This toolkit, part 1 of the Welfare Benefits toolkits, covers benefits relating to replacing employment income, as well as help with housing costs.

For information about benefits for those who are disabled or bereaved, please see Part 2.

For information about Universal Credit and claiming benefits under special circumstances (e.g. self-employment, terminally ill), please see Part 3.

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 how you might replace lost income from employment with state welfare benefits.

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 0000. 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 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.

Income and housing related benefits:

If you are in work, your main concern when you are unwell is likely be maintaining an income and ensuring you can pay your bills. The state benefits listed in this toolkit are most relevant to those who were in work until the point of diagnosis but are currently unable to work, whether that is likely to be for the short or long term.

1. Statutory Sick Pay:

[https://www.gov.uk/statutory-sick-pay](https://www.gov.uk/statutory-sick-pay)

Statutory Sick Pay (SSP) is not a state benefit but an entitlement under law for employed people. It is paid to you as you would normally be paid by your employer. You do not need to have a contract to be entitled, you just need to be employed. Most employers provide extra pay while you are ill for a limited time and this is usually only after you have worked there for a certain length of time, so it is advisable to check your contract. If you sign a document that removes your right to SSP, this is not legal. Seek advice if you are asked to sign a similar document or are dismissed and you believe it is to avoid paying you SSP.
You qualify for SSP after 4 days of being ill or "incapable for work" as the first 3 days are discounted. These are called "waiting days" and are counted as each day you were supposed to work, starting from the day you were first ill and didn’t go to work. Take an example of people who work Monday to Friday. If you are ill on Monday, and continue to be ill for some time, you will start getting paid SSP from the Thursday. If you are ill on Friday and into the following week, you will only be paid SSP from the following Wednesday as you do not normally work Saturday and Sunday. Take advice if you work more complicated shift patterns or if you are worried about being underpaid.

Your employer will usually request to see a "statement of fitness for work" after 7 days of illness, which is a medical certificate from your doctor that states you are not capable of doing your usual duties. This then certifies that you are "incapable of work" and therefore eligible for SSP. You are also eligible for SSP if you feel capable for work, but your doctor has advised you to do not work AND you decide not to go. For example, this may be the case if you are immunocompromised, so are at risk of becoming ill, but are not currently unwell.

You are only eligible for SSP if you usually earn enough to pay national insurance (NI) contributions. This was earning more than £116 a week at the time of writing. If you are paid monthly, the weekly earnings are calculated based on what you earnt last pay day, multiplied by 12 and divided by 52 to give a weekly earnings estimate. Included in the earnings calculation is any employment pay (before tax and NI) and also any other statutory payments such as SSP, maternity or paternity pay.

SSP is paid weekly; the current rate is advertised on the gov.uk website or feel free to get in touch if you need more information. If you are only sick for part of a week (after your waiting days) you will be paid pro-rata for that week. For example, if SSP is £90 a week and you only are only ill and off work two days out of 5, you will be paid £36. You will be paid as normal for the other 3 non-sick days. SSP is only paid for a maximum of 28 weeks in one year.
2. Employment Support Allowance

https://www.gov.uk/employment-support-allowance

Employment and Support Allowance (ESA) is a benefit that is designed to help those who are not able to work. This may be either long or short term and can be available to those that are unemployed or those that are employed but their SSP entitlement has run out.

There are two types of ESA; contributory or income related.

- Contributory ESA is a non-means tested benefit. Whether you are eligible will depend on whether you have enough paid NI contributions. How long you must have paid NI for and how many contributions you need to have paid can be complicated to work out, especially if you have been in and out of work or if you are self-employed, so this is an area where it is advisable to seek advice.

  Although contributory ESA is non-means tested, some pension payments can cause the amount you receive to be reduced. This is another area where advice should be taken before applying.

