Employment rights 1: Being/becoming employed

Cancer and work: is it possible?
Employment rights 1: Being/becoming employed

Most people will need to take time off after diagnosis to begin treatment unless you are on “watch and wait” and feel well enough to work during that time. This is because treatments can have side effects that make you feel too ill to work. This is most important after a stem cell transplant, to allow your immune system to strengthen again.

It is natural to wonder how long you will feel ill for and to want to get back to "normal" or to how your life was before you were diagnosed. At the same time, you need make sure you give yourself sufficient time to recover and not put extra stress to yourself that might lengthen your recovery time. Always seek advice from professionals and other people you trust.

Working when you have leukaemia is possible, and it has been shown to make a positive difference to a cancer patient’s prognosis and emotional wellbeing. Other benefits to work include:

- Giving you a routine to follow
- Allowing you to maintain contact with friends
- Stable and predictable income
- Improved self esteem

However, continuing to work is a decision to be made between an individual and their healthcare team. No one should pressure you to make a certain decision or give you advice without giving you time to consider all options. You might consider other activities in the meantime, such as volunteering, internships or temping. This may allow you more flexibility for days off and to avoid gaps in your CV.

Your decisions about work are likely to depend on many things:

- Type of leukaemia; especially whether it is chronic or acute
- Whether you are in active treatment
- Type of treatment and whether you are experiencing side effects
- Symptoms you are experiencing
- Whether you need to work for financial reasons
- Whether you have other practical support in place to help you (childcare, help at home when you tired etc.)
- How you feel about being away from work (e.g. missing the social aspect, causing you financial worries).

This toolkit is designed to help you explore your rights, whatever your decision might be. Leukaemia care have also written a toolkit entitled "Employment rights 2: Leaving work" if you decide not to continue.
If you are already employed:

Telling your employer

A leukaemia diagnosis is often unexpected and will usually require immediate treatment and time off work. You’ll need to follow your employer’s rules about informing them you are ill. For example, an office may specify you phone before 9am, not just email in, and that you speak to a manager rather than another colleague. If the contract doesn’t specify, you’ll need to give your employer a doctors note within 3 days to get SSP, so it’s best practice to tell them as soon as possible, regardless of the contract.

It is also a good idea to put in place, either at this point or very soon after, a plan to keep in touch with your manager. Lay out how often and in what way you are willing to stay in touch to help you avoid unexpected calls and feel less worried about returning out of touch.

Whilst it is strongly advisable to tell your direct manager you are ill, they are not allowed to share this information with anyone else without your permission. They may wish to share your information with other managers, HR or occupational health to help you, but they should ask your permission first. You might also like to tell your colleagues too, as they can then support you better, but this should always be your choice.

Discrimination

Cancer is defined as a disability under the Equality Act 2010 (England, Wales and Scotland) or the Disability Discrimination Act 1995 (Northern Ireland). Therefore, your employer cannot treat you differently, directly or indirectly, due to your illness. This protection is provided from diagnosis and continues for life, i.e. they cannot discriminate based on past illnesses if you have recovered.

Leukaemia Care have produced another toolkit entitled "Discrimination and Cancer – your rights". It explains what to do if you think are being discriminated against, either at work or at any other organisation you interact with, because of your leukaemia.

Sick pay

Employers must pay Statutory Sick Pay (SSP), if you are eligible and have been off work ill for long enough. To be eligible:

- you must have already been ill for 4 days in a row (including weekends and holidays)
- AND earn an average over £116 a week or more.
You will then be paid £95.05 a week for a total of 28 weeks. If earn any other money while ill, SSP will count towards your taxable income. These numbers are correct at the time of going to print: please see https://www.gov.uk/statutory-sick-pay for the most up to date figures.

Some employers also choose to pay more, up to your full wage. This will usually depend on your length of service at the company. The rules should be outlined in your employee handbook or contract or contact your HR department.

