



















Summary

There has been remarkable progress in cancer treatment and survival over the past 50 years - the number of working age people with cancer being treated, cured and returning to their employment has only grown with these successes. But it is also predicted that new annual cancer cases will increase from around 420,000 in 2023-2025, up to over half a million by 2040¹. With more people living and working with cancer, and other long term conditions, more needs to be done to support them to live a full life and return to work, should they be ready.

A number of studies have pointed to both the <u>increased costs</u> and reduced income that people being diagnosed with cancer can face². A person's sick pay arrangements and ability to access other forms of financial support are another major factor in the treatment and recovery of people diagnosed with cancer.

Whilst most cancer diagnoses occur in the over 65 age group, who can draw upon the income of a pension to support them, around 900,000 working age people are now estimated to be living with cancer in the UK³. An estimated one third (33%) of all contract and agency workers will only have access to Statutory Sick Pay (SSP), the legal minimum an employer pays. A further 4%, 1.3 million of these workers receive no sick pay at all as they are below SSP's lower earnings limit for their main employment⁴.

Paid at just £116.75 a week from the fourth day of illness, SSP is an effective income replacement rate of just 17% for a worker on the average salary, one of the least generous rates in the OECD nations. We have hundreds of pieces of testimony from workers living with cancer and other conditions as to the very difficult financial situation this has caused.

We estimate that at least 250,000 people with cancer working in the UK were left either reliant on SSP or without any sick pay from day one of illness⁵.

Many of these same people may be ineligible for sickness benefits or Universal Credit, or face delays in accessing them.

This briefing examines how much income people with 3 common cancer treatment regimens stand to lose whilst receiving SSP. We assess this income loss against Minimum Income Standard (MIS), a widely accepted standard based on public consultation that assesses what everyone needs in order to meet their essential needs - food, clothes and shelter - but also what they need to feel included in society and live with dignity.

The recommendations we make are in line with those of the <u>Safe Sick Pay campaign</u> and build on evidence given by charities, business groups and experts to the recent Work & Pensions Select Committee sick pay inquiry. They include increasing the weekly amount sick pay is paid at, paying it from day one, not day four, and ensuring more effective support for people with cancer from the benefits system.

Improvements to SSP should be extended to every worker, both people living with both cancer and other health conditions. The evidence shows these reforms would bring wider benefits to employers, the NHS and the wider economy

OUR RECOMMENDATIONS

- Increasing Statutory Sick Pay (SSP), In line with a worker's wages up to the living wage
- · Making SSP payable from the first day of sickness
- Abolishing the earnings threshold for SSP
- Ensuring benefits such as Personal Independence Payments and Universal Credit, are sufficient and available as soon as possible at the point of need beyond SSP

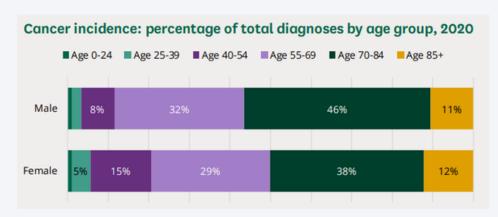
Cancer in the working age population

Half (50%) of people diagnosed with cancer in England and Wales survive their disease for ten years or more (2010-11). Cancer survival is improving and has doubled in the last 50 years in the UK.

Around 4 in 10 of those now diagnosed with cancer each year are of working age. This, together with improved survival rates, means that employees who want or need to continue working after a diagnosis will be more common in workplaces of the future.

Around 900,000 people of working age are living with cancer. Each year - 127,000 people of working age are diagnosed with cancer.

Women are more likely to be diagnosed with cancer at a younger working age. Of 288,753 cancer cases in 2020 in England, 20% of women diagnosed were aged 25-54, compared with 10% of men aged 25-54. Cancer, as with inadequate access to sick pay, is more likely to affect people on a low income, compounding health inequalities.



Statutory Sick Pay - How much is it and who gets it

Most workers in the UK receive employer sick pay, at full or part of salary. However, an estimated one third of contracted or agency workers get SSP, which at £116.75 per week is the legal minimum employers can offer. It is paid from the fourth consecutive day of illness. Around 1.3 million workers get no sick pay as they fall below the lower earnings limit.

