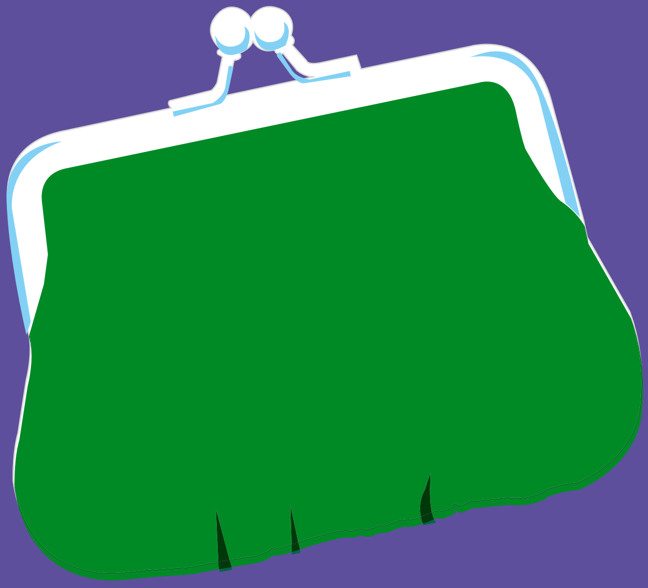
CANCER AND SOCIAL SECURITY

What people with cancer need from the benefits system and what they get

MACMILLAN
CANCER SUPPORT

> ‘I think probably…80% of my money coming in just goes on bills rent and petrol… sometimes I really worry about being able to keep the heating on if it’s a really big bill.’

Thelma, New-Style-ESA & PIP, thyroid cancer



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Introduction

At Macmillan, every day our Welfare Rights Advisers speak to people like Thelma, who are struggling with the financial impact of cancer alongside managing the physical and psychological consequences of their condition.

We know the financial impact of a cancer diagnosis can be devastating. Of those with a diagnosis, 75% will experience a loss of income, which often comes at a time when costs are rising significantly, with 90% of people experiencing additional costs relating to their condition. The types of costs vary from travelling to hospital appointments to higher heating bills because they feel the cold more, to having to spend more money on specific foods or clothing and wigs.[†]

The financial impact of a cancer diagnosis can be sudden and most people aren't prepared for their finances to be impacted so significantly. Additional costs can spiral quickly, which can also lead to an emotional impact as people struggle to adjust. This can be particularly true for people of working age. Macmillan's research has shown that people with cancer of working age are more likely than people of non-working age to be severely financially impacted as a result of their diagnosis. Nearly three-quarters (72%) of people with cancer who are most severely impacted were in some form of employment before they were diagnosed. Many in this most impacted group have to cut down or stop work as they go through treatment and recovery, making them more likely to face a substantial loss in income. Meanwhile, they are more likely to have significant financial commitments such as paying a mortgage or rent or supporting children.

Because of this, many people with cancer of working age will need to turn to the social security system for support, claiming working age benefits like Universal Credit (UC) Employment and Support Allowance (ESA) and Personal Independence Payment (PIP). These benefits are designed to help people who are on low incomes or out of work, and to cover extra costs of a disability or health condition, like cancer. More broadly, they are meant to help people manage at a time when their finances are under significant strain.

However, our experience from talking to thousands of people claiming these benefits tells us that navigating the system is complex and draining and even if claims are successful – many are not – the support the system provides is often inadequate. This must change.

Macmillan is dedicated to supporting people with cancer to get the benefits they are entitled to. We are also committed to ensuring that the voices of people with cancer are heard and that their experiences are at the heart of conversations and decisions about the future design of the social security system in the UK.

90% of people with a cancer diagnosis experiences additional costs related to their condition

To help us achieve this, we've completed a research project to better understand what people with cancer, particularly those of working age, want and need from the social security system and to what extent their current experiences are meeting these expectations.

This report outlines the findings of this research. It sets out a series of principles which articulate what people with cancer told us the system should deliver for people in their situation, describes the current experiences of people with cancer who claim benefits and sets out what must change to ensure social security is more responsive to their individual needs and aspirations.

[†] Reference: Macmillan Cancer Support/Truth survey of 1,329 adults who have received a cancer diagnosis. Fieldwork was undertaken between 13th January and 9th February 2020. The survey was carried out online. Sample is weighted to represent national population of people who have received a cancer diagnosis in terms of demographics (age, gender, region) and cancer type/time since diagnosis using prevalence data.

A word about our research methodology

Throughout this project we've worked with social research agency Revealing Reality to speak to people with cancer about their experiences of claiming and receiving working-age benefits.

We wanted a clear picture of what it feels like to have cancer and claim benefits in the UK. We made sure we spoke to people across age groups, genders, ethnicities, and the four nations of the UK.

To ensure confidentiality, the names of those involved in the research have been changed.

We split the research into two phases.

Phase 1
Understanding expectations

In the first phase of the project we wanted to understand in depth what people's needs were and how they felt the social security system could best meet those needs. We spoke to people with cancer of working-age who had claimed disability benefits across the UK, to develop and test a set of principles, which set out what people wanted and needed the system to deliver for them.

Phase 1 consisted of telephone and in-person in-depth interviews with 17 people, and a focus group of 6 participants.

Phase 2
Understanding experiences

In the second phase of the project we wanted to test whether people with cancer felt that the principles were being delivered.

We talked to people about their experiences of the current system and then compared these to the expectations set out in the principles. This allowed us to build a detailed understanding of how the system is currently working for people with cancer, and to identify areas where improvement is needed.

Phase 2 consisted of screening interviews with 50 people, telephone interviews with 25 of these and in-depth home interviews with a final 8 people.

Covid-19

The second phase of our research with people with cancer was completed in January 2020. This was before the outbreak and escalation of the Covid-19 pandemic, which has had a significant impact on all aspects of society, including cancer care and the social security system.

While our conversations with people with cancer do not make reference to the impact of the pandemic, we believe that the themes and issues identified through our research remain relevant now and beyond Covid-19. In fact, ongoing insight from our benefits advice services during the pandemic has indicated that many of the issues people with cancer had identified in this research are being exacerbated by the impact of the pandemic.