If you are still unable to work at the end of your 28-week allowance, but wish to remain employed, ask your employer for the SSP1 form. You’ll need to so this before the SSP ends and it will then tell you when your last SSP payment is due. The form will then allow you to make a claim for Employment and Support Allowance (ESA), a government benefit to support those who cannot work due to illness. ESA is also included in the new Universal Credit system for certain people. For more information on ESA and other benefits, see the "Financial help for cancer patients" toolkit, also produced by Leukaemia Care. Claiming ESA does not mean that you are no longer employed, it just means that the government, rather than your employer, supports you financially. You should continue to stay in contact with your employer about your condition and when you would like to return.

Fit notes

GPs or hospital doctors can issue Statements of Fitness for Work (also called fit notes or known colloquially as sick notes). This will be required by your employer to pay SSP to you and to claim benefits after SSP where applicable. Most employers also ask for a fit note if you have been ill for more than a certain number of days, usually 7. This is also an opportunity for doctors to communicate your condition and any help you might need to your employer, so make sure you talk to your doctor about the contents. You can use the contents of a fit note to support your requests for reasonable adjustments (see sections below).

For more information on what fit notes contain, please see the government’s website: https://www.gov.uk/government/collections/fit-note.

Reasonable adjustments

In addition to not discriminating against you, the Equality Act and Disability Discrimination Act state that employers must put
in place reasonable adjustments to enable you to return to work. "Reasonable" is not a specifically defined term; it depends on an analysis as to the whether the benefit justifies any cost to the employer. Your employer can get advice on what is deemed reasonable from occupational health professionals. Ask to meet with your manager, and any other relevant people, to put together a return to work plan. You should get the opportunity to put forward your views as well as your employers suggestions. Plan for the meeting by bringing your ideas as well as knowing your rights.

Here are some ideas that may help you:

- **Phased return:** this is a common adjustment, where you agree to come back a certain number of days or hours and slowly increase that over time. You should ensure you have the right to review the arrangement should you realise you have not given yourself enough time.

- **Retraining or time to catch up,** should things have changed in your absence.

- **Flexible working** e.g. working from home or part time

- **Changing or reducing your duties or targets**

- **Extra breaks**

- **Moving your desk to more suitable location** (closer to toilets, downstairs etc.)

- **Technological help** (e.g. voice recognition software)

If you suggest an adjustment that your employer thinks may be too costly, the government’s Access to Work scheme may be able to help. It is a fund of money that can cover transport costs if you can’t use public transport, someone employed specially to support you or any special equipment you might want. For more information, visit the gov.uk website here: https://www.gov.uk/access-to-work.
Occupational health

Occupational health advisers work independently to give advice on staying healthy at work. You can refer yourself, but your employer is likely to refer you if you have been ill long term. Their advice will likely set out what needs to be put in place to help you get back into work and discuss the options with you. Therefore, it will bolster your requests to your employer for reasonable adjustments if you agree or choose to be assessed.

Small businesses may not have contact with an Occupational Health Services. There are some free services available to you for advice if you work for a small business.

https://fitforwork.org/ - England and Wales, for employees or employers in a business of up to 249 employees. There is a live chat option, or you can phone: 0800 032 6235 (English) or 0800 032 6233 (Welsh/Cymraeg).

https://www.healthyworkinglives.scot/Pages/default.aspx - Scotland, available to anyone. There is a live chat option, or you can phone: 0800 019 2211.

Other time off

If you work throughout treatment or once in remission, you will still need time off, e.g. for appointments. You should mention this as part of your reasonable adjustment requests and find out from your employer what the policy for such things is. You do not have a legal right to be paid for this time unless stated in your contract. You or your employer might suggest:

- Make up the time at another time; consider the impact on your health before you agree, this is probably not suitable for time longer than a GP appointment or similar.
- Temporarily reducing your hours
- Sick leave
- Unpaid leave
- Compassionate leave (your contract will say whether this is time limited and paid or unpaid)