Comparing these figures to the employment rate and working age cancer population gives us estimates of the scale of the cancer population surviving on just SSP or on SSP and sickness benefits.

WE ESTIMATE...

At least 35,400 people each year are going through their cancer treatment with inadequate sick pay

249,000 working people are living with cancer on or below SSP.

Around 275,000 working people are caring for / taking time off to support someone else with cancer whilst on SSP, or ineligible for sick pay

See reference for workings⁶. The above are conservative estimates, as we do not include self-employed people who cannot access SSP, or those whose SSP runs out after a matter of weeks, yet face months of treatment.

What a good recovery from cancer looks like

Having cancer is different for everyone.

The experience someone has when living with cancer will vary depending on a range of factors including their age, ethnicity, where they live, and other health and lifestyle factors.

People's experience of cancer is primarily impacted by the type of cancer diagnosed with, and the type of treatment(s) that they will have. Different treatments (such as chemotherapy, radiotherapy, immunotherapy, surgery, stem cell transplants etc) take place over different periods of time, using different techniques which require different experiences of attending hospital, and also have differing side effects which impact day-to-day life outside of cancer treatment. Treatments are often given in combination with each other.

You may not be able to be around lots of people, or do things you would normally do.

Treatment with chemotherapy may take place over a period of several months. Everyone will have their own treatment plan, but this will usually require regularly attending hospital. Side effects of chemotherapy include being immunocompromised and at greater risk of other illnesses and infections.

This means you may not be able to be around lots of people, or do things you would normally do. Other side effects can include sickness, tiredness, weakness, and other changes in the way your body and organs work. The combination of treatment regimen and side effects mean that staying in regular employment will likely be difficult to manage.

Surgery is another example of treatment that may be given for cancer, where it is possible to remove the cancer and tissue around it. Surgery will usually require attending hospital for a procedure, which may require a stay in hospita. Depending on the location and size of the cancer being removed, side effects may be minimal or include caring for a wound, infection risk, weakness or nerve damage. Surgery may be a standalone treatment, or another form of treatment such as radiotherapy or chemotherapy, may be given in addition. Similarly, radiotherapy may be used as a standalone treatment or in combination with another treatment. This may cause short term side effects in the weeks after treatment ends, and longer term side effects that may last for years or for life.

It is expected that people with cancer should begin treatment within two months (62 days) of an urgent referral, and people with cancer should begin their treatment within a month (31 days) of deciding to treat their cancer — bringing significant change to someone's life over a period of a matter of weeks.

Surgery will usually require attending hospital for a procedure, which may require a stay in hospital afterwards.

Depending on the type of cancer, treatment, side effects and other factors, recovery following cancer treatment will vary. Rebuilding strength physically, managing short and long-term side effects, and the mental health impacts will all play a role in recovery and how quickly someone may be able to return to work or other activities. Follow-up care and check-ups are also usually required after treatment over a period of months or years.

Some types of cancer, such as chronic lymphocytic leukaemia (CLL), aren't currently able to be "cured". Treatment may be used to control the cancer and slow its progress, and people may be living with their cancer and its impacts for many years.

In 2023 Young Lives vs Cancer undertook research into the financial impacts of a cancer diagnosis for young people (and children). This assessed the additional costs caused by the diagnosis, the loss of household income, and measures people took to manage these impacts.

This briefing focuses on loss of income and impacts on employment linked to provision of sick pay. This will be outlined using three example case studies, which cover just some of the experiences people may face.

