A close-up photograph of a person's hands tearing open a white envelope. The person is wearing a grey and white striped shirt. The envelope is being held by both hands, and the top flap is being pulled apart, revealing a blue patterned interior. The background is blurred, showing other people in a crowd.

NO SMALL CHANGE

**WE ARE
MACMILLAN.
CANCER SUPPORT**

**Time to act on
the financial
impact of cancer**

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Lynda Thomas,
Chief Executive,
Macmillan
Cancer Support

Foreword

The physical implications of cancer are widely recognised. However, people with cancer – and those around them – face another, less obvious burden: the financial impact of their diagnosis. This means that across the UK, many are forced to contend with the double hit of reduced income and increased costs.

Previous Macmillan research has shown that four out of five people with cancer are, on average, £570 a month worse off because of their diagnosis. Our evidence – and our experience of working with people affected by cancer – also shines a light on the devastating toll this financial impact can have on an individual's quality of life, physical wellbeing and mental health.

We know of people with cancer who are struggling to pay their bills, cutting back on food or not going to their medical appointments because they can't afford the cost of travel. Many find themselves in serious financial difficulty and are forced to rely on improvised financial solutions, such as selling assets or borrowing from family members. A recent Macmillan survey found that 40% of people with cancer who have savings have used at least some of them to cover the financial impact of their diagnosis. Meanwhile, we estimate at least 30,000 people with cancer in their 40s and 50s have had to borrow money from their elderly parents. In some cases, people with cancer have ended up bankrupt or homeless.

However, when people get the right help and support at the right time, they have a much better chance of coping with the financial impact of cancer.

Through its services, Macmillan helps thousands of people every year to claim benefits, while providing free financial guidance and one-off grants. Our Make Money One Less Worry campaign also raises awareness of cancer's financial impact amongst patients and at-risk groups.

However, the issues faced by those affected by cancer are complex and challenging, with no silver bullet solution. This report sets out what governments across the UK, health bodies and financial services firms can do to better support people who experience the financial impact of cancer.

With the number of people living with cancer set to grow from 2.5 million to four million by 2030, it's imperative that these stakeholders act now. By following the recommendations set out in this report, they can make a real contribution to ensuring that every person affected by cancer gets the financial support they need, when they need it.

A handwritten signature in black ink, which appears to read 'Lynda Thomas'.

The financial impact of cancer – a growing issue

Macmillan talks to people affected by cancer¹ every day. So, alongside the physical and emotional effects, we know the devastating impact that a cancer diagnosis can have on an individual's finances. Many are left in serious financial difficulty and, more worrying still, facing a reduced quality of life or negative impacts on their mental and physical health. Our research bears this out. And, what's more, it shows that the number of people living with the financial impact of cancer is set to grow in the coming years.



'I pretty quickly worked out that I had to find some financial options, otherwise I wouldn't be able to pay my rent and I wouldn't be able to pay all my bills. That was just the simple truth.'

27-year-old Thom had emergency surgery for colon cancer, followed by nearly six months of chemotherapy. His diagnosis affected his ability to work and, as a self-employed person, he worried about being able to pay his bills.

Cancer's Hidden Price Tag – the financial impact, quantified

In 2013, Macmillan published *Cancer's Hidden Price Tag*; the first ever report to set out the scale of the financial strain faced by people with cancer in the UK. Based on research from the University of Bristol, it showed that four in five people with cancer are, on average, £570 a month worse off as a result of their diagnosis.² Furthermore, it outlined the two major components of this financial impact: reduced income and increased costs.

The research, which included a survey of more than 1,600 people living with

cancer, showed the effect that undergoing often gruelling treatment – or recovering from it – has on people's ability to maintain an income through work. Of those surveyed, a third (33%) had stopped work either permanently or temporarily, while a further 8% had been forced to reduce their hours or take unpaid leave. It also found that six in seven (85%) people living with cancer face a myriad of increased costs as a direct result of their diagnosis. These range from paying for travel to and from hospital to increased energy bills due to feeling the cold more.



FOUR IN FIVE
(83%)

people with cancer are on average
£570 a month worse off
as a result of their diagnosis.



'If Macmillan hadn't have helped me, the chances are I would have had to sell my house because of this illness. I've lived in this house 40 years and it would have been heart-breaking having to leave it.'

When Cath was diagnosed with bowel cancer, she had to deal with the shock of her diagnosis on top of the financial implications of taking a year off work. She was anxious about the cost of bills and found herself worrying more about her finances than about getting through treatment.



The effects of the impact

The numbers set out in *Cancer's Hidden Price Tag* only tell half the story. The true nature of cancer's financial impact is revealed in its practical and material effects on those it touches.

