Welfare Benefits - Part 3:
Universal credit, special circumstances and other sources of help
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 look at Universal Credit, circumstances where special rules apply when claiming benefits and other sources of help that are available from national or local government organisations.

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/](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/](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 need you 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 already 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 more on getting better. Some people feel claiming benefits lessens their feelings 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. Universal Credit

[https://www.gov.uk/universal-credit](https://www.gov.uk/universal-credit)

Universal Credit (UC) is a new system that replaces several payments with a single payment. It provides means-tested support and replaces the following 6 benefits:

- **Income Support (IS)**
- **Income based job seekers allowance (JSA)**
- **Income related employment and support allowance (ESA)**
- **Housing benefit (HB)**
- **Child Tax Credit (CTC)**
- **Working Tax Credit (WTC)**

It is being introduced in stages and whether you can claim for UC or the other benefits will depend on your location. A benefits calculator (see further questions at the end of this toolkit) will tell you which to apply for, or you can find out with a postcode checker from Citizen’s Advice. If you are not in a UC area, please see our first Welfare Benefits Toolkit for information on the individual benefits.

The government are also preparing to move everyone who claims the 6 benefits over to UC, with the promise that no one will
lose any money by doing so. The
timetable for this is subject to
change. You may wish to seek
advice during the switch in order
to ensure that you do not lose
money.

If you are in a UC area already, the
application process is online. If
you have any problems or you feel
you are unable to complete the
form online, ring the helpline on
0800 328 5644, open from 8am to
6pm Monday to Friday.

As UC is means tested, there
are lower and upper savings
limits that apply; you get the full
amount if you have savings less
than the lower limit, then lose a
certain amount of money for every
increase in savings you have up to
the higher limit, above which you
will no longer be eligible for UC.

The amount of UC you receive
will vary from person to person
based on the individual reasons
for applying for UC. There is a
standard allowance, the amount
of which is determined by your
age and whether you are single
or in a couple. This is the money
you get if you need help whilst
unemployed, in a low paid job
or searching for a job, replacing
income based JSA and IS. There
are then additional payments
added: for instance, if you have
children, if you are sick and so
have limited capability for work or
work related activities (for which
you might be required to have an
assessment, as with ESA), if you
are a carer, if you have childcare
costs to enable you to work or if
you need help with rent (the HB
replacement). Your rent payment
may be reduced if you live in a
house that has more bedrooms
than you are deemed to need;
this was discussed a lot in the
press as the "bedroom tax" and
it is advised that you take extra
advice if you think this might
affect your ability to pay your rent.
You can work whilst receiving
UC; money will be deducted from
your UC payment depending on
the amount you earn, until you
earn so much that you become
ineligible for UC altogether.
2. Receiving benefits following a diagnosis of a terminal illness

Receiving the news that you have a limited lifespan can be very shocking. Any extra financial help during this time allows the affected person to not need to work if they are unwell and could also mean they have the finances to make the most of their time.

Terminal illness can fast track certain benefits, which are then paid at the highest rate possible. This is called special rules and it applies to:

- Personal Independence Payment (PIP)
- Disability Living Allowance (DLA)
- Attendance Allowance (AA)
- ESA
- UC

How much faster the benefits are given compared to other claimants without a terminal diagnosis depends on the benefits applied for. It is advisable to contact a professional for help completing the forms, as they can make sure they are filled out in a way that avoids further delay.

A doctor must confirm that the person is reasonably expected to die within the next 6 months to qualify as a terminal diagnosis in this context. The factual statement made by the doctor to confirm this is called the DS1500. If the person then lives beyond this, you are still eligible for the benefits as benefits awarded under special rule are usually given for 3 years. The application process can be started before the form is received from the doctor, just make it clear that the claim is under special rules.

If you receive any of these benefits before you are aware you are terminally ill, you do not need to submit another claim. You can simply contact the Department for Work and Pensions to update them with the DS1500. The only exception is if you currently receive DLA as an adult; becoming terminally ill will count as a change of circumstances and so you will be asked to claim PIP instead.

Marie Curie explain the rules around terminal illness [here](#).
3. Claiming benefits if you are self-employed

https://www.moneyadviceservice.org.uk/en/articles/universal-credit-for-the-self-employed

Self-employment-and-benefits-Frequently-asked-ques

One myth around self-employment is that you aren’t eligible for benefits in the event you lose your job. However, this is not true across the board. It can affect your entitlement to contribution-based benefits (i.e. ones based on your national insurance record, see below), but you are still entitled to claim all means-tested benefits if you have a low or no income, for example if you can’t work due to illness.