A summary of what we found

People of working-age with a cancer diagnosis helped us to identify eight principles that outline what they want and need from the social security system. The first principle outlines the overall outcome that the system should deliver for people with a cancer diagnosis. The other seven principles outline how it should deliver this, both in terms of the level and type of financial support provided, and the experience people with cancer have of engaging with the system.

Principle 1: Help to live the best life possible & achieve my goals

Overall, the system should support people to adjust to the impact of their diagnosis so they can live the best life possible with cancer. It should help people to work towards their own goals without feeling pressured or dictated to by the system.

Financial needs and lifestyle

Principle 2: A reasonable standard of living

Social security should cover the cost of day-to-day living, as well as essential extra costs that come with a cancer diagnosis.

Principle 3: Help to feel good

Financial support should go beyond 'the basics' to help cover the costs of things that promote wellbeing.

Principle 4: Short-term and long-term support

People with cancer should be supported to cope with the initial financial shock of a cancer diagnosis and then adjusting to living with cancer.

Engaging with the system

Principle 5: Easy, obvious and efficient

Processes and communication should be responsive, clearly understandable and easy to navigate.

Principle 6: Expectations that reflect my capabilities

The system should only ask things of claimants which are reasonable and reflect their capabilities whilst coping with the impact of their diagnosis and treatment.

Principle 7: The system is on my side

People should feel trusted by the system and that they can trust it to treat them respectfully and fairly.

Principle 8: A consistent service

Having a good experience of social security should not rely on luck or individual staff going above and beyond the normal standard of service.

Principle 1

Help to live the best life possible & achieve my goals

People with cancer felt the overarching principle that should underpin the social security system was that it should help people live the best life possible. People with cancer should be supported to adjust to their life with cancer, and to pursue their personal goals, not have them dictated by the system. For the majority, this means maintaining the lives they had prior to diagnosis or finding ways of adjusting to living with cancer.

> **‘Hobbies and social life are also important to … feel part of the human race. You’re not less of a human being [because you have cancer and are receiving benefits].’**
> Sally, 55, peritoneal cancer

To achieve this, the system should:

- Empower people to achieve their own goals, not those dictated by others. This could mean supporting people to stay on track with aspirations they held prior to their diagnosis or pursue new ambitions.
- Recognise that these ambitions might relate to finding or maintaining work but may also include priorities like maintaining an active social life or sorting out affairs at end of life.
- Provide support that is personalised and modified as people’s circumstances change.

Experiences

Most of the people we spoke to didn’t feel that the system supported them to achieve their goals. Many described just ‘surviving’ and not having enough money or mental energy to think about any goals beyond this. Those who wanted to return to work after cancer did not feel the employment support available recognised their needs, and many were fearful that engaging with this support would result in their benefits being reduced.

Adjusting to life with cancer
People with cancer felt they had to adjust their priorities, or put them on hold, as a result of their diagnosis, so that they could focus on their health.

While some people appreciated that support from benefits allowed them to stop work and focus on their health, the social security system often failed to adequately support goals beyond this, with many feeling they couldn’t afford to do anything besides ‘survive’. Whether they were able to think about goals such as spending time with family and friends, or pursuing new hobbies or a social life, depended on whether they had income from other sources.

> **‘I don’t go anywhere… honestly, a hospital check-up is as close as I get to a day out’**
> Denzel, 57, prostate and stomach cancer

Work
In terms of goals around returning to work, people did not put much faith in the help available from the system, and many felt that it was not tailored enough to their situation.

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Keeping the sense of who you really are

Wilson was diagnosed with testicular cancer. After two surgeries and three months of chemotherapy, he found himself struggling with fatigue and chronic pain at work.

A mechanic by trade, Wilson was known as the ‘Clutch Kid’ at the garage he worked at because of his ability to rip out car gearboxes with great speed. This work was hard and physically demanding, but gave Wilson a sense of identity, as well as a decent weekly wage. Before he became ill, he would take home £600 on a good week.

Later, when work became unmanageable, he recalls losing a sense of himself, which he has struggled to regain since. Wilson is in the Limited Capability for Work Group for Universal Credit, but feels that many of the courses he attends are too physically demanding. He once had to leave a course half way through because of the pain and discomfort he was in.

> **‘ I feel the system is set up to force people who aren’t ready to go back to work ’**

Wilson would appreciate more help from the benefits system to retrain in a different field, but doesn’t feel that his chronic pain is being taken into account with the opportunities he is currently being offered.

Wilson is 23, and was diagnosed with testicular cancer. He receives Universal Credit (he previously received New-Style ESA for a year). He also claimed PIP.

Some people also worried that if they talked to staff within the benefits system about ambitions to return to work, this could result in their claim being closed before they were fully recovered.

‘I’m scared they [Universal Credit staff] would use it against me… I’d rather try it out myself’ Rory, 27, adrenal cancer

Managing their claim
For some, especially those who struggled to meet essential costs or who faced delays in their claim, making and managing their claim became their priority ‘goal’. These people reported that the demands and mental strain of engaging with the system and managing their money overrode other priorities, including their health.

‘The benefits system dictates my planning… my priorities haven’t existed’.
Josie, 51, bowel and rectal cancer

What does this tell us?

These stories show that people with cancer need more support to feel empowered to achieve their own goals, which will be different for everyone. While some will be looking to return to work, for others being able to spend quality time with family or friends will be crucial to their health and wellbeing.

‘I’d love to be able to make some memories with my children – fun, childhood memories.’
Thelma, 30, thyroid cancer

The financial support available from the system doesn’t currently allow most people to look beyond day-to-day survival to think about their goals. While there is support available around returning to work, it isn’t tailored enough to the specific needs of people with cancer. Some people are also mistrustful of this support and may be reluctant to engage with it because they fear doing so will be ‘held against them’ or cause them to lose financial support.

Principle 2

A reasonable standard of living

People with cancer felt that the benefits system should provide them with enough money to maintain a reasonable and dignified lifestyle, which allows them to function as a valuable citizen.