- Income related ESA is a means-tested benefit, meaning that your income is considered when calculating whether or not you are eligible. Your partner's income is also considered in the calculations. For instance, you will not be eligible if they are working full time, and one of you must claim on behalf of the couple if you both want to claim ESA. How much you are entitled to involves starting with the personal allowance (the maximum amount of ESA you can get) and then deducting money based on how much you or your partner earns. There will also be an amount deducted based on the value of any savings you have. An online benefits calculator will often be able to do this for you, but this is a complicated process and worth seeking advice on.

  NOTE: Income related ESA is one of the six benefits that have been combined to make up Universal Credit. Therefore, if you live in an area where Universal Credit applies, you must apply for Universal Credit instead of income related ESA. You can still apply for contributory ESA alongside Universal Credit.
The process to getting the benefit is the same once you have applied for one or both types. First there is an assessment phase, where you are paid a basic allowance but must undergo a Work Capability Assessment. This assesses two things:

1. Whether you have "limited capability for work", i.e. whether you qualify for ESA at all.

2. If you do qualify for ESA, how much support you should be given.

The assessment phase lasts 13 weeks, unless it is extended by the Department for Work and Pensions (DWP); for example, if you have not yet been assessed due to a backlog or if you have been unwell. The assessment will be done by looking at the evidence you send with your application, plus a questionnaire sent to you for further information, along with a face to face assessment with a healthcare professional if necessary. A decision is then sent to you, which you can ask to be looked at again if you disagree (a mandatory reconsideration) and then appeal if you still disagree.

If you have been assessed and deemed to qualify, ESA claimants are separated into 2 groups:

1. The work-related activity group: This is where you are assessed as unable to work currently but you can undertake certain activities that may help you to be employed in the future. The activities you do will be decided between you and an assessor who you meet regularly; if you fail to attend, you may be sanctioned and lose some of your ESA temporarily.

NOTE: Applicants who applied for ESA before 3rd of April 2017 were entitled to an extra payment on top of the basic allowance if assigned to the work-related activity group. Any claimants after this date will now only continue to receive the basic allowance rate of ESA if put into the work-related activity group.

NOTE: If placed in this group when applying for contributory ESA payments, these payments will only last 365 days. You may be able to reapply for contributory ESA if you fall into the support group after this. Otherwise, you will lose entitlement to contributory ESA and will need to apply for income-based ESA instead. Take advice on what to do.
next if you feel unable to return to work near to the end of the 365 days entitlement period.

2. The support group: This is a group for people who are unable to work or do any work-related activity. Being put in this group will attract a top up payment and you do not have to undertake any further activities.

You may be asked to undergo the work capability assessment at regular intervals (annually, for example) to assess your eligibility for ESA over the long term. This applies to both groups.

There are also premiums (additional payments) available for those who are severely disabled or are caring for others whilst claiming income-related ESA; seek advice on the criteria for these if you feel you might qualify.

3. Housing Benefit

https://www.gov.uk/housing-benefit

Housing benefit (HB) is designed to help people on a low income pay rent. It is only available to those in rented accommodation. You can only get the payment if you or your partner is the one who is liable to pay the rent (i.e. you are in a legally enforceable agreement to pay the rent). You may also be eligible if the person liable does not live you because you have recently ended a relationship with them or something similar; the rules are complicated and you should take advice if you are unsure if you are legally obligated to pay rent.

NOTE: HB is one of the six benefits that have been combined to make up Universal Credit. Therefore, if you live in an area where Universal Credit applies, you must apply for Universal Credit instead of HB. There may be some areas where Universal Credit is not fully in place but you must apply for HB through the Universal Credit system. Take advice if you are not sure which system is in place in your area.

There are lots of rules about receiving HB whilst absent from home (for example, if you go to prison, leave home through fear of violence, go on holiday etc.) and
rules on how much time you can spend abroad. If you are likely to spend any time away from home, seek advice when applying and ensure you talk through your situation with the benefits adviser in detail.

