Benefits and financial support

Living well with myeloma Infosheet

This Infosheet provides information on the main benefits and allowances that may be available to you if you are a myeloma patient or a carer of a myeloma patient.

In general, the benefits system is the same across the UK. Unless otherwise specified, the information in this Infosheet applies in all four UK countries (England, Scotland, Wales, and Northern Ireland).



For more information about other financial issues that may affect you, see the **Infopack for living well with myeloma** from Myeloma UK

What benefits may I be entitled to?

There are a number of different benefits and credits you may be able to claim. The type and number of benefits available vary from person to person. This may be affected by:

- Any savings you have
- Your income, including your partner's income
- Benefits and pensions you and anyone living with you are currently receiving

- Outgoings you have such as rent, mortgage payments, and childcare payments
- Your age
- Where you live

The benefits system, types of benefits, and who can qualify for benefits can change yearly. Tools and benefits calculators such as **entitledto** and **Turn2us** can be useful to understand what you may be eligible for (see page 13 and page 15 for details).

The most common, current benefits and credits you may be entitled to include:

- Personal Independence Payment (PIP) – if you are aged between 16 and the State Pension age
- Attendance Allowance – if you are over the State Pension age and you have care needs
- Statutory Sick Pay or Employment Support Allowance – if you are unable to work
- Universal Credit – if you have low income
- Carer's Allowance or Carer's Credit – if you care for someone who has myeloma

Further information about each benefit or credit can be found on the following pages.

A summary of these benefits can be found in Table 1 on page 7.

Personal Independence Payment (PIP)

There are two parts to PIP. There is a daily living part, if you need help with everyday tasks. There is also a mobility part, if you need help with getting around. You can claim for one of these parts or both.

To claim PIP you must meet all the following criteria:

- Aged between 16 and State Pension age
- Have a long term physical or mental health condition or disability
- Have difficulty doing certain everyday tasks or moving around
- You expect the difficulties to last for at least 12 months from when they started

You can get PIP even if you are working. How much you receive will depend on the extent to which your myeloma affects your day-to-day living and mobility.

PIP has replaced Disability Living Allowance (DLA). Anyone claiming DLA will be contacted by the Department for Work and Pensions (Department for Communities in Northern Ireland) and asked to make a new claim for PIP. Until you are contacted you will continue receiving DLA. If you live in Scotland, you need to apply for Adult Disability Payment (ADP) instead.

The Government are planning changes to PIP which will make the criteria for those applying stricter. These changes will not be immediate because they must go through a government process.

Details of PIP at **gov.uk/pip**

Disability Living Allowance (DLA)

DLA was previously a benefit available to people who had personal care needs or difficulty with walking because of either a physical or mental disability. Unless you are under 16 you cannot make a new claim for DLA and must claim PIP instead.

If you are already receiving DLA, you will have to make a new claim for PIP. However, you do not need to do anything about transferring your claim until the Department for Work and Pensions (Department for Communities in Northern Ireland) contacts you. If you are receiving DLA and were born on or before 8 April 1948 (or 20 June 1951 in Northern Ireland), then you will continue to receive it.

Details of DLA at **gov.uk/dla-disability-living-allowance-benefit**

Adult Disability Payment (ADP)

ADP is a benefit for adults living with disabilities in Scotland. It replaces DLA and PIP. There are 2 parts to ADP. There is a daily living part, if you need help with everyday tasks. There is also a mobility part, if you need help with getting around. You can claim for one of these parts or both.

You can apply for this if you have a disability or long-term physical or mental health condition or a terminal illness. You must also be aged between 16 and the State Pension age.

You do not need to apply if you are already receiving PIP or DLA from the Department for Work and Pensions. Social Security Scotland will move your benefit to Adult Disability Payment for you.

Details of ADP at **mygov.scot/adult-disability-payment**

Attendance Allowance (AA)

This allowance is paid to people State Pension age or older who require help with their personal care. AA does not cover mobility needs. This allowance has two different rates depending on how much care is required. You can claim AA even if you do not have a carer.

Details of AA at
gov.uk/attendance-allowance

If you live in Scotland you will need to apply for a Pension Age Disability Payment instead of AA. If you already get AA you do not need to do anything.