'People need a little bit of cash in their pocket to hold their head up. If you pay your bills and have nothing left, that causes a great deal of depression and frustration' Jack, 57, stomach cancer

To achieve this, the system should:

- Cover the essential costs of day to day living, including the additional costs resulting from a cancer diagnosis.
- Support people to maintain their housing situation for as long as possible.
- Provide people with enough money to engage with society, build meaningful relationships with family and friends and stay physically and mentally healthy.

Experiences

Our research showed that experiences varied significantly between people who had alternative sources of income – including occupational sick pay or income from a partner – and people whose sole income came from benefits.

People who had additional sources of income tended to be more comfortable, although many still reported having little breathing room for changes in circumstances and having to live month-to-month.

Those whose income came solely from benefits told us that they could usually just about afford 'the basics' – rent, bills, groceries – but that this was a struggle. They often weren't able to cover additional costs related to their cancer. Some reported taking out credit cards or loans, or relying on support from family, friends, or charities to cover essential costs.

'We weren't in a good way after I got diagnosed. There were a couple of months when we were going to the food bank. It was very worrying really.'
Cassie, 36, breast cancer

Costs of cancer
Some people struggled to cover the additional costs of their cancer, such as higher travel and energy costs, particularly during treatment and recovery. People with young children often could not afford childcare when they were in hospital and had to rely on friends and relatives.

'There are weeks where I barely leave the house because I just can't afford to do anything. Some nights I have to go to bed early because I can't afford to keep the heating on.' Rebecca, 50, breast cancer

Making up for lost income

While many people claimed benefits, which enabled them to take time off work during their treatment and recovery, most felt that this support wasn't sufficient, and financial pressure caused them to go back to work before they were ready.

While Sarah was having treatment, she received half-pay from work and her husband took up extra shifts, but they still struggled. When this half-pay ended, she felt she had no choice but to rush back to work.

'My benefits are not enough, I'm not [eligible] for Universal Credit at all – we might have had to sell the house, move in with my husband's parents … or go bankrupt' Sarah, 43, placenta tissue cancer

What does this tell us?

Ultimately, this insight shows that for many people with cancer there is a gap between the amount of money they feel they need to live a reasonable and dignified lifestyle, and the level of support available from the social security system. Some people told us that the support they received left them struggling to afford their essentials, especially as costs such as heating bills increased with the impact of their cancer. Others felt pushed back to work before they were ready because the support they received was not enough for them to manage.

> **'Some nights I have to go to bed early because I can't afford to keep the heating on.'**
>
> Rebecca, 50, breast cancer

Principle 3

Help to feel good

Most people we spoke to recognised and expected the need to adapt their lifestyle to live on benefits. However, on top of needing to cover essentials, people with cancer felt strongly that social security should cover the cost of things that promote wellbeing and help them cope with the impact of a cancer diagnosis on their quality of life. People were clear that being able to afford such things was vital for them to stay physically and mentally healthy.

'Being able to put the heating on, being able to shop for healthy food, having an occasional coffee with a friend, maybe an outing once in a while.'
Sally, 55, peritoneal cancer

To achieve this, the system should:

- Cover the cost of undertaking activities that people enjoy, like socialising, taking the kids out, getting some respite etc.
- Support people affected by cancer to cover costs related to maintaining self-confidence and dignity – including aesthetic costs associated with dealing with the effects of cancer and its treatment (wigs, prosthetics, bras etc).
- Recognise that some people need this type of support to feel like themselves and maintain good mental health.
- Ensure there is no stigma on spending money on things which support quality of life.

Experiences

Some of the people we spoke to described using their social security payments to spend time with family or buy healthier food to aid their recovery. However, the majority felt they were just 'surviving' and couldn't afford anything beyond their rent, bills and groceries, with some struggling to cover these. Many people also talked about the feelings that claiming benefits gave them and being concerned about how spending money on things that helped them 'feel good' would be perceived.

More than just the 'basics'?
Some of the people with cancer we spoke to were able to use their income from benefits to make positive choices about their health and treatment, or to spend time with family.

'It took the stress away… I could afford to have juice and buy my own water.'
Winona, 64, breast cancer

However, many people, particularly those relying solely on benefits for income, felt the amount they received left them just about 'surviving'. They felt socially isolated, disconnected from friends or family, and struggled with their mental health.

'I barely have a life outside of the home'
Wilson, 23, testicular cancer

Stigma and anxiety
A few people we spoke to wanted to emphasise that they had never claimed benefits before and thought they would never have to. Despite knowing they were entitled to benefits, some put off applying or took a while to 'come around to the idea'.

'I was hesitant about applying, I've never had to do anything like this in my life.'
Molly, 31, sarcoma

Some also described a stigma around claiming benefits, either feeling uncomfortable spending their benefits on anything but essentials or feeling they didn't deserve the things that supported their wellbeing whilst living on benefits.

'I wouldn't feel comfortable spending money on things that aren't essential.'
Dawn, 56, breast cancer

What does this tell us?

The fact that so many people we spoke to felt they didn't have enough money to afford things that supported their wellbeing or recovery, prevented social security from playing the positive role it can and should in the lives of people with cancer. It is also clear that the experience of receiving benefits has a certain stigma attached, with many people internalising feelings that they shouldn't spend money from social security on things that aren't deemed 'essential'.

> **'I was hesitant about applying, I've never had to do anything like this in my life'**
>
> Molly, 31, sarcoma

Principle 4

Short-term and long-term support

People with cancer felt that the benefits system should recognise the differing financial needs they can have at different stages of their journey and provide support that is responsive to this. They talked about needing both swift support immediately after diagnosis and more tailored longer-term support.

'There was a big impact from day one.' Ella, 52, stomach cancer

'In the long-term people need all sorts of different support. Some have recurring issues that put them out of action regularly, but this can be quite unexpected.' Romy, 34, brain cancer

To achieve this, the system should:

- Provide swift short-term financial support to people with a recent diagnosis, who need immediate relief due to the often unexpected financial shock caused by cancer.
- Provide tailored support for people in the long-term, who could experience several different needs as their cancer progresses and recognising that some people's financial needs will not decrease over time.
- Offer support for those who are able to establish a new financial equilibrium (e.g. getting back to work, adjusting their spending patterns).

