Support Line to speak to a nurse or trained staff member on **0800 090 2309***.

For more information about Marie Curie hospice and nursing services, visit **mariecurie.org.uk**

About this information

This booklet was produced by Marie Curie's Information and Support team. It has been reviewed by health and social care professionals.

If you have any feedback, please email **review@mariecurie.org.uk** or call the Marie Curie Support Line on **0800 090 2309***.

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Marie Curie – who we're here for

We're here for people living with any terminal illness, and their families. We offer expert care, guidance and support to help them get the most from the time they have left.

Marie Curie Support Line

0800 090 2309*

Ask questions and find support from trained staff and nurses.

Open 8am to 6pm Monday to Friday, 11am to 5pm Saturday.

mariecurie.org.uk/support

You can also visit **community.mariecurie.org.uk** to share experiences and find support by talking to people in a similar situation.

We can't do it without you

Our Information and Support service is entirely funded by your generous donations, so the work we do would not be possible without your help. Thanks to you, we can continue to offer people the free information and support they need, when they need it.

mariecurie.org.uk/donate

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