Disability premiums (DPs)

You qualify for DPs if you are getting certain benefits because of a health condition, including PIP or AA. DPs are extra amounts of money added to other specific benefits that you receive. These benefits are:

- Income Support
- Income-based Jobseeker's Allowance (JSA)
- Income-related Employment and Support Allowance (ESA)
- Housing Benefit

Details of DPs at
gov.uk/disability-premiums

Statutory Sick Pay (SSP)

You may be entitled to SPP if you:

- Are employed
- Have been unable to work for at least one full working day because of ill health or disability

SSP is paid at a fixed rate of £123.25 a week and it is paid for up to 28 weeks. If you have contractual or occupational sick pay in the terms of your employment then you may be entitled to this as well as SSP.

Details of SSP at
gov.uk/statutory-sick-pay

Employment and Support Allowance (ESA)

ESA is for people who have a disability or health condition that affects how much they can work, and who are not receiving SSP. It offers financial support if you are unable to work, or personal help to enable you to work. Most new claimants will receive what is called 'new style' ESA. You need to have made enough National Insurance contributions to receive this. You may receive Universal Credit as well (see next section).

Some existing claimants receive contribution-based or income-related ESA (depending on their level of National Insurance contributions).

Details of ESA at **gov.uk/employment-support-allowance**

Universal Credit

Universal Credit is a benefit for people who are out of work, who cannot work, or who are on a low income. It is a single means-tested benefit paid to people of working age. It replaces most means-tested benefits including:

- Income-based Jobseeker's Allowance (JSA) (this scheme has already ended)
- Income-related Employment and Support Allowance (ESA)
- Income Support (this scheme has already ended)
- Housing Benefit
- Working Tax Credit (this scheme has already ended)
- Child Tax Credit (this scheme has already ended)

Universal Credit consists of a standard allowance. There are extra amounts in some circumstances. This can include if you have a health condition which limits your ability to work.

New claimants now apply for Universal Credit, rather than for the individual benefits that it replaces.

If you are on other benefits but have a change in circumstances, such as leaving a job, you will also have to claim Universal Credit.

Other people who are claiming existing benefits will be gradually moved to Universal Credit, in a process called 'managed migration'. The Government currently expects all households to have moved to Universal Credit by the end of summer 2026.

Unless there is a change in your circumstances you do not need to do anything about moving to Universal Credit until you are contacted by the Department for Work and Pensions (or the Department for Communities in Northern Ireland).

There are some differences to the Universal Credit system in Northern Ireland – find details at **nidirect.gov.uk**

Details of Universal Credit at **gov.uk/universal-credit**

Carer's Allowance

If you are a carer and are caring for someone for at least 35 hours per week you may be entitled to Carer's Allowance. The person you care for must be receiving a disability benefit, such as PIP or AA, and you must be earning under £204 a week (after tax, National Insurance, and allowable expenses) if you are working.

Claiming Carer's Allowance may affect other benefits or allowances that you or the person you are caring for claims.

If you are in Scotland, Carer's Allowance is being replaced by Carer Support Payment. If you already get Carer's Allowance, you do not need to apply for Carer Support Payment. The Department for Work and Pensions and Social Security Scotland will move your benefit for you.

Details of Carer's Allowance at **gov.uk/carers-allowance**

Details of Carer Support Payment at **mygov.scot/carer-support-payment**

Carer's Credit

Carer's credit is a National Insurance credit and enables carers to protect their State Pension.

If you are a carer who cares for someone at least 20 hours per week, and are working part time or not in work, you may be entitled to Carer's Credit. Carer's Credit can top up your National Insurance contributions so you can still claim your State Pension when you reach State Pension age. You may be eligible for Carer's Credit if the person you are caring for is claiming AA or certain types of DLA or PIP.

If you are claiming Carer's Allowance you do not need to apply for Carer's Credit, as you will already be getting credits. However, you may be eligible for Carer's Credit even if you are not eligible for Carer's Allowance.

Details of Carer's Credit at **gov.uk/carers-credit**

These benefits are summarised in Table 1 on page 7.