Experiences

Most of the people we spoke to struggled with a lack of support somewhere along their journey. Some found the waiting periods built into the system meant they couldn't get support quickly, while others faced errors and delays which left them without support for long periods. Many who relied on support in the long-term felt that this was less adequate than what they had been offered initially and felt abandoned or forgotten.

Need for speed

Many respondents struggled with a lack of support immediately after their diagnosis. For many the financial impact of cancer was immediate, but the speed at which they were able to get support from the social security system did not match up. While some people took up advances (loans to be paid back from future benefit payment) to cover the 5-week wait for UC, others talked about being forced to rely on income from other sources to get by in these early stages.

Errors and delays

As well as frustrations with in-built waiting periods, many people told us that errors or delays in claims and assessments left them struggling for longer than they needed to.

Dawn started a claim for PIP in March, but it took 6 months before she was told she had been granted the benefit. During this period, she was in a crucial stage of her recovery from treatment, and really struggled financially.

'You don't get anything while you're waiting.' Dawn, 53, breast cancer

Kelly's PIP assessment was cancelled twice, leaving her with no financial support while waiting.

'They apologised but said there was nothing they could do other than reschedule another assessment. So now I'm at the bottom of the queue again.' Kelly, 25, bone cancer.

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When you can’t afford to wait for help

Immediately after her diagnosis, Cassie’s costs rose. She had to buy a range of new clothes, pay for additional travel, and spend more on food. Cassie estimated her diagnosis added ‘£200-300 per month easily’. Despite this, as Cassie was waiting to complete the assessment period, at this point she didn’t receive any additional support from Universal Credit and had to rely on support from food banks and charities.

‘Without that help, we would have been really struggling.’

Once she began receiving the LCWRA (Limited Capability for work-related activity) element things ‘weren’t so tight’, and Cassie was able to afford things like takeaways as she was too fatigued to cook, but she still wasn’t able to afford all the things she’d like to, such as ‘little treats’ for her children.

‘£300 sounds like a lot, but if you’re already £100 short, that makes it hard.’

Cassie is 36 and was diagnosed with breast cancer. She receives Universal Credit and PIP.

Planning ahead
Some people also struggled to adapt to their change in income and felt they didn’t have enough money to plan ahead or manage unforeseen costs.

‘We manage reasonably well, but if there was an unexpected expense we’d struggle. We take things week by week.’
Mona, 61, multiple myeloma

Many found that a lack of longer-term support left them feeling abandoned when they finished cancer treatment. Lots of people were re-assessed and, despite still struggling with the physical and emotional impact of their diagnosis, found that they were entitled to less support than they had been previously.

‘The recent cut back to my PIP has been devastating… I’ve now eroded all of our savings, including money set aside for funerals. I don’t know if I can bury myself.’
Winona, 64, breast cancer

‘The system is not set up for long-term illness. I don’t think they understand what it means to live with the effects of cancer… I’m in constant pain.’
Wilson, 23, testicular cancer

What does this tell us?

These insights show that the points in someone’s cancer journey where financial need is most acute are often not aligned with when support is available from the social security system. There is a clear need for the system to be more responsive to the needs of people with cancer, both in recognising and mitigating the financial shock immediately after diagnosis, and adapting to the changing needs people have in the longer-term, particularly for those who aren’t able to return to work.

Principle 5

Easy, obvious and efficient

As well as talking about the financial support they needed, we talked to people with cancer about how they wanted the system to deliver this support. People felt strongly that the system should be easy for people with cancer to engage with, especially as many will be going through treatment or struggling physically and mentally at the time they apply. They were also clear that the system should be responsive to changes in circumstances.

'It's difficult to know what you can claim for initially. It's difficult to find forms and the application process is too slow.' Matthew, 56, hairy cell leukaemia

To achieve this, the system should:

- Respond promptly to claimants, especially regarding changes in circumstances.
- Promote information about entitlements widely.
- Make information and guidance around claiming clear and engaging, so it is easy for people who are ill, tired or in hospital to engage with the system.
- Empower people affected by cancer to make good decisions for themselves, make truthful assessments and set realistic objectives.

Experiences

Our research found that there were recurring difficulties people with cancer faced when engaging with the system. Lots of people struggled to understand what benefits they were entitled to and how to make a claim. Once they had started a claim, many faced difficulties with rigid application processes, confusion about what was happening with their claim, and the overall complexity of the system.

Complexity

For many people with cancer, claiming after a diagnosis is their first contact with the social security system. Many of the people we spoke to didn't know they were eligible for benefits or how to apply, and found the information provided by the Department for Work and Pensions (DWP) insufficient or confusing. Lots of the people struggled with the process of claiming and only managed to claim with support from charities or advice services.

'The Citizens Advice Bureau helped me out a great deal, without them I think I would have struggled'. Denzel, 57, prostate and stomach cancer

