

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

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

Introduction

Many people are concerned about the rising cost of living, including energy bills such as electricity, gas and water. It may be especially worrying if you are also affected by a terminal illness.

If you, or someone you know, is worried about money, this leaflet has information about actions you could take, and support you could get, to help with the cost of living.

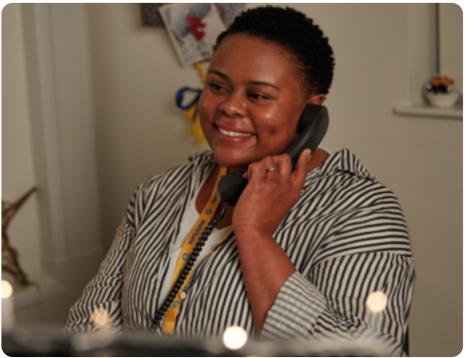
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Marie Curie's Energy Support Officers are here to help

If you're living with a terminal illness, or caring for someone who is, you might be worried about energy bills. You can call Marie Curie's free Support Line and ask to speak to one of our Energy Support Officers. They can give you expert information on things like getting support from your energy suppliers, grants, and ways to make your home energy efficient. They can also talk about the support we mention in this booklet.

Call on **0800 090 2309*** or email <u>support@mariecurie.org.uk</u>. When you call, ask for the language you'd like to use and we can get an interpreter to join.



The Priority Services Register in England, Scotland and Wales

The Priority Services Register is a free support service offered by electricity, gas and water suppliers in England, Scotland and Wales. It's for people who could be vulnerable, including if you have a terminal illness.

The support it offers includes:

- · advance notice of planned power or water cuts
- priority support in an emergency
- nominee scheme you can choose a family member, carer or someone you trust to communicate on your behalf
- moving your meter or regular meter reading services for example, if you cannot get to your meter
- accessible information for example, bills in large print or a different language.

Ask your energy supplier what other support they can offer through the Priority Services Register.

Who can get on the Priority Services Register?

You can get on the Priority Services Register if you:

- have a disability or a long-term medical condition including a terminal illness
- use medical equipment that requires a power supply or need to keep medication in the fridge
- would struggle to answer the door or get help in an emergency
- have reached your State Pension age
- have extra communication needs.

There are other reasons you may be able to get on the Priority Services Register that we do not list above. See them at **ofgem.gov.uk/get-help-your-supplierpriority-services-register** The Priority Services Register in England, Scotland and Wales

How to sign up for the Priority Services Register

There are different ways for you to sign up:

 Go to <u>thepsr.co.uk</u>. Enter your postcode to find your network operator and sign up for the Priority Services Register.

or

 Contact the gas, electricity and water supplier you use by phone or online. You can do this yourself or nominate someone else to do it for you. Give your supplier your contact details. Give them as much information as you can about your situation. For example, if you struggle to keep warm due to illness or are using electricity for medical equipment.

In England and Wales, find your water supplier at **ccw.org.uk/water-companies**

In Scotland, contact Scottish Water.

The Customer Care Register in Northern Ireland

The Customer Care Register is the Northern Ireland equivalent of the Priority Services Register. It means you can get extra support if:

- you're of State Pension age or
- you have a disability for example, being blind, partially sighted, deaf or have hearing loss or
- you're chronically sick, including living with a terminal illness.

Being on the Customer Care Register means your details are a priority for your energy supplier. For example, you'll be contacted ahead of time about planned energy outages (if energy will be switched off for some time).

There is also a Medical Customer Care Register. This Register is for people who rely on electricity for their healthcare needs – for example, for equipment.

Visit the Utility Regulator at **<u>uregni.gov.uk/supplier-</u>** <u>**contact-information**</u> to find your electricity, gas or water supplier.

How to sign up for the Customer Care Register

- 1. Contact the gas, electricity and water suppliers you use. You or someone close to you could do this.
- 2. Give them your contact details.
- 3. Give them as much information as you can about your situation. For example, if you struggle to keep warm due to illness or are using electricity for medical equipment.

You can also go to:

- <u>nienetworks.co.uk/help-advice/vulnerable-</u> <u>customers/medical-customer-care-register</u> to sign up for the electricity Medical Customer Care Register.
- <u>niwater.com/customer-care-register</u> to sign up for the water Customer Care Register.

Support with gas and electricity bills

Winter Fuel Payment

- A tax-free amount to help with your heating bills.
- It's paid once a year.
- You must live in the UK, be born before 23rd September 1958 (at time of publishing) and receive a qualifying benefit. It's not means-tested – your income, savings or investments will not affect whether you can get it.
- It will not affect any other benefits you may get.
- If you are eligible, you will usually get it without needing to apply.