Benefit/credit	Tax free	Means-tested	Age criteria	Work criteria	Caring criteria
Personal Independence Payment	Yes	No	Over 16, below State Pension age	N/A	Need help with personal care or mobility
Disability Living Allowance	Yes	No	No new claimants over 16	N/A	Need help with personal care
Adult Disability Payment	Yes	No	Over 16, below State Pension age	N/A	Need help with personal care or mobility
Attendance Allowance	Yes	No	State Pension age or older	N/A	Need help with personal care
Statutory Sick Pay	No	No	Over 16	Employed but cannot work due to illness	N/A
Employment and Support Allowance	Depends on type of ESA	Depends on type of ESA	Under State Pension age	Health condition affects how much you can work	N/A
Universal Credit	Yes	Yes	Over 18, below State Pension age	N/A	N/A
Carer's Allowance	No	Yes	Over 16	Can work but must earn under £204 a week (after tax)	Care for at least 35 hours a week
Carer's Credit	N/A	No	Over 16, below State Pension age	Not in work, or in part-time work	Care for at least 20 hours a week

Table 1. Summary of available benefits

What else can affect my benefits?

There are some additional things to be aware of if you are claiming benefits.

Benefit cap

There is a limit to the amount of benefits that people between 16 and State Pension age can receive. This does not affect those claiming certain benefits including PIP, DLA, AA, or Carer's Allowance. The benefit cap affects those claiming Universal Credit and any benefits that Universal Credit is replacing.

However, you are not affected if you get Universal Credit because of a health condition that stops you from working, or because you care for someone with a disability.

Hospital and care home stays

If you are admitted to a hospital or care home for one night or longer, some of the benefits you get may be stopped. This may include PIP, DLA, AA, and Carer's Allowance.

Tell the Department for Work and Pensions (Department for Communities in Northern Ireland) if you, or the person you are caring for, is admitted to a hospital or care home for any period. A friend or relative can call them on your behalf.

Going abroad

You may still be able to claim some benefits if you travel or move abroad, or if you are already living abroad. What you are entitled to depends on where you are going and how long for.

You should tell your benefit provider if you are going abroad and when you are returning. Benefits that may be affected (depending on the length of time abroad) include PIP, DLA, AA, ESA, and Carer's Allowance.

Terminal illness: special rules

If you have a terminal illness and your doctor has said you might have less than 12 months to live, you can apply for some benefits using special rules. This means you may get extra money, and start getting payments quicker than usual.

Ask your healthcare team to fill in a form called an **SR1** and send it to the Department for Work and Pensions (Department for Communities in Northern Ireland).

What other benefits may I be entitled to?

You may be able to get other benefits as well, depending on your circumstances. This may include Housing Benefit or benefits because you have children. These benefits may be covered by Universal Credit. You may also be able to claim Council Tax Reduction from your local council (in England, Wales or Scotland), or Rate Relief from Land & Property Services (in Northern Ireland).

Other support you may be entitled to includes:

Support with your work

If you have a health condition that makes it hard for you to do your job, you can talk to your employer about changes they must consider making (known as 'reasonable adjustments'). This could include changing your working hours or providing equipment to help you. You may also be able to get extra help with an Access to Work grant.

Details at **gov.uk/access-to-work**

Find information relevant to Northern Ireland at **nidirect.gov.uk/articles/employment-support-information**

Unpaid carer's leave

If you are employed in England, Wales, or Scotland and need to take leave to give or arrange care for a dependant with myeloma you are protected by the Carer's Leave Act.

You can take up to 1 week of carer's leave every 12 months. 1 week refers to the number of days or hours you would usually work in a week. For example if you work part-time for 3 days a week, then 3 days is a full week of carer's leave. This week can be done as:

- Half days
- Full days
- A whole week at once

A dependant you are caring for can include:

- Your partner, civil partner, husband or wife
- Your child
- Your parent
- A person who lives in your household, but this excludes tenants, lodgers, or employees
- A person who relies on you for care, such as an elderly neighbour

This is intended for planned and foreseen caring commitments, and you need to give your employer advance notice. You are also entitled to a reasonable amount of time off to deal with emergency caring situations. Find more information at **gov.uk/carers-leave**

Blue Badge scheme

The Blue Badge scheme allows people with severe mobility problems to park in parking restricted areas. The Blue Badge enables badge holders to park close to where they need to go. The scheme operates throughout the UK; however, parking concessions may be different depending on where you live. See page 13 for details of how to apply.

Other help with transport

In some circumstances you may not have to pay vehicle tax, or the amount you pay may be reduced. You may be eligible for a bus pass or Disabled Persons Railcard, and your local council may operate dial-a-ride or taxi schemes.