Information for employers

Your employer may have never heard of leukaemia, not understand that it is a type of cancer or simply not had to deal with someone who is ill for a long time before. It can be worrying that you might have to educate them yourself. Your doctor should be able to help you explain the medical side and occupational health will explain how it affects you, so make sure you are actively
involved in all conversations and correspondence. If you would like more information to give your employer, Macmillan has put together a range of resources, such as leaflets, that might help you to explain: https://www.macmillan.org.uk/information-and-support/organising/work-and-cancer/if-youre-an-employer#161443

Not in employment but would like to be:

Applying and interviewing for jobs

Looking for work can be stressful at the best of times, let alone after a period away from employment or feeling ill. However, work has many benefits, as outlined above, and the time away may have given you time to think of new, more enjoyable or more relaxing jobs you could do.

The most important thing to remember is you are still protected under the Equality Act (2010) or Disability Discrimination Act (1995) once you are remission and then for the rest of your life. If you are asked if you consider yourself disabled, such as on an application form, it is best to say yes. You may not consider yourself disabled but saying yes means you want to be protected from discrimination under these Acts, as you deserve to be.

In England, Wales and Scotland, the Equality Act states that employers can only ask about your health, during applications or interviews, to:

- avoid discriminating against you
- try to recruit more disabled people
- check if you need adjustments for the interview
- or check if you can do an essential part of the job (e.g. driving).

Therefore, it may be best not to mention your diagnosis until after you have been offered a job, to avoid the potential of it affecting the decision to employ you. Whether you disclose your condition should always be your decision. It can be particularly useful to talk about your diagnosis if you are undergoing treatment currently. You might also choose to tell employers to help explain gaps in your CV or to use it to emphasise your
abilities and attributes despite your illness. If you are later rejected, you can then start a discrimination claim if you think the rejection was due to you telling them you had cancer.

Employers may ask about your health at the stage of offering the job, so they can make reasonable adjustments before you start, but cannot withdraw the offer for discriminatory reasons. You can choose to disclose your previous illness should you wish, although you are under no obligation to do so and it should not influence your application or any offer you might have received.

In Northern Ireland, the DDA does not prevent employers from asking about health in the same way as the Equality Act. However, any information they receive about your cancer diagnosis from asking such questions cannot be used to discriminate against you.

Overall, try to be honest with employers; you will be in a difficult position if you say you are capable of something which you turn out not to be. Be realistic about your health to keep the number of interviews to a minimum; they can be tiring and stressful so save your energy for the jobs you can do and want to do.

If you need a reference, previous employers don't have to state why you left so talk to them first if you don't want them to mention your illness.

Financial help while looking for a job:

If you are need of financial help during your time of looking for work, it may be helpful to apply for Job Seekers Allowance (JSA). This is a benefit that is paid for 6 months, and the amount depends on your age and whether you are claiming alone or in a couple. It replaces benefits such as Income Support, so take advice about whether it is appropriate for your situation. JSA is paid if you have contributed enough National Insurance payments in the past or can be means-tested if not. It is also paid with certain conditions attached. For more information, visit the government’s webpage on JSA: https://www.gov.uk/jobseekers-allowance.

Carers/parents:

If you are carer of someone with cancer, or you have someone caring for you during your cancer journey, we have made a separate toolkit which explains your rights. It covers both support if you are working whilst caring and if you are not.

If you are a parent of a child with leukaemia, we have made a
Separate toolkit that explains your rights at your own place of work.

**Self-employment:**

If you are self-employed and would like advice on how to deal with your business after a cancer diagnosis, please see the toolkit "Employment rights 3: Self Employment".

**Further questions:**

Here are some additional resources if you feel you need some more information:

[https://www.workingwithcancer.co.uk/](https://www.workingwithcancer.co.uk/) - Working with Cancer train and provide support for employees, employers and cancer charities.

[https://www.macmillan.org.uk/information-and-support/organising/work-and-cancer](https://www.macmillan.org.uk/information-and-support/organising/work-and-cancer) - Macmillan have a range of leaflets covering all situations. They also have specially trained advisors for advice on financial matters.

If you have any further questions about being employed during your cancer journey, you can contact our Campaigns and 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

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