'If it wasn't for Macmillan, I wouldn't have a clue'. Rebecca, 50, breast cancer

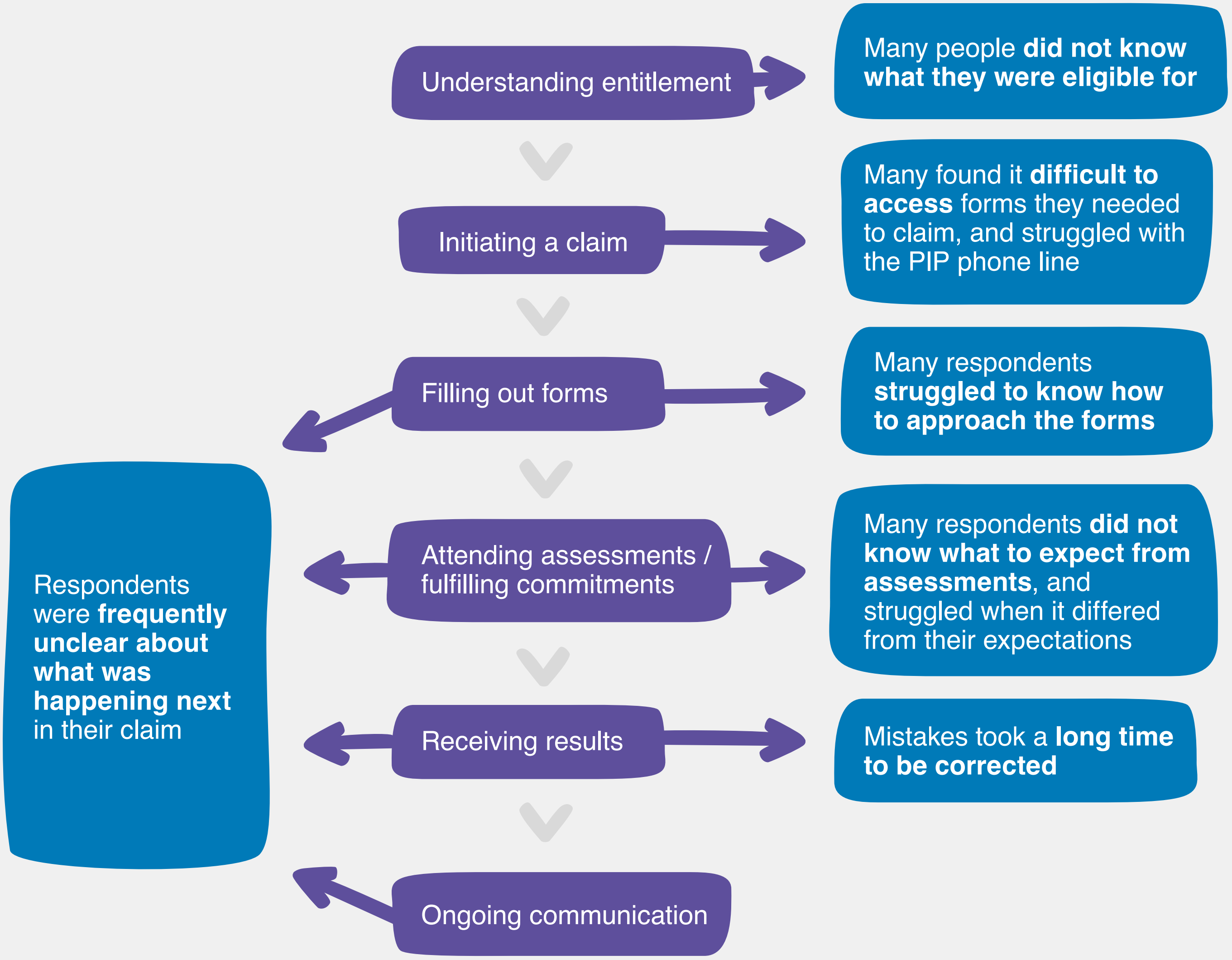
Making a claim

Others found the lack of flexibility in how they were able to complete an application difficult, particularly while struggling with the impact of their condition and treatment.

'My hands often hurt following treatment, it's an inconvenient side effect and made filling in the PIP form by hand quite painful.' Sarah, 43, placenta tissue cancer

'It felt like I was on my own with it all… I just had to sit at the computer, it took me a really long time as I'm no good with computers.' Tom, 64, throat cancer

Recurring issues across all benefits:



Understanding entitlement → Many people **did not know what they were eligible for**

Initiating a claim → Many found it **difficult to access** forms they needed to claim, and struggled with the PIP phone line

Filling out forms → Many respondents **struggled to know how to approach the forms**

Attending assessments / fulfilling commitments → Many respondents **did not know what to expect from assessments**, and struggled when it differed from their expectations

Receiving results → Mistakes took a **long time to be corrected**

Ongoing communication

Filling out forms, Attending assessments / fulfilling commitments, Receiving results, Ongoing communication → Respondents were **frequently unclear about what was happening next** in their claim

Throughout the process: Most respondents felt they had to rely on external support to navigate through the benefits system

Evidence
People we spoke to found the requirements to provide evidence about their condition arduous and complicated. Many felt like their illness was being 'tested' and believed that medical evidence or doctors notes should be enough to 'prove' their condition.

'I can understand why they need to see evidence but a single discharge letter should be enough… I shouldn't have to see six different doctors.'
Wilson, 23, testicular cancer

Pete was frustrated at having to repeatedly provide fit notes for Universal Credit while waiting for his assessment.

'They don't seem to take notice of the sick notes… the doctor says I'm not fit to work. You have to keep proving your health.' Pete, 50, testicular cancer

Lost in the system

Pat had been living with cancer for seven years when she found out about PIP through a friend. She hadn't realised she was eligible as she didn't think of her cancer as a 'disability'. Pat believes at the time of her diagnosis someone probably told her about PIP, but she had a lot of information to take in and it could have slipped her mind. She thinks there needs to be better signposting and awareness – had she known she was eligible she would have started claiming a lot earlier.

Once Pat decided to apply, she and her husband struggled to fill in the form, which took them a whole week to complete.

'I've never filled in anything like it before, [so] I had nothing to compare it to.'

Pat reflected that she felt like the language in the form was designed for people with degenerative illnesses, and not cancer. She therefore struggled to quantify her illness and was struggling to adjust to the idea that her cancer is considered a disability.

After sending the forms off, Pat heard nothing for a few weeks, she was incredibly stressed and wished someone had confirmed that her application had been received.

'I just wanted some reassurance that they had received my application.'

After hearing nothing for another week, she rang up and was informed that her application had not been received and she was advised to do it again. After sending off her second application, Pat was informed her first one had arrived and there was a 'mailing problem'. She asked if her application was going to be processed from the date on the original form and was informed this would not be possible.

Pat, 50, has been living with recurrent breast cancer. She has applied for PIP.

Communication
Many people found the system was impenetrable and struggled to understand what was happening with their claim. Communication from the DWP was described as unclear, infrequent and unpredictable, which caused additional stress. When errors were made, many had to wait a long time and go to a lot of effort to get them resolved.

Dawn had a telephone assessment for PIP but was surprised by the call and had not been expecting it.