Find out more at GOV.UK/winter-fuel-payment

Cold Weather Payment

- Tax-free payments for when the weather drops below a certain temperature.
- You must live in England, Wales and Northern Ireland. You usually need to claim certain benefits to qualify.
- If you are eligible, you do not need to apply. It will be paid automatically.

Find out more at GOV.UK/cold-weather-payment

Winter Heating Payment (Scotland)

- An annual payment of £50.
- You must live in Scotland and claim certain benefits.
- It will not affect any other benefits you may get.
- If you are eligible, you do not need to apply. It will be paid automatically.

Find out more at mygov.scot/winter-heating-payment

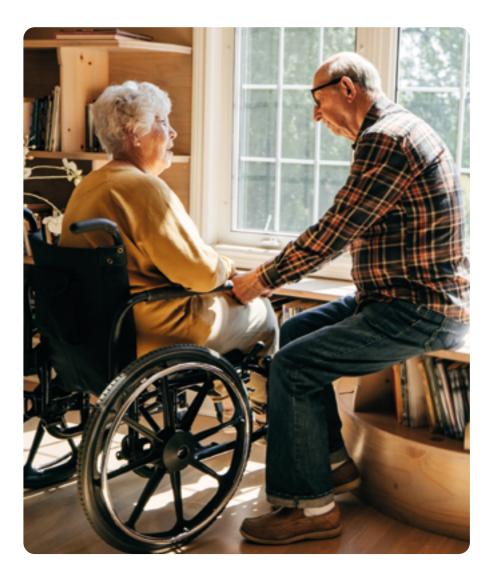
Warm Home Discount (England, Scotland and Wales)

- A one-off £150 discount on your energy bill offered by some energy companies.
- You must live in England, Scotland and Wales.
- If you are able to get this discount, your energy supplier will let you know. If you live in England or Wales, you can check at <u>gov.uk/check-if-youre-eligible-for-warm-</u> <u>home-discount</u> (this link will only work at certain times of year).
- If you live in England or Wales, you do not need to apply. The money is an automatic discount on your energy bill – it is not paid to you.
- If you live in Scotland, you may need to apply visit <u>GOV.UK/the-warm-home-discount-scheme/low-</u> <u>income-scotland</u> to learn more.

Find out more at <u>GOV.UK/the-warm-home-discount-</u> scheme

Fuel vouchers

If you live in England, Scotland or Wales and cannot afford to top up your prepayment meter, you might be able to get a fuel voucher. Your local council or food bank may be able to help you get a fuel voucher. See where else you may be able to get support.



Grants, benefits and other financial support

Grants

- England and Wales: Visit <u>GOV.UK/improve-energy-</u> <u>efficiency</u> or call 0800 098 7950 to find energy grants and ways to save energy in your home.
- Scotland: Visit <u>mygov.scot/help-energy-bills</u> for information about other benefits, grants and loans to help with energy bills.
- Wales: Visit <u>nest.gov.wales</u> or call Freephone 0808 808
 2244 or email <u>advicewales@est.org.uk</u> for information about the Nest scheme, which provides free energy efficiency improvements to eligible households.
- Northern Ireland: Visit <u>nidirect.gov.uk/articles/</u> <u>energy-saving-grants-your-area</u> or call Freephone
 0800 111 4455 or email <u>nienergyadvice@nihe.gov.uk</u> to find energy saving grants in your area.

You might be able to get other grants too – find out more at **mariecurie.org.uk/grants**

Benefits

There is not a specific benefit for people with a terminal illness, but you may be able to claim:

- · other disability and sickness benefits
- benefits for people with limited income or savings.

You could also receive benefits more quickly because you are ill. This is called the **special rules**.

You can check which benefits you may be able to claim by using our free Benefits Calculator at **mariecurie.entitledto.co.uk**

If you have questions or need help filling in the calculator, call our free Support Line on **0800 090 2309*** or email **<u>support@mariecurie.org.uk</u>**.

Which benefits could I claim?

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

Here are the main benefits you could apply for, with some information about who is eligible for each one when you first apply.

 Personal Independence Payment (PIP) – If you're aged 16 or over, under State Pension age (with some exceptions) and need help with daily living or getting around. You need to live in England, Wales or Northern Ireland.