- Person A diagnosed with melanoma (skin cancer), needing 2-3 months off work Person A needs surgery to remove the cancerous cells, and a skin graft. They continuing to work whilst waiting for surgery, but may need time off for appointments. They then undergo surgical treatment, taking time off from work for this and the period following surgery. They experience side effects including pain. Six weeks later they see their consultant and no further treatment is needed. They return to work after healing.
- Person B diagnosed with breast cancer, needing a minimum of 6 months off work- After being diagnosed, which will have necessitated trips to hospital, person B waits for their treatment to start, but may need time off for appointments. Person B undergos surgery to remove the tumour, taking time off from work from this point onwards. A month later they start chemotherapy every 2 weeks for 4 months. They then have radiotherapy every day for a week, and start a 5 year course of hormone treatment.
- Person C diagnosed with acute lymphoblastic leukaemia (ALL), needing over 1 year off work Person C is admitted to hospital within 24 hours of diagnosis, beginning treatment quickly. During the first year they undergo treatment that includes chemotherapy, and a stem cell transplant, both physically intense treatments with varied side effects that mean they are unable to work for at least a year. We studied costs in the first year. Beyond this there is also a significant risk of relapse for person C, and they may experience long-term side-effects like Graft versus Host Disease. They may require further time off and support.

The cost of a cancer diagnosis

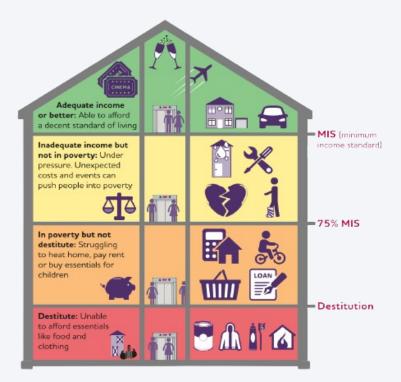
A cancer diagnosis comes with an additional financial burden, with cancer patients and their families facing a range of extra monthly costs throughout their treatment. The cost of travel, food, energy and clothing mount up, alongside the losses experienced by having to reduce or stop working during their treatment. There is a growing body of evidence on how people are impacted:

- Research by Working with Cancer found that the proportion of people who return to work successfully after cancer treatment "remained disappointingly low" one-third of workers did not phase their return to work. One-quarter used annual leave during their treatment⁷.
- In 2023 Young Lives vs Cancer found that almost £700 extra a month was spent by young cancer patients and their families following a cancer diagnosis, including £250 extra a month in travel costs, due to hospital visits⁸.
- Data from Macmillan from 2020 shows that 83% of people with cancer in the UK experience some kind of financial impact from their diagnosis, and for those affected, this reaches an average of £891 a month - a combination of loss of income and additional cost⁹.
- Leukaemia Care studied the costs facing working people as part of its 2023 Leukaemia Levy campaign. More than a quarter of patients reported losing up to 60% of their monthly income after diagnosis, and 21% received no income at all during their treatment¹⁰.
- Anthony Nolan's 2023 survey revealed that cost of living issues were so severe for some patients that they reported going without food, avoiding putting the heating on, with 3 in 10 people unable to afford their rent or mortgage during the 12 months treatment period ¹¹.

Minimum income and a safe recovery

The Centre for Research in Social Policy (CRSP), Loughborough University has assessed the impact of falling ill and relying on Statutory Sick Pay.

CRSP's annual minimum income standard (MIS) calculation determines the weekly UK household budget needed to maintain a socially acceptable standard of living, based on a basket of everyday goods and services. In 2023, a single person needs to earn £29,500 a year to reach a minimum acceptable standard of living ¹².



Source: Joseph Rowntree Foundation / CRSP, Loughborough University

SSP: jeopardising a safe recovery for cancer patients

We have used the MIS standard as a basis for assessing the impact on a workers standard of living after a cancer diagnosis led them to move from a median salary onto SSP, comparing 2023 rates.

Each individual was assumed to be a full time worker in their 50s cohabiting with a partner on the ONS median salary, of £34,693. Both they and their partner are relatively comfortable before diagnosis, earning 135% of MIS so putting them in a middle income household bracket. They are not eligible for benefits at the point of diagnosis due to their combined income.

On the next page we calculates how many days would be taken off under the three treatment criteria and both monthly and cumulative real terms income losses and shortfalls against MIS for:

- Someone with melanoma skin cancer diagnosed. total two months of sick pay taken at SSP.
- Someone with breast cancer diagnosed, total ~6 months of sick pay taken at SSP
- Someone with leukaemia (ALL) diagnosed, total ~ 12 month continuous period off during year one of treatment, with some additional time off whilst waiting for treatment and in years 2-3. First 28 weeks paid at SSP. They receive Personal Independence Payments at month 7 in line with current waiting periods.