Most hospitals provide free parking for cancer patients. This is not always well advertised, ask your healthcare team for details.

Details at
gov.uk/financial-help-disabled/vehicles-and-transport

Help with heating bills

There are some benefits in place to help you pay gas and electricity bills during the winter months.

- Winter Fuel Payments - if you are over State Pension age you might be eligible for a one-off payment to help cover heating bills in winter
- Winter Heating Payment - if you live in Scotland and receive one of a number of UK benefits including Universal Credit, you might be eligible for help to cover heating bills in winter
- Cold Weather Payment - this is an additional payment if you receive certain benefits and the temperature drops to zero degrees Celsius or below for 7 days in a row
- Warm Home Discount - this is a £150 discount on bills if you get Pension Credit or live in a low-income household
- Household Support Fund - you might be eligible under your local council's rules. You must check on your local council's website

Details at
gov.uk/winter-fuel-payment

Prescription charges

In Wales, Scotland, and Northern Ireland, all prescriptions are free of charge regardless of individual circumstances.

In England, prescriptions are free for cancer patients on production of an exemption certificate. Your GP or hospital clinic will be able to give you the form to apply for an exemption certificate.

VAT relief

If you have a long-term illness like myeloma, you will not be charged value added tax (VAT) on products designed or adapted for your personal use, or for repairs to such products. This includes items such as stair lifts and wheelchairs. Both you and the supplier of the product will need to sign a declaration to get the VAT exemption.

Details at **gov.uk/financial-help-disabled/vat-relief**

Help with food costs

Some myeloma patients struggle with food costs because of increased costs elsewhere in their lives, or changes to their taste due to myeloma treatments. Food banks and community meal schemes exist to make sure no one is hungry.

You can find useful organisations on page 14. You will not be judged for needing support.

Help with housekeeping challenges

If you are finding it difficult to take on domestic tasks with your myeloma it can be expensive to hire a cleaner or maintenance service.

Age UK can provide a handyperson service for maintenance work in your home. The availability of this service varies by location across the UK. Age UK also provides a home help service for day-to-day domestic tasks in your home such as, laundry, housework, and preparing light meals.

Details at **ageuk.org.uk/services**

Disabled Facilities Grants

In England, Wales, or Northern Ireland, you could get a grant from your local council if you need to make changes to your home, such as installing ramps, stairlifts, or a downstairs bathroom. The grants are means-tested, but will not affect any benefits you get. You might not get a grant if you start the work before the council approves your application.

Charitable grants

There are some charities that may be able to provide discretional financial help depending on your individual circumstances.

The charity Anthony Nolan offer a small, one-off payment to help with unexpected costs of a stem cell transplant.

Details **anthonynolan.org**

In some parts of the UK, Macmillan also offer small one-off payments to help with unexpected healthcare costs.

Details at **macmillan.org**

Further information and useful organisations

A social worker can provide information on any extra help that might be available. They can also support you with the necessary forms or put you in touch with a local welfare rights officer. You can ask to be referred to a social worker through your healthcare team.

Details about the above benefits and how to apply for them can be obtained from the organisations listed below. Several of these organisations have online benefit calculators to help you work out your position. Some have online access to advisors by web chat, and this can be a faster way to contact an advisor if the phone line is very busy.

Fake money advice

Unfortunately, there are many scams by organisations pretending to offer genuine advice about debt or benefits. Make sure you get advice from trustworthy organisations. Check the web address carefully to be sure that you are on the correct website for the organisation. Be very cautious about sharing personal information. Genuine organisations will not cold call people to offer advice.

Advice NI
adviceni.net
0800 915 4604

An independent charity that provides free debt advice by phone and online in Northern Ireland. Online advice tool and webchat options available.

Blue Badge Scheme
gov.uk/apply-blue-badge
England, Wales and Scotland: apply online or contact your local council for information or to apply by post.

Northern Ireland: apply online **nidirect.gov.uk** or phone 0300 200 7818

Christians Against Poverty (CAP)
capuk.org
0800 328 0006

CAP provide free debt counselling to anyone worried about their finances through their local Debt Centres around the country. They can work with your creditors on your behalf to help you get out of debt.