'There was no warning it would happen… it came out of the blue… it was a number I didn't recognise'. Dawn, 53, breast cancer

'Sometimes you have to wait on the phone for over an hour, only to get through to someone that doesn't really want to speak to you.'
Rachel, 56, breast cancer

What does this tell us?

These insights show that the social security system is not easy for people with cancer to engage with. The fact that most people had to rely on support from outside the system to navigate it demonstrates the need for a fundamental redesign, with a focus on reducing complexity, providing clearer, proactive information, and reducing barriers to accessing support. The high rate of delays and errors reported also raises concerns and it is clear that the DWP needs to take greater responsibility for resolving issues, rather than the onus being on claimants to chase up problems which can cause further distress.

Principle 6

Expectations that reflect my capabilities

People with cancer were clear that they needed the social security system to recognise the impact of a cancer diagnosis on their physical and mental capabilities. They wanted the expectations that were placed on them – during applications, assessments and other touchpoints with the system – to reflect their capabilities and not put them under undue pressure or stress

'Doing anything is an effort.'
Rodney, 63, metastatic lung cancer

To achieve this, the system should:

- Ensure that people are not faced with unrealistic expectations, which can cause undue worry and stress.
- Provide support to those who wish to work but recognise that some people with cancer cannot work and ensure that any expectations placed on them to undertake work related activity are aligned to this.
- Encourage people to present their capabilities as truthfully as possible, by empowering them to have a say in the nature of the work they are able to undertake.
- Recognise that people often want to feel they are 'contributing' in some way – whether through work or volunteering – and value support to do so in a way that works for them.

Experiences

Many people acknowledged and appreciated flexibility in the claims process where it was applied because of their diagnosis or treatment. However, most of the people we spoke to felt that their interactions with the system put them under unnecessary pressure and stress. Many felt that they were asked to do things that were unreasonable given the impact of their diagnosis, and lots of people described an imbalance between what was expected of them as claimants and the service received from DWP in return.

Flexibility
Some of the people we spoke to felt that the system was flexible and understanding of their capabilities, especially those who did not have to attend assessments, who reported being grateful for this flexibility.

Kelly was told that she didn't need to provide additional evidence for her assessment.

'I had some more doctors notes that I offered to show but she said she didn't need to see them and had enough information from me.'
Kelly, 25, bone cancer

Laura was diagnosed with terminal bowel cancer. She believes her terminal diagnosis allowed her to receive support from Universal Credit more easily than she might have otherwise.

'When I came to do it with the cancer… I was expecting to have to jump through the hoops, and I didn't have to. I do believe that the piece of paper they had with my diagnosis on it helped me enormously.' Laura, 52, bowel cancer

However, most people also felt that what was asked of them at certain points was extremely difficult given their health condition.

Universal Credit

People found the initial application challenging as many needed to complete it when they were having treatment. Those who claimed Universal Credit found it difficult and frustrating to have to travel to a Jobcentre, often at a time when they were more at risk of infections because of their treatment and suffering from fatigue.

‘I was in hospital at this stage, really out of it’ Josie, 51, bowel and rectal cancer

‘It felt a bit unfair that I had to go to the Jobcentre… for ESA all I had to do was ring up.’ Rory, 27, adrenal cancer

Others on Universal Credit reported feeling there was a significant burden on them to complete tasks or submit information that felt beyond their physical and mental capabilities, and that the stress of what would happen if they weren’t able to comply was very difficult.

‘I told them I have cancer and that I am going through treatment and they still kept asking me to sign things that I didn’t need to sign.’ Jolene, 42, bowel cancer

‘My commitments were things like ‘I’ll attend and take part fully in meetings’… [Having to reply] was stressful, annoying and trivial.’ Amber, 31, breast cancer

Shelly was placed in the wrong conditionality group for Universal Credit while having cancer treatment and was asked to take steps to look for work.

‘I was worried if I didn’t sign them, they’d stop my benefits. I just had to leave a follow up note saying, ‘I’m not actually looking for work, I’m incurable and on a clinical trial.’ Shelly, 36, multiple myeloma

‘You wait and wait for a reply… but if I’m late providing them with something, I get sanctioned.’ Wilson, 23, testicular cancer

Assessments

When it came to PIP assessments, many reported finding this difficult, especially when they were already struggling physically and emotionally because of their cancer

Thelma had just come out of hospital after having treatment when she was visited for a home assessment, which she found very difficult.

‘There was lots of mental pressure… I didn’t have any energy and couldn’t think straight.’ Thelma, 30, thyroid cancer

I told them I have cancer and that I am going through treatment and they still kept asking me to sign things that I didn’t need to sign

What does this tell us?

Where there is flexibility in the system to take account of someone’s cancer diagnosis it can have a positive impact on the experience of making a claim. However, many people feel the expectations placed on them by the social security system are often unrealistic and not reflective of their physical and mental capabilities and even where there is flexibility it is often not consistently applied. People with cancer – from those having treatment to those attempting a return to work – told us that they felt pressured by the system to do things they felt were unreasonable, or that added to their stress at an already difficult time. People also felt frustrated that while they were expected to do a lot by the system, the level of service delivered by the DWP in return was too often inadequate.

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Principle 7

The system is on my side

People with cancer told us it was really important to them that they felt the system was on their side. Many had struggled with feelings of stigma around claiming benefits and felt the system should play a role in ensuring people felt deserving of the support available. In practice this meant being supported to access the support they were entitled to and being treated with respect and consideration when engaging with the system. People with cancer told us that they wanted to feel like they can trust the benefits system and that they are trusted by it.

‘I was expecting to be treated fairly by everyone, but on the phone, I felt I was a fraud. They wanted to catch me out, I really had to prove myself. I wanted to be treated with respect.’
Sally, 55, peritoneal cancer

‘I don’t trust the system at all. I have to justify myself at every corner.’
Mark, 63, colon cancer

Experiences

Most people we spoke to felt like the system was not on their side. People felt distrusted and exhausted by having to ‘prove’ themselves and were often left feeling deflated after interactions with the social security system. Many were frustrated by feeling that their condition and its impact were not well understood or recognised. Where some people reported that there were times when they felt the system was on their side, they thought it was because individual staff were sensitive and more flexible towards them because they had a cancer diagnosis. These positive individual interactions significantly improved their experience of claiming benefits.