Grants, benefits and other financial support

- Adult Disability Payment This is replacing PIP in Scotland. You can apply if you're aged 16 or over, under State Pension age, have an illness or disability, and live in Scotland.
- Employment and Support Allowance (ESA) If you're aged 16 or over, under State Pension age and your illness or disability makes it difficult or impossible to work.
- Attendance Allowance If you're State Pension age or older and need help caring for yourself. In Scotland, Pension Age Disability Payment is replacing this.
- Universal Credit If you're aged 18 or over (with some exceptions), you (or your partner, if you have one) are under State Pension age, you have a low income and £16,000 or less in money, savings and investments.
- Disability Living Allowance (DLA) for children For children with disabilities aged under 16 in England, Wales or Northern Ireland. In Scotland, this has been replaced by Child Disability Payment.

Food banks

Food banks offer free food to people who cannot afford what they need.

Getting a referral

Food banks offer free food to people who cannot afford what they need.

You sometimes need a referral before you can use a food bank:

 Ask Citizens Advice to refer you – call 0808 223 1133 or visit <u>citizensadvice.org.uk</u>

- If you have one, your GP, social worker or social prescribing link worker might be able to refer you.
- Contact your local council to find out how to get a referral.

Your local food bank can tell you whether you need a referral.

Find a food bank

There are lots of food banks across the UK. You can ask your health or social care professional or your local council about food banks close to you. You can also search for food banks:

- The Independent Food Aid Network has a map of food banks and food aid providers in the UK: <u>foodaidnetwork.org.uk/our-members</u>
- The Trussell Trust has food banks across the UK.
 You need a referral to use these: <u>trusselltrust.org/find-</u> <u>a-foodbank</u>

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-line**

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 online at **mariecurie.org.uk/information** or to order at **mariecurie.org.uk/publications**

Where to get more information and advice

Advice NI

0800 915 4604

adviceni.net

Offers independent advice about benefits, debt and the cost of living in Northern Ireland online and over the phone.

British Gas Energy Trust

britishgasenergytrust.org.uk

Helps families and individuals who are struggling to pay their energy bills across England, Wales and Scotland, no matter which energy supplier you are with.

Citizens Advice

Citizens Advice Consumer Service: **0808 223 1133** (England and Wales)

citizensadvice.org.uk

Has trained advisers you can speak to and provides information on your rights, including benefits, housing, employment, debt, consumer and legal issues. Search the site for your nearest bureau in England or Wales. If you live in Scotland, search for your nearest bureau at **cas.org.uk**. If you live in Northern Ireland, Citizens Advice has a list of local, independent agencies on its website.

The Consumer Council

028 9025 1600

consumercouncil.org.uk/energy

Provides free, independent support and advice for all consumers and businesses in Northern Ireland, including tips about saving money on household costs.

Disability Action

disabilityaction.org

Provides practical information for anyone with a disability, including a learning disability, in Northern Ireland. Has information about benefits and financial support.

Energy Advice Scot

0808 800 9060

energyadvice.scot

Provides free, practical advice and information on energy-related matters to people in Scotland.

Energy Saving Trust

energysavingtrust.org.uk

Has information about how to make your home more energy efficient and lower your energy bills.

Green Doctor

groundwork.org.uk/greendoctor

Has a Green Doctor service that offers free, impartial advice to help you take control of your bills, save energy where possible, and access other services available.

Housing Executive – Energy Advice Centre

nihe.gov.uk/housing-help/ni-energy-advice nienergyadvice@nihe.gov.uk

Offers energy advice for people in Northern Ireland, including signposting to energy efficiency grants, energy saving tips, and debt assistance.

National Energy Action

0800 304 7159

<u>nea.org.uk</u>

Provides advice and support to people in England, Wales and Northern Ireland struggling to heat their homes affordably, including a Warm and Safe Homes (WASH) Advice Service.

Ofgem

ofgem.gov.uk

The Office of Gas and Electricity Markets. Protects consumers by working to deliver a greener, fairer energy system and has energy advice for households.

Ofwat

ofwat.gov.uk

The Office for Water Services. Regulates water companies to provide consumers with a good quality and efficient service at a fair price. Has tips about how to save water for households.

Scope

0808 800 3333

scope.org.uk

Provides practical information and emotional support for anyone with a learning disability or physical impairment in England and Wales. This includes a Disability Energy Support service where they offer free energy and water advice to disabled people.

Turn2us

turn2us.org.uk

Has a search function to find benefits advisers in your area, and provides people with financial support and information on benefits and grants.

Utility Regulator

uregni.gov.uk

Has a list of energy companies in Northern Ireland and guidance about the support those companies can offer.

About this information

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***.

Your notes

Your notes		

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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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Patient Information Forum