Citizens Advice
citizensadvice.org.uk
Northern Ireland: **adviceni.net**
England: 0800 144 8848
Wales: 0800 702 2020
Scotland: 0800 028 1456
Northern Ireland: 0800 915 4604
Citizens Advice offers advice about debt and consumer issues, benefits, housing, legal matters, and employment. It provides assistance with claiming welfare benefits, including practical help with filling out benefit application forms. Information and advice can be accessed online, by telephone, or face to face at local Citizens Advice offices.

Community Fridge Network
communityfridgemap.org.uk
Community fridges are public spaces where you can collect surplus food for free.

entitledto
entitledto.co.uk
entitledto provides free online benefits calculators to help you work out what benefits you are eligible for.

FoodCycle
foodcycle.org.uk
0207 729 2775
FoodCycle host community meals across the UK for free to help people facing hunger or loneliness.

Government websites
England and Wales: **gov.uk**
Scotland: **mygov.scot**
Northern Ireland: **nidirect.gov.uk**
The government websites provide information about a wide range of public services including benefits such as Attendance Allowance, Personal Independence Payments, and Carer's Allowance. You will find details about how to apply for benefits and phone numbers listed to discuss the different benefits that are available.

Help with Health Costs
nhs.uk/nhs-services/help-with-health-costs/
0300 330 1343
Help with Health Costs gives information about prescription charges and other help that patients can get with their health costs.

MoneyHelper
moneyhelper.org.uk
0800 011 3797
The MoneyHelper Service is a free and impartial service, set up by the government. It includes advice on insurance, benefits and care, and disability, and has an online finance calculator and webchat option.

National Debtline
nationaldebtline.org
0808 808 4000
An independent charity that provides free debt advice by phone and online in England, Scotland, and Wales. Online advice tool and webchat options available. For free debt advice in Northern Ireland, see Advice NI.

StepChange
stepchange.org
0800 138 1111
StepChange is a charity that provides free, confidential, and expert debt advice online and over the phone.

Trussell
trussell.org.uk
0172 258 0180]
Trussell is an anti-poverty charity and community of foodbanks.

Turn2us
turn2us.org.uk
0808 802 2000
Turn2us is a national charity that helps people get access to welfare benefits. It has an online benefits calculator to help you work out which means-tested benefits you are eligible to receive.

Unbiased
unbiased.co.uk
0800 023 6868
This is a directory of professional advisers which you can search. Unbiased can also match you with a suitable adviser to give you financial, mortgage, legal, and accounting information.

Key points

- You may be able to claim a number of different benefits if you are living with myeloma, or are caring for someone with myeloma
- Factors such as your age, where you live, household income, and savings can affect the benefits you may be entitled to
- In addition to financial allowances, you may be able to get additional benefits from your local council to help with things such as council tax and transport costs
- Be aware of fake money advice or scams offered by cold callers pretending to offer you genuine advice
- There are a number of organisations, such as charities and government services, that provide free financial advice and useful online tools to help you access the benefits you may be entitled to
- The Government has proposed a number of changes to the benefits system. If accepted by Parliament, these will be slowly coming into place until April 2030

About this Infosheet

The information in this Infosheet is not meant to replace the advice of your healthcare team. They are the people to ask if you have questions about your individual situation.

For more about how we produce our information, visit **myeloma.org.uk/about-our-information**

We value your feedback about our patient information.

For a short online survey go to **myeloma.org.uk/pifeedback** or email comments to **patientinfo@myeloma.org.uk**

Other information available from Myeloma UK

Myeloma UK has a range of information booklets available covering all aspects of myeloma and related conditions. Download or order them from **myeloma.org.uk/publications**

To talk to one of our Myeloma Information Specialists about any aspect of myeloma, call our Myeloma Infoline on **0800 980 3332** or **1800 937 773** from Ireland.

The Infoline is open from Monday to Friday, 9am to 5pm and is free to phone from anywhere in the UK and Ireland.

Information and support about myeloma is also available at **myeloma.org.uk**

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MyelomaUK

We're here for everything a diagnosis of myeloma brings

Get in touch to find out more about how we can support you

Call the Myeloma Infoline on
0800 980 3332

Email Ask the Nurse at
AskTheNurse@myeloma.org.uk

Visit our website at
myeloma.org.uk

Trusted Information Creator
Patient Information Forum

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Registered Charity No: SC026116

Published by:	Myeloma UK
Publication date:	August 2014
Last updated:	September 2026
Review date:	September 2027