To achieve this, the system should:

- Reduce as far as possible any difficult barriers to accessing support.
- Assume that people with cancer applying for financial support are ‘deserving’ – so people feel entitled to this support rather than having to fight for it.
- Have a degree of personalisation, so it can cater for people in different circumstances.
- Provide clear guidance about what the criteria for accessing support is, so people feel that regulations are clear and transparent.
- Ensure touchpoints with the system (e.g. assessments) are set up sensitively, so that people do not feel they are unreasonably challenged to prove themselves.
- Ensure that all elements of the process of claiming benefits are respectful and supportive of claimants.

Fighting for support

More often than not, people said they had felt that they had to ‘fight’ for the support they received or had to ‘prove’ they were deserving of help.

‘The system would rather spend time trying to get you back to work and off benefits, rather than helping you get more.’ Chris, 60, non-Hodgkin lymphoma

‘I’ve had to fight every which way.’
Denzel, 57, prostate and stomach cancer

People felt that the language and approach used by some of the DWP staff they interacted with created a culture of distrust, and many did not feel respected in their interactions with the system. This was common among those who claimed Universal Credit, and some felt that having to attend the Jobcentre felt unnecessary and made them feel distressed.

‘I’ve felt like a scrounger… spoken to like a piece of sh*t.’ Rebecca, 50, breast cancer

‘It’s [the Jobcentre] not very welcoming. The whole atmosphere, [there’s signs everywhere saying] ‘you must look for work 35 hours each week.’
Rory, 27, adrenal cancer

Recognising the impact of cancer

The most common touchpoint in claims where people felt the system was not on their side was during assessments. Many reported that the assessors did not seem to understand cancer and the impact it has, which led to feelings of frustration or that they were not being taken seriously by the system. This was compounded by the structure and type of questions asked, which made the process feel impersonal and left people worrying they had not given a full account of their capabilities.

Shelly said her assessor didn’t know myeloma was a type of cancer.

‘After briefly explaining what [multiple myeloma] was, I didn’t have much faith that she’d understand it and the impact it has on my life’.
Shelly, 36, multiple myeloma

Dawn had expected the assessment to be a chance to discuss openly her physical and mental health challenges, but found the questions were very specific and closed.

‘I didn’t get a chance to feed my own concerns into their criteria.’
Dawn, 52, breast cancer

Many also expressed concerns that, because their cancer was not a ‘visible’ illness, they would not receive the support they needed. People reported feeling a pressure to present a ‘certain way’ to be taken seriously, which led to confusion and anxiety.

‘You can be seriously ill on the inside but look fine on the outside, they don’t take that into account, especially if you are young and look fit.’
Shelly, 36, multiple myeloma

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Feeling under investigation

Jolene felt lots of the questions she was asked were ‘investigative’ and designed to encourage inconsistency and contradiction. This ‘game’ of interpretation caused her significant anxiety.

‘Questions were phrased in a certain way... [I felt my] responses were being spun. It’s a lot to deal with when you’re already at the end of your tether.’

The atmosphere of distrust meant that when Jolene’s assessor left her scarf behind, she questioned whether or not this was part of the test.

‘I did think, if I try and catch up to her will she think I can walk easily?’

Jolene is 42 and was diagnosed with bowel cancer.

Feeling ‘on trial’

Many people told us that they felt like the assessor ‘viewed them with suspicion’ and was trying to ‘catch them out’. When it came to the outcomes of the assessments, many reported these not reflecting what was discussed during the assessment, and their awards not being what they expected or felt they needed.

‘What was said at the time was not what they had written down. It made me so angry… we were both in the same assessment.’ Winona, 64 breast cancer

What does this tell us?

These insights demonstrate that too many people with cancer do not feel trusted, supported or respected by the social security system. Some people with cancer talked about feeling that there was a culture of distrust around claiming benefits. People often felt that they weren’t given the opportunity to authentically and truthfully describe the impact of their condition, instead feeling like they had to ‘play’ the system to avoid being ‘caught out’. When people do feel the system is on their side it can significantly improve the experience of claiming benefits.

Principle 8

A consistent service

People with cancer wanted the system to offer a consistent service, regardless of geographical location or other circumstances. People felt that they should be able to expect the same service and support throughout their experience of engaging with the system, and from all the staff they interacted with.

‘Everyone should be on the same playing field.’ Jon, 61, oesophageal cancer

To achieve this, the system should:

- Mitigate challenges in specific locations which impact access to support (e.g. services only available in certain areas).
- Provide a consistent standard of service and support, ensuring people affected by cancer can navigate the system without encountering obstacles or relying on the ‘luck’ of encountering staff who are willing to go the extra mile to help.

Experiences

Our conversations with people with cancer showed a lot of inconsistency in experiences of the social security system, and in the level of service received. Those who had positive experiences to share described these as rare interactions, rather than consistent across their engagement with the system. Others described barriers they faced when accessing support, and a disjointed system that did not feel set up to meet their needs.

Some went the extra mile

People we spoke to as part of this research felt that the standard of service they received from the social security system was generally poor. Although some respondents spoke positively of interactions they’d had with the system, which tended to be based on individual staff or elements of the system, rather than their overall experience.

‘My first assessor was very warm – I felt like I could talk to her honestly.’ Winona, 64, breast cancer

‘The lady in my assessment was understanding and listened carefully… [but staff I spoke to on the phone] wanted to pass me off.’ Thelma, 30, thyroid cancer

Looking for a joined-up experience
Many people we spoke to were frustrated by a lack of consistency with whom they interacted. They were often left confused by contradictory advice.

When Jolene's work coach went off sick, several of her messages and questions posted in her Universal Credit journal went unanswered for a long period of time. Over the period of a few months she had 11 different people leave comments in her journal. Jolene was very anxious that her temporary work coaches didn't understand her condition or the history of her claim, and a number of her payments have stopped and started without explanation.

