

Welfare Benefits

- Part 2:

Disability and bereavement



Leukaemia Care

YOUR Blood Cancer Charity

Finances can be a worry, whatever stage of your leukaemia journey you are at. From our survey, "Living with Leukaemia", we found that:

- 43% of all patients report a negative impact on finances AND:
- 64% of those said this was due to an increase in their costs
- 70% of those said this was due to a reduction in income

In this "Know your Rights" toolkit, we address benefits you or those you care for might be entitled to because of how a blood cancer diagnosis affects your day to day activities. We also cover the support you may be entitled to if your partner has passed away whilst you are caring for or are expecting children.

Below we give an overview of the benefits that may be relevant to you as a leukaemia patient. This advice is not intended to be used to work out if you as an individual are eligible for these benefits, but instead should be used as a guide to what the benefits system can help you pay for. Whether you can get the benefits individually or whether you must claim Universal Credit will depend on your location; please get in touch if you would like help in finding out what you need to apply for.

The information here has been adapted from the gov.uk website and the Welfare Benefits and Tax Credits Handbook (CPAG, 2018).

NOTE: We have not included the amount of money currently available for each benefit or the income or savings limits for means-tested benefits, as these are likely to change regularly. Please get in contact with the Advocacy team if you would like help finding out the most current information.

The welfare system is deceptively complex. We have provided the corresponding government webpage for each benefit as we talk about it throughout the toolkit. Where the phrase "seek advice" or similar has been used within the toolkit, we have identified particularly complex issues and recommend you seek specialist advice. However, we recommend anyone thinking of applying for any benefit to seek advice from a benefits adviser, as they are not only trained to know who can apply but also how to maximise income for your individual circumstances and avoid you losing money if you already claim some benefits. Here are some places to go for additional advice:

- **The Patient Advocacy Team at Leukaemia Care:** Our details are at the bottom of the toolkit. We

can currently only offer general advice or help you find the information you need.

- **Macmillan helpline:** 0808 808 00 00. Macmillan provide financial advice by phone to anyone diagnosed with a cancer at any stage of their journey.
- **Citizens Advice:** Citizen's Advice can provide financial advice to anyone. Some branches also have a Macmillan funded adviser for cancer patients, either in their local branch or attending local hospitals. To find out where your nearest Citizens Advice branch is and the services they offer, visit their website and give your postcode: <https://www.citizensadvice.org.uk/>. There is also a live chat service on the website or a helpline: 03444 111 444 (England) and 03444 77 20 20 (Wales).
- **Maggie's Centres** is another cancer charity that provides clinics with trained benefits advisers in hospitals and other locations. You can find your local centre by visiting the website and giving your postcode: <https://www.maggiescentres.org/> or by phoning 0300 123 1801.

Should I apply for state benefits?

Most patients, whether they have an acute or a chronic diagnosis, will at some point feel too unwell to work. This is normal and to be expected; even if you feel physically fit or do not immediately need treatment, you might feel the need to take some time off to deal with the psychological impact of a diagnosis. There are state benefits that are available to help you during this time. As mentioned above, what you are entitled to can be very complex and we recommend taking specialist advice, especially if you claim some benefits already.

You may have mixed feelings about applying for state benefits or heard negative things about those who receive them in the press. It is important to remember that you did not choose to be ill and having less to worry about in terms of finances will leave you less stressed and better able to focus on getting better. Some people feel that claiming benefits lessens their sense of independence, but they may have the opposite effect; for example, if you receive PIP because you have limited mobility, you can put that towards the cost of a car that can be used to help you get out and about. Benefits are there to help those most in need, so try not to be harsh on yourself for needing

to accept some help. Being eligible for some benefits can also lead a process known as "passporting"; this is where entitlement to one form of help can lead to automatic entitlement for other forms of help, such as free school meals, free prescriptions or a blue badge.

But don't I earn too much/have too much saved to apply?

It is a myth that all state benefits are means-tested (i.e. dependent on your income or savings); some are paid based on your health, regardless of income, and others are available to support you if you have previously paid enough national insurance contributions.