Universal Credit deductions due to the partners income mean the couple receive £5.38 per week Work Capability Allowance from week 13. In these scenarios the worker will run out of SSP at week 28 and become eligible for £101.75 per week Personal Independence Payments at month 7, factoring in the built in waiting period and usual delays.

Lost income, higher costs

Analysis from CRSP, University of Loughborough¹³ found that a person's income would fall from 135% to between 67% - 85% below the minimum income standard needed to live a dignified life, before the extra costs of cancer diagnosis are considered. A couple with a mortgage would face a greater shortfall, and would not be eligible for Universal Credit until week 13 (if it all). By month 7 the person undergoing treatment will claim Personal Independence Payments but will not longer get sick pay.

Total losses	MIS shortfall (mortgage)	MIS shortfall (renting)	total lost income	cost & lost income total
Melanoma 2 months off	-£1,960	-£1,210	-£3,561	£4,961
Breast cancer 6 months off	-£5,468	-£3,302	-£10,093	£14,293
Leukemia 12 months off	-£10,792	-£6,460	-£20,042	£28,442

Cost and combined impact

Factoring in costs would send the couple even further below the minimum income standard. We have assumed £700 a month based on previous research from several cancer charities. This includes extra bills from travel, hospital parking, heating costs, childcare and changed diet. Costs range from £1400 in the 2 month scenario to £8400 in the 12 month scenario.

A worker on the median salary taking 6 months off for cancer treatment stands to lose £10,093 income, whilst facing £4,200 in extra costs.

Key numbers summarised

526,000

estimated number of people taking time off for their own treatment, or taking time out to care for people with cancer, subject to unpaid SSP sick pay waiting days

249,000

estimated number of people of working age living with cancer on SSP, or with no sick pay

35,400

estimated number of people diagnosed with cancer each year on SSP or ineligible for SSP

£3,561-£20,042

total loss in income over 2 - 12 month time period

£177 - £276

weekly minimum income standard (MIS) shortfall

17%

proportion of median earnings sick pay replaces after week 1

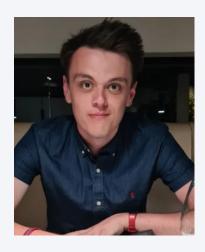
The work so far describes scenarios that might exist for the large number of people diagnosed with cancer each year without adequate sick pay.

The reality for many people who experience a cancer diagnosis on SSP is that they might get some grant based support from charities in the early stages of treatment. As things go on goes on they can be forced back to work before they are ready, forced to take annual leave as paid holiday, or forced to borrow and get into debt or risk bankruptcy or even homelessness. The next section summarises some real life experiences people living and working with cancer shared with us.

Dan Berry, 23

Accountant, Essex

I went to see my GP and was referred for a biopsy, where they take a tissue sample for testing. Even this part of the experience turned out to be very stressful. I had a three month delay due to a cancelled appointment and lost paperwork. When it finally arrived, I discovered that I had stage two cancer.



I was told I was going to need 32 rounds of radiotherapy treatment, and that there were few specialist cancer treatment centres for young people. I'd have to travel at least 40 miles each way to the hospital, every day of the week for 5 weeks.

I left my job, and was out of work for over a year, because of the negative impact of my illness and SSP on my mental health.

At the time I was working for a big supermarket chain as an assistant store manager. I'd been there six years and worked through the pandemic with them. I'd never had much time off before so didn't know what I'd get. They offered me just two weeks sick pay at my salary then I was on £99 a week SSP.

When I looked at my outgoings, gas, food, electric and my share of the rent, I could see I wouldn't be able to stay afloat financially on SSP.

Mphango Simwaka, 25

Consultant, London

In October 2022, I was settling into my new job with excitement and anticipation, having moved from Bradford to London. Just two months later I received a shock diagnosis that led to me being placed on sick pay. My monthly income plummeted from £1700 to £464. This financial strain persisted until I was unfortunately made redundant in August 2023. Despite this, my medical treatment continues, I've been advised not to return to work for at least a year to aid my recovery.