You are only eligible for housing benefits if you do not have too much savings or other assets (your capital). Seek advice or get in touch with the advocacy team if you are unsure what counts as capital. There is a lower limit, where you are eligible for full housing benefit if you have capital of less than this amount. There is also an upper limit; if you have capital between the lower and upper limit, you will lose a certain amount of housing benefit depending on how much capital you have (as an example, you may lose £1 of your HB for every £500 capital you own). If you own over the upper capital limit, you are not eligible for housing benefit. An online benefits calculator can do this for you but it is still advisable to seek professional help when applying.

Once you have determined if you are eligible in terms of capital, there are different rates of housing benefit to consider. The basic allowance amount depends on who you live with and whether other adults or children are dependent upon you. There are also premiums for certain situations like being a carer, being disabled or having disabled children. You may also receive less money if you live with people who are able to work, such as older children or non-relatives, as they are then assumed to be able to contribute to the housing costs, even if they do not. There are also special rules for if you live in shared accommodation and if service charges and payments for communal areas are essential to your living costs.

HB is paid by the local authority and this is who you will make a claim to, unless you are applying for HB at the same time as income support, job seekers allowance, pension credit or ESA. It is paid at intervals that are determined by when your rent is due.
4. Income Support

https://www.gov.uk/income-support

Income Support (IS) is a benefit for people who are on a low income, such as due to being too ill to work or can only work part time. You must not be eligible for ESA or job seekers allowance, not work full time and have less savings than the current limit set. You are still eligible if your partner works more hours than you, but neither of you must work full time. Seek advice if you think either you or your partner works too many hours to qualify or if you would like to know if you have too much capital. Additionally, there are only certain groups of people on a low income who can apply for IS:

- If you are a lone parent (including someone who is adopting, a foster carer, or you are another relative with sole caring responsibility), are pregnant and not able to work, are within 11 weeks of your due date, have recently given birth or your pregnancy ended, or are on parental leave and not eligible for statutory payments like maternity or paternity pay.
- Being sick or disabled, such as in receipt of SSP.
- You care for someone sick or disabled who receives certain benefits, or you receive Carer’s Allowance.
- You are a full-time student (not including at university) and not living with your parents
- You are a full-time student (not including at university) and a parent
- You don’t have a permanent address
- You are a refugee and are learning English in a class for more the 15 hours a week (this is for a maximum of 9 months)
- You are called to court as a witness, juror or similar
Therefore, the idea of income support is to top up the income of those who’s other responsibilities or worries prevent them from being able to earn more money through work. An online benefits calculator may help you to see if you entitled based on your individual situation, but it is advisable to seek professional help when applying.

You can apply for IS through the DWP and it is normally paid fortnightly.

NOTE: IS is one of the six benefits that have been combined to make up Universal Credit. Therefore, if you live in an area where Universal Credit applies, you must apply for Universal Credit instead of IS. Take advice if you are not sure which system is in place in your area.

5. Working Tax Credit

https://www.gov.uk/working-tax-credit

Working Tax Credit (WTC) is designed to top up the income of someone who works full time but still has a low income. Benefits do not count as income in the calculation of WTC. The number of hours that count towards full time work depends on your age, whether you have children in a couple or as a lone parent or if you are disabled. You can also claim whilst on SSP or parental leave if you normally work the correct number of hours for your situation; you can also claim ESA or IS whilst on SSP and WTC, whereas healthy WTC claimants cannot claim these other benefits. Students may also be eligible with they work for longer than 4 weeks on a particular job that isn’t part of their course and meets the minimum hours for their circumstances.

Each factor (e.g. having children, having a disability, having to pay for childcare) corresponds to a top up amount on top of the basic WTC amount. Online benefits calculators may help you to calculate your entitlement, but it is best to seek advice when applying.

WTC is paid by Her Majesty’s Revenue and Customs (HMRC,
the department of government that collects taxes) rather than the DWP and so you must apply to HMRC using form TC600. HMRC calculate your income based on the previous tax year, so if you think you are eligible now but weren't in the last tax year, you can apply for a protective claim to help with falls in income. Because WTC is paid based on last year, if your income turns out to be different at the end of the year, you may be given extra money or asked to repay some money. Seek advice if you want to make a protective claim or if your income varies a lot and you think having to repay will have a negative impact on your finances.