1. Personal Independence Payment

<https://www.gov.uk/pip>

Personal Independence Payment (PIP) is a non-means tested benefit for those who need extra financial support due to limited ability to take care of yourself and/or move around independently. It is only available to adults under state pension age (see disability living allowance (DLA) and attendance allowance if you are out of this age range). You may also be asked to move from DLA to PIP; please seek advice if this is the case as it is possible that you may receive less money by doing this.

PIP is made up of two payments:

- The daily living component is concerned with activities that everyone must do to live a comfortable life, such as managing toilet needs, feeding yourself, washing or taking medication. There are two rates, standard and enhanced rate, depending on your level of need.
- The mobility component is concerned about your ability to physically move as well as your physical and/or mental ability to deal with undertaking journeys outside the house. This is also paid at a standard

or an enhanced rate.

You can qualify for one or both components, depending on how your disability affects you individually. Having a disability or illness, such as leukaemia, does not automatically qualify you; PIP is decided on how your illness affects your ability to do everyday things.

Whether you get an enhanced payment, standard payment or don't qualify is based on your score. The PIP application form has a set of activities to be assessed; examples include "making budgeting decisions", "communicating verbally" and "dressing and undressing". You are asked to tick whether you can do an activity or not, how often

you are affected and then asked to give further details.

When the assessor is checking your application form, each activity has a set of descriptors, which are statements that describe your ability to fulfil that activity. Depending on which descriptor best matches what you have described, you will be given a score that reflects your ability to carry out that particular activity. Below is an example of the descriptors for the activity "preparing food".

Activity	Descriptors	Points
1. Preparing food	a. Can prepare and cook a simple meal unaided.	0
	b. Needs to use an aid or appliance to be able to either prepare or cook a simple meal.	2
	c. Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave.	2
	d. Needs prompting to be able to either prepare or cook a simple meal.	2
	e. Needs supervision or assistance to either prepare or cook a simple meal.	4
	f. Cannot prepare and cook food.	8

Therefore, it is important that when you fill out the application form for PIP, you make yourself aware of the descriptors for each activity. You must not lie, as this will be considered fraud and you are likely to have a face to face assessment too. It is good practice to describe your circumstances in the way that makes it easier for the assessor to match your circumstances to a descriptor. If how you are affected varies, give a description of yourself on your worst day and then indicate how often this happens; the score you get will be determined by the percentage of the time you are at your worst.

You can view all the descriptors here. The score for each activity is added together to make an overall score; you get one score for the daily living part and another score for mobility, so you can qualify for one, both or neither part. A total score of between 8 and 11 points (per part) qualifies you for the standard rate, 12 or more points (per part) means you will receive the enhanced rate.

It is strongly advisable that you get help in filling out the form from a professional, such as Macmillan financial advisors, Citizen's Advice or Maggie's Centre benefits advisors, as they will ensure you describe your condition in the most effective

way. Certain words such as "aid", "assistance" and "supervision" have set definitions when used on a PIP form, so this is another area where you may benefit from help to fill out the form.

After you submit the form, you may be asked to meet with a health professional for an assessment. The health professional could be a doctor, nurse, physiotherapist, paramedic or occupational therapist. Here they will ask you to describe how your condition affects you, what a typical day might look like and your work or social life history. They may also ask you to move around or undergo a short examination. You can request a home appointment and you can also make a complaint about the examination if you are unhappy about how it was conducted. The health professional will then make a report and send it to the Department of Work and Pensions, where it will be added to your application for the assessment.

You should then receive a letter stating whether you are being awarded PIP, how long for and at what rate. If you are unhappy about the decision, you may ask for it to be reconsidered (known as mandatory reconsideration notice) and submit more evidence. If you still disagree with

decision, you can then appeal. Appealing is a complicated process and you should seek further advice from benefits advisors to help you prepare for the appeal. There are deadlines for asking for a reconsideration or an appeal, which can be found in your letters from the Department for Work and Pensions.

2. Disability Living Allowance

<https://www.gov.uk/disability-living-allowance-children>

Disability Living Allowance (DLA) was the main benefit for those with a disability before PIP was introduced. It is also non-means tested and independent of previous national insurance contributions. New claims can now only be considered for children under 16, everyone else must make a claim for PIP or attendance allowance. If you are currently receiving DLA, you may be asked to move to receiving PIP; you should seek professional advice before doing so to check the impact this may have on your finances.