'I kept having to repeat myself, no one seemed to care or take the time to read my messages on the journal – it felt like my case was at the bottom of the priority.' Jolene, 42, bowel cancer

'It's not very reassuring. I kept having to repeat myself… if they can't even get my name right, God knows what else might go wrong.' Dawn, 53, breast cancer

'Luck' plays a role in positive experiences
Across the people we spoke to, there were a range of experiences, even between people who were in similar circumstances at the time of applying. Some felt that their positive experiences were down to 'luck', such as living close to a Jobcentre or being assessed by someone who was familiar with their condition.

Shelly was given bone strengtheners the day before her PIP assessment, which gave her flu-like symptoms. She felt this was a lucky coincidence and that if she had not looked 'visibly ill' she would not be receiving as much support as she does. She described knowing other people with the same diagnosis who had not been as 'fortunate' to receive the higher rate, particularly those who were young and 'looked well'.

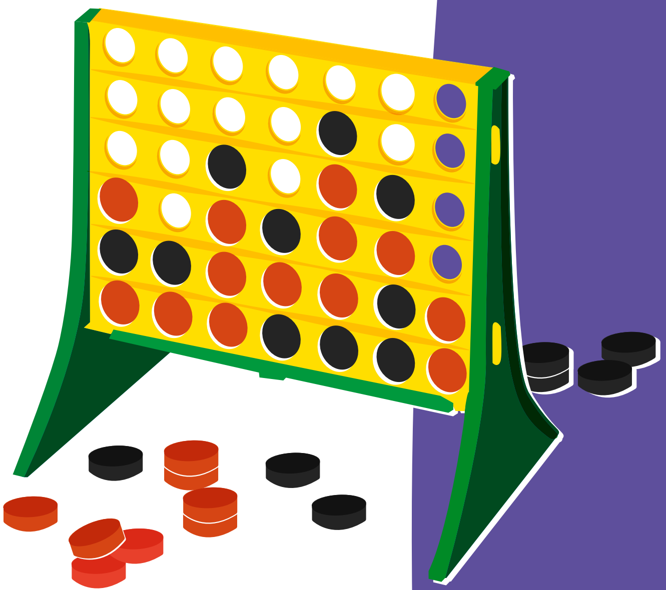
'I looked visibly very ill which definitely worked to my advantage. I think I was pretty lucky to have my assessment [on a day]…when I was feeling really terrible.' Shelly, 36, multiple myeloma

Not the right 'type of claimant'
Others felt that the system was not designed or able to meet their needs due to their condition and felt that the DWP was used to dealing with a certain 'type of claimant', who could easily be moved back into work.

'The system is made out to look easy, but only for people who fit the 'right' category.' Alex, 60, non-Hodgkin lymphoma

What does this tell us?

These insights show us a lack of consistency in how people with cancer experience the DWP's service, and that positive experiences rely heavily on discretion or additional support from individual staff. There is a clear tension for people with cancer who don't feel like the system is designed to support them, either because their illness was not obvious enough for the PIP criteria, or because the focus of Universal Credit on moving people into work clashed with what they felt they needed or were able to do.



Summary and conclusions

This research helps us to understand what people with cancer want and need when they claim working-age benefits, and the gap between these expectations and what the current system is delivering.

The eight principles set out above, co-produced with people with cancer, describe modest expectations that should not be seen as unrealistic or out of reach for a key public service. Unfortunately, this research demonstrates that to a significant extent these expectations are not being met and improvements are required across all aspects of the system to make it more responsive to the needs of people with cancer. While there were pockets of good practice and examples of DWP and JobCentre staff going above and beyond, too many people told us that they didn't feel like they got adequate support from the system, and that accessing support was difficult, stressful, and demoralising.

In summary, the research highlights the following key lessons:

1. For many people with cancer who need to claim working-age benefits, particularly those without other sources of support, the amount of money provided is insufficient to allow them to think about much beyond 'just surviving'.
2. The social security system often does not provide people with cancer the support they need quickly enough, particularly when they are first diagnosed and begin treatment.
3. In the longer-term, the level of support is often unpredictable and can be withdrawn when it is still needed.
4. Claiming working-age benefits can frequently be complex, time-consuming and emotionally draining, particularly for people who are coping with a health condition like cancer.
5. Too often people with cancer do not trust or, feel trusted by, the social security system and often feel like they have to 'fight' to access support that they are entitled to.
6. Many people with cancer feel like the expectations placed on them to claim and receive benefits are not always reasonable and reflective of their capabilities. At the same time, there is a sense that the expectations placed on the system are too low.
7. Most people with cancer do not feel like their goals or aspirations are well supported by the social security system.
8. When people feel the system is responsive and flexible to their needs or individuals working within the system go above and beyond, it can positively impact the experience of claiming benefits.

Clearly, our research demonstrates that change is necessary. While it is reflective of the experiences of people with cancer of working age, it is likely that the principles and these findings would resonate with a wide range of claimants, particularly those with a disability or health condition.

We are hopeful that change is possible. The principles identified in this research show us what a system that recognises and responds to the needs of people with a condition like cancer could look and feel like. The testimony in the research also points to examples that live up to claimants' expectations, which we can learn from.

Macmillan will continue to use these principles and experiences to shape our thinking and contributions towards improving working-age benefits for people with cancer. We encourage policy-makers across the UK to do likewise and to seek to build a social security system that meets the needs of all those who rely on it for support, and empowers people not just to survive but to live well.

With thanks

We would like to express our heartfelt gratitude to everyone who took part in this research for their time, openness and willingness to share their stories in the hope that their experiences will help improve the experiences of others. We would also like to thank Revealing Reality for carrying out the research on behalf of Macmillan.

At Macmillan, we give people with cancer everything we've got. If you're diagnosed, your worries are our worries. We will move mountains to help you live life as fully as you can.

And we don't stop there. We're going all out to find ever better ways to help people with cancer, helping to bring forward the day when everyone gets life-transforming support from day one.

We'll do whatever it takes. For information, support or just someone to talk to, call 0808 808 00 00 or visit macmillan.org.uk

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