NOTE: WTC is one of the six benefits that have been combined to make up Universal Credit. Therefore, if you live in an area where Universal Credit applies, you must apply for Universal Credit instead of WTC. Take advice if you are not sure which system is in place in your area.

6. Child Tax Credit

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

Child Tax Credit (CTC) is designed to top up the income of those who are caring for children whilst on a low income. A child is anyone under 16, although you may qualify CTC is your child is over 16 in certain circumstances. You do not have to be the parent of the child, but they must be living with you and you must have main responsibility for them. Having "main responsibility" is not defined, but the decision maker is likely to be influenced by any court orders in place and whether you are the one paying for the child's essential outgoings, like food and clothes. Seek further advice to determine if you and your children are eligible.

You automatically qualify for CTC if you are on a means tested benefit (e.g. IS). This is called "passporting". There are also top up payments for caring for disabled children; online benefits calculators can help you determine what you apply for.

Like WTC, CTC is paid by HMRC and you must apply to HMRC in order to claim. You can then indicate whether you would prefer to be paid every week or every four weeks, although the final decision can be made by HMRC.
NOTE: CTC is one of the six benefits that have been combined to make up Universal Credit. Therefore, if you live in an area where Universal Credit applies, you must apply for Universal Credit instead of CTC. Take advice if you are not sure which system is in place in your area.

Jobseekers Allowance:

https://www.gov.uk/jobseekers-allowance

While not relevant for those who are currently too ill to work, Jobseekers Allowance (JSA) is a benefit that may be helpful if you want to look for a new job once you feel well enough to work. You can apply if you are over 18, not currently working, not in full time education and your parents are no longer receiving child benefit to look after you.

You will be asked to attend an initial interview at a Jobcentre and sign a commitment document to receive JSA. The agreement will take into account your responsibilities at home and your health if needed. JSA will only continue to be paid if you complete activities, as suggested by your work coach and outlined in the agreement you sign, in order to help you find work. You must also go to any interview or take any job you may be offered, unless you can show you have good reason not to.

There are two types of JSA, like the two types of ESA: income-related JSA and contribution-based JSA. As with ESA, you will be able to claim for contributory JSA if you have made enough NI
contributions in the previous two years. Your ability to claim income related JSA is dependent on how much work you AND your partner (if applicable) do currently, and how much you have in savings.

NOTE: Contributory-based JSA is one of the six benefits that have been combined to make up Universal Credit. Therefore, if you live in an area where Universal Credit applies, you must apply for the new style JSA instead. Take advice if you are not sure which system is in place in your area.

Support for Mortgage Interest:

https://www.gov.uk/support-for-mortgage-interest

If you are paying a mortgage, rather than renting a property, you cannot claim HB. The government provides an alternative loan called Support for Mortgage Interest (SMI). This differs from housing benefits as it only pays for the interest on the mortgage, not a payment towards the balance of the mortgage. It is also different in that it is a loan, rather than a payment, and so you must pay it back. You can choose to do this when you are able to or you must do so when you sell your home. The loan also attracts interest, seek advice on the latest interest rate if you are interested in applying.

You can qualify for SMI if you are also be in receipt of a qualifying benefit. These include IS, income-based ESA or JSA, Universal Credit or Pension Credit. Receiving these benefits indicates that the income you receive is low enough that you qualify for SMI. You can also apply if you have a low income but do not get other benefits; seek advice to find out the income threshold for this. Depending on how you qualify (i.e. which benefits you are in receipt of), you may be asked to wait a period of time before you...
can receive SMI.

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=BAAdviser&utm_medium=referral&utm_campaign=GovUK and https://www.entitledto.co.uk/?utm_source=BAAdviser&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.