Navigating this period was particularly challenging due to complications with Universal Credit (UC) covering my rent payments initially. The delay in accessing my full UC entitlement meant my sole income was the meagre sick pay, which proved insufficient, especially given the high cost of living in London. I found myself relying heavily on the support of my community to cover essential living expenses and rent.

A more equitable sick pay system would offer payments closer to an individual's prediagnosis wage.

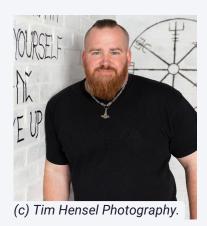
It's unfair to penalise someone financially for falling ill; after all, a diagnosis is beyond their control. A safe sick pay system would alleviate financial stress during an already challenging time, allowing individuals to focus on their recovery.

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Tony Pullen, 48

Engineer, Kent

Before I was diagnosed with leukaemia, I was doing more than full time work because of financial pressures. I was working every weekend. Then, when I was told I had hairy cell leukaemia, everything came crashing down on me.



The next day, as soon as I was in hospital, I told my workplace, "Look, I'm in no fit state to come in the moment".

I was continuously tired and out of breath. From that day, I was off work for a full 7 months, in and out of hospital with septicaemia. I got full pay for the first six months, but I was already struggling at the time of diagnosis and we had no savings.

What people don't realise is that your costs also go up when you get cancer. For example, because I was unable to drive, my partner had to get the bus to a lot of places, and rely on cabs to get shopping back. Then I went onto Statutory Sick Pay. This is when we needed to really look into more support, because of the huge drop in the amount of income. I was told to try for benefits, but they said straight away that I didn't qualify. I was refused PIP, as I was able to move around enough according to the assessor.

To top it all off, I had to field phone calls coming through making demands on some small debts.

I was an emotional wreck and it was a very, very bad time. My dad kindly put forward the money, some of his life savings, to keep a roof over our heads. But the only option was to declare myself bankrupt. It was a long and hard process, which I'm still in five years later.

Your costs also go up when you get cancer... I was unable to drive, so my partner had to get the bus to a lot of places, and rely on cabs to get shopping back.

It's how the impact goes beyond the person diagnosed that upsets me the most. I wanted to support this campaign to help anyone like me. To show them that there's always a light at the end of the tunnel, and we can stop this happening to other people in the future.

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Clare Randall, 55

Project manager, Dorset

I was diagnosed with Stage 4 Hodgkin Lymphoma for the second time five years ago and needed chemotherapy followed by a bone marrow stem cell transplant.

Due to the ridiculously low level of SSP, I had no choice but to work during treatment, and the qualifying days meant that my treatment days weren't covered.





Given the taxpayer had just saved my life at considerable expense, I found it baffling that my recovery was jeopardised for want of a sensible SSP system.

In between in-patient chemo, I worked weekends so that I could afford 'days off'. When I went into hospital for the stem cell transplant, I managed to work for a few days from my hospital bed - the rest of the four weeks I took off on 'holiday'.

After I got out, I cracked and had two weeks on SSP, which I was lucky to be able to afford due to savings, before going back to work on part-time hours. This was possible for me only because of the nature of my job. It scares me what would have happened if this had not been possible.

All this had a knock on impact on my long term health. I'd like this unjust system fixed so that no-one else has to go through what I did.

Alan Barton, 65

Engineer, Sussex

I was diagnosed with stage 3 cancer bowel cancer earlier last year and had to take four months off initially for the operation and treatment. At the time I discovered I was ill, I was an engineer with around 40 years' experience. I had always paid my taxes and worked since leaving school at age 16. I was only with the company for just over a year so I only got SSP from day one.





On top of all the stress of being told you could be dying, I had to worry if I could provide for my family. I wanted to speak out, because no-one should go through what I did.



I went from a healthy salary to surviving on what amounted to around £3 an hour. What I got in sick pay each month didn't even cover one third of my £1,200 a month rent. Things got so bad I nearly went bankrupt, but I was lucky my brother and family helped me get through.

I've now left work and I'm getting nothing, not even the state pension, after 40 years of working. Macmillan have been a brilliant help, they are trying and get access to employment and support allowance. But they can only do so much.