DLA is broken down in to two components like PIP, known as the mobility component and the care component. The care component has a lowest, middle and higher rate, whereas mobility just has a lower and higher rate.

The rate of DLA is decided by the amount of extra care your child needs beyond the needs of a child without a disability. There are fewer qualifying criteria than PIP; the care component is determined by the amount of supervision needed during the day and night, whilst the mobility component is decided by how mobile the child is or how easy it is for them to

move around if you are able. More information on eligibility for DLA can be found here.

3. Attendance Allowance

<https://www.gov.uk/attendance-allowance>

Attendance Allowance (AA) is a benefit to help people over the state pension age at the time they claim. It is non-means tested and you do not have to have paid national insurance contributions. Instead of focusing on how a disability affects you, it focuses on whether you need attention or supervision from others in order to live safely or in order to help you with bodily functions.

There are two rates of AA, a lower and enhanced rate. It is also assessed whether your needs apply at night, in the day or both. You receive the lower rate if you are judged to need supervision or attention in either the day OR night, or some people who are having renal dialysis will also be eligible. The higher rate is paid if the person needs help during both the day and night. You can find more information on eligibility here.

In addition to the disability criteria, you must have also have had the needs (i.e. qualified for AA) for 6 months before you apply for the benefit.

4. Carers Allowance

<https://www.gov.uk/carers-allowance>

If you are caring for someone who is receiving any of the above benefits at the highest rate and you care for them for 35 hours or more a week, you may be eligible to receive Carer's Allowance.

We have created separate information for carers which has the details of this benefit, as well as other support available, which you can read [here](#).

Bereavement support payment

<https://www.gov.uk/bereavement-support-payment>

Bereavement support payment is designed to support those whose spouse or civil partner died on or after the 6th of April 2017 and are supporting children at the time of death. You will get an initial lump sum, followed by monthly payments for up to 18 months (or until you reach state pension age, whichever occurs first). The death of a partner can lead to a sudden loss of earnings, which can make it difficult to continue to care for children, particularly if the surviving parent is primarily looking after the children and working part time or not at all. Therefore, one condition of eligibility is that the deceased must have paid national insurance contributions equivalent to 25 times the lower earnings limit (the amount you can earn before you pay national insurance) for at least one year of their working life. Seek advice if your partner was not working at the time of death or you are unsure as to whether they will have met this condition.

You must have been married or in a civil partnership and not living with another person when your partner passed away. There are two rates of payment that can be

paid as well. You can receive the higher rate if you were pregnant at the time of death, entitled to child benefit at the time or you become entitled to child benefits as a result of your partner's death. You do not lose your entitlement if you start a new relationship after your partner dies.

If your partner died before the 6th of April 2017, you may have been entitled to widowed parents' allowance, bereavement payment or bereavement allowance. As these need to be claimed between 3 and 12 months after death, you can no longer claim for this support. Seek professional advice if you would like to know more about your situation, or if you are already receiving these and have questions about your payments.

Further questions

Benefits calculator can help you determine whether you are personally eligible for any benefit. There are several available online, including: https://benefits-calculator.turn2us.org.uk/AboutYou?utm_source=BAdviser&utm_medium=referral&utm_campaign=GovUK and https://www.entitledto.co.uk/?utm_source=BAdviser&utm_medium=referral&utm_campaign=GovUK.

The organisations listed at the start of this toolkit can also give advice on individual circumstances.

If you have any further questions about the benefits system, you can contact our Patient Advocacy team. They are available Monday to Friday from 9:00am - 5:30pm. If you would like to speak to them, you can:

- Call our office line on 01905 755977
- Send them an email at advocacy@leukaemiacare.org.uk
- You can also call the help line, free of charge on 08088 010 444. The team will pass your enquiry onto the Campaigns and Advocacy team.

Please note that our Campaigns and Advocacy team are unable to provide:

- Detailed medical advice or recommendations
- Legal advice
- Advocacy for a course of action which is contrary to the aims and objectives of Leukaemia Care.