Being self-employed can make the welfare system more complicated. There are a couple of reasons for this, including:

- Self-employed people pay a different type of national insurance contribution called Class 2 payments, whereas employed people pay Class 1. Class 2 don’t count towards some contribution-based benefits, such as contribution based JSA.

- For some benefits, your income is calculated differently. Being self-employed can mean that income is irregular, and it would be difficult for both you and the DWP to examine your income every month. Therefore, when claiming UC for example, you are given what is known as a "minimum income floor", an amount you are presumed to have earned based on the minimum wage for your age group (this only applies if you have been self-employed for more than 12 months). This is calculated by multiplying the minimum wage by the 35 hours of work (you are expected to work full time except in certain circumstances, such as if you receive the carer element too). You then multiply this by 52 and divide by 12 to make a monthly amount. The minimum income floor is then this monthly figure, minus income tax and national insurance contributions. This income floor is then deducted from your UC payment, just like the income of an employed person is, to work out how much UC you will get.

Because the minimum floor exists, you may not get a regular amount of UC, or any at all in your most profitable months. It is a good idea to keep money aside when you
have had a profitable month, to account for the months when you earn less. You can get more help on budgeting for a fluctuating income from the Money Advice Service. You could ask customers to pay you monthly, to ensure your income is spread out and maximises your UC.

Working Tax Credit can be particularly useful for those on a low income whilst self-employed, such as those initially starting up a business. However, rules have been tightened up. If you are self-employed on a low income, you must show that your business is a "commercial" venture, rather than a hobby you make money from or an idea that is unlikely ever to make a profit. Seek advice if you disagree with a decision about your business when you apply for WTC.

When applying for any benefit, the DWP will want to see proof that you are self-employed and evidence of your income. Therefore, it is important that you keep good records as a self-employed person, including receipts, invoices, bank statements, self-assessment tax records and a business plan.

4. Any other benefits

There are benefits and other payments that have not been mentioned in this series of toolkits. These include:

- **Pension Credit**: a benefit to top up your state pension if you have a low income. [https://www.gov.uk/pension-credit](https://www.gov.uk/pension-credit)

- **Child benefit**: this is available to most families with children or those who are responsible for children. However, you have to return a certain proportion of it back in tax for every £100 you or your partner earns over £50,000, and pay it all back in tax if you earn over £60,000. It is particularly useful to claim if you one of you is not working, even if the other earns so much that you have to pay the benefit back, as it allows the claimant to earn national insurance credits towards their state pension, something which they would not receive if they chose not to work. [https://www.gov.uk/child-benefit](https://www.gov.uk/child-benefit)

- **Guardian’s Allowance**: this is an allowance for those who care for a child whose parents have died. It can be claimed in addition to child benefit. [https://www.gov.uk/guardians-allowance](https://www.gov.uk/guardians-allowance)
Industrial injuries disablement benefit: This is paid to people who are disabled as a result of an accident at work or a disease caused by their job (not including self-employment or injuries that develop long term, such as chronic back pain). The causes of blood cancer are unknown at the time of writing, so you will not be able to claim this benefit as a result of your blood cancer diagnosis. However, you may have other reasons for claiming this benefit. [https://www.gov.uk/industrial-injuries-disablement-benefit](https://www.gov.uk/industrial-injuries-disablement-benefit)

Maternity Allowance: this is a benefit for pregnant women who are not entitled to statutory maternity pay; one example is if you are self-employed at the time of pregnancy. It is non-means tested, but if you are claiming other earnings-replacing benefits, due to being too ill to work since a blood cancer diagnosis for example, you may not be entitled to this (known as the overlapping benefit rule). [https://www.gov.uk/maternity-allowance](https://www.gov.uk/maternity-allowance)

Social fund payments.
Examples include: the cold weather payment, an extra grant given to those on certain benefits to help them pay for fuel bills when the weather is particularly cold; the winter fuel payment, a grant paid annually and automatically to those claiming a state pension or selected benefits to help them pay fuel bills over winter.

Applying for certain benefits also gives you access to a range of additional help; this is known as passporting. Examples of help available to those on selected benefits include free school meals, free or cheaper prescriptions, free eye tests, free dental appointments, a reduction on your council tax bill and local schemes such as food bank access. This is where it can be particularly important to go to a professional, such as those listed at the start of the toolkit, in order to maximise your access to benefits and additional help, however small that contribution may be.
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 Patient Advocacy team.

Please note that our Patient 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.