I've now signed up with employments rights campaigners Organise! to try to change this and would encourage others to join the campaign.

What a safe sick pay system looks like

The situation facing people with cancer is a cause for deep concern and is reflective of the experiences of working age people with a wider variety of long term conditions.

Given the prolonged periods of illness people may face with cancer, an adequate weekly and monthly level of income replacement is critical to ensuring workers and their families can achieve the minimum income standard needed to recover safely and live a dignified life.

OUR RECOMMENDATIONS

- 1. Increasing Statutory Sick Pay (SSP), In line with a worker's wages up to the living wage
- 2. Making SSP payable from the first day of sickness
- 3. Abolishing the earnings threshold for SSP
- 4. Ensuring benefits such as Personal Independence Payments and Universal Credit, are sufficient and available as soon as possible at the point of need beyond SSP

Reforms towards a safe sick pay system could be achieved through a mix of primary and secondary legislation in Parliament. Improvements to SSP should be extended to every worker, both people living with both cancer and other health conditions. The evidence shows these reforms would bring wider benefits to employers, the NHS and the wider economy. 14

Cost-benefit analysis of the reforms

Previous modelling of the three sick pay reforms proposed in this briefing found the direct cost of these to business would largely be outweighed by benefits brought by increased productivity, reduced presenteeism and a reduced flow on to long term benefits

WPI Economics tested different options for raising the weekly amount of SSP, scrapping the 3 unpaid waiting days and removing the lower earnings limit and found business, the taxpayer and economy would all benefit to a total of £4.2 billon a year taking direct costs into account.



Further evidence

Macmillan has previously explained the shortcomings in the benefits system in enabling people to afford everyday essentials, the interlinked challenges presented to people diagnosed with cancer between sick pay and the benefits system are a vital part of the picture, if we are to improve the experience of people diagnosed with cancer of working age¹⁵.

National Voices, the leading coalition of health and social care charities has looked at the link between elective care waiting times and SSP. As patients face treatment delays, they require more days off and inadequate sick pay risks further deterioration of long term health¹⁶.

References and workings

- [1] Cancer research UK Cancer incidence for all cancers combined.
- [2] Young Lives vs Cancer: The £700 a month cancer premium.
- [3] Macmillan Cancer Support: Work and Cancer, 2016.
- [4] WPI Economics average forecast for proportion of workers receiving SSP. 1.3 million workers under the LEL limit is from the TUC's latest evidence.
- [5] Source. Stats and chart: Cancer research UK: Cancer statistics demographic.
- [6] Figures on page 5 are estimates: b] 249,075 is calculated from 36.9% of 675,000 people in work living with cancer, 33% who get either SSP or 3.9% no sick pay. Source: 33% of contracted and agency workers access on SSP [WPI Economics: Making Sick Pay work]. 3.9% are under the LEL limit [TUC].
- **We exclude self employed people [ONS: 13% of the labour market], so our figures likely underestimate the total not eligible for any sick pay in the wider labour market.
- c] 276,750 people are juggling work and caring for someone with cancer without adequate sick pay. (36.9% of 750,000 [Source: Macmillan]. Added to 249,075 gives us the estimate of 525,825 workers paid SSP or receiving no sick pay due to their own / others treatment.
- [7] Working with Cancer: Cancer and Employment Survey
- [8] Young Lives vs Cancer: Cancer Costs research.
- [9] Macmillan: Macmillan Cancer Support/Truth survey of 1,329 adults who have received a cancer diagnosis. Fieldwork: 13th January 7th February 2020.
- [10] Leukaemia Care: <u>Leukaemia Levy campaign</u>.
- [11] Anthony Nolan: Cost of living survey June 2023.
- [12] CRSP, Loughborough University, Minimum Income Standard.
- [13] CRSP, Loughborough Universityh: analysis for the Centre for Progressive Change for this policy brief. The data compares 2023 SSP and 2023 living costs.
- [14] WPI Economics, Making Statutory Sick Pay work.
- [15] Macmillan: Evidence to the Work & Pensions inquiry on benefit levels. See also: Pay PIP now campaign.
- [16] National Voices: Evidence to the Work & Pensions Select Committee inquiry.