To begin with, the financial implications themselves are far reaching. A cancer diagnosis is typically sudden and unexpected, and people often don't realise the extent to which their finances are likely to be affected. Macmillan research carried out in 2015 shows that 45% of people with cancer are taken by surprise by the extent of the financial impact of their diagnosis.³

Living with cancer can leave people struggling to make ends meet and relying on short-term financial solutions. Every year almost 400,000 people living with cancer across the UK struggle to pay their household bills as a result of their diagnosis.⁴ Furthermore, we've found that four in ten (39%) people with cancer have used savings, sold assets or borrowed to cover the costs or the loss of income caused by their diagnosis.⁵ A recent survey found that 40% of people with cancer who had savings used at least some of them to cover the financial impact of their diagnosis. This is a worrying statistic given that a quarter (28%) of people with cancer said they had no savings at all to rely on. Ultimately, this leaves too many people at a significant risk of facing spiralling debts and falling into serious financial hardship.

We also know that family members and friends who care for people with cancer are financially affected by their diagnosis. Almost one in three carers (30%) say their income or household finances are affected by caring, as a result of them spending more on

travel and other caring-related costs.⁶ Meanwhile, an estimated 30,000 people with cancer in their 40s and 50s have had to borrow money from their parents, while an estimated 16,000 of all people with cancer had to borrow money from their children.⁷

Beyond finances, the effects of the financial impact of cancer are deep and wide ranging. Our research has found that six in ten (61%) of those people who experienced a financial impact of their cancer diagnosis said it had negatively affected their quality of life. The implications on their physical and mental wellbeing was even more alarming. 43% of people said it had a detrimental effect on their overall health and more than half (53%) reported feeling more anxious or stressed. More than a third (37%) said it had made them feel more isolated or alone.⁸

Time to act

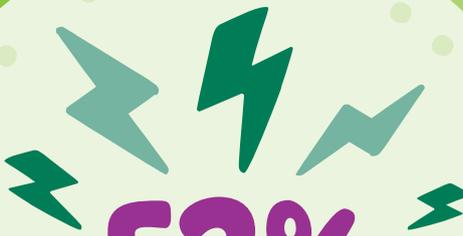
Macmillan believes action is needed to make sure everyone who experiences a financial impact of cancer gets the help and support they need when they need it. While the scale of the impact and its far-reaching effects underline the importance of reform, there are two further factors which make the case for change all the more urgent.

Firstly, the cancer population – and by extension the number of people facing the financial impact of cancer – is growing. There are currently 2.5 million people living with cancer in the UK. However, Macmillan's research shows that by 2030 this number is set to rise to four million.⁹

Secondly, in recent years much of the financial support that many people affected by cancer have traditionally relied upon has been affected by ever tighter constraints on public spending. Since 2010, the UK has experienced an unprecedented drive to reduce welfare spending. Following net cuts of approximately £17 billion in the last Parliament, in 2015 the Government committed to making a further £12 billion in savings.¹⁰ Many entitlements have been reduced or even withdrawn. Meanwhile, health and local authority budgets have been subject to consistent pressure.¹¹

Put simply, the number of people who need the right financial help and support following a cancer diagnosis is set to grow at a time when key sources of support are being squeezed.

Of those who experienced a financial impact of their cancer diagnosis, **61% said it had negatively affected their quality of life.** Of those:



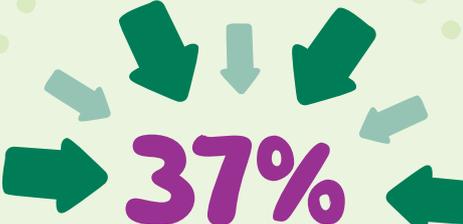
52%

reported feeling more anxious or stressed



43%

said it had a detrimental effect on their overall health



37%

said it had made them feel more isolated or alone

No small change – an obligation for us all

Macmillan's vision: by 2030, every person affected by cancer should get the support they need to cope with the financial impact of cancer, when they need it.

Wherever people affected by cancer present with financial needs – be it to a health or social care professional, the benefits system, a financial services firm or a charity like Macmillan – and no matter what stage of their cancer journey they are at, they should get the support they need.

At present, this isn't always the case. And, given the scale of the challenge posed by the financial impact of cancer, making it happen requires no small change. We need:

- **people affected by cancer to be made aware of the financial impact of cancer and signposted to the appropriate financial information, guidance or advice at key points in their journey,**
- **the benefits system to operate effectively and to provide an adequate level of support for people affected by cancer, and**
- **the banking and insurance sectors to do more to ensure their customers with cancer have consistently positive outcomes.**

Macmillan offers a range of specialist support services to help people affected by cancer cope with the financial impact of their diagnosis. Through our Make Money One Less Worry campaign, we're raising awareness of this impact and we're signposting people to this support.

But, we also need others to do more. This report sets out recommendations for governments, health bodies, financial services firms, regulators, Whitehall and devolved administration departments. We look forward to working with all of these stakeholders to make our recommendations a reality, and to ensure that every person affected by cancer gets the support they need.



'It's particularly good when you can really help someone and ease that pressure on their life. Quite often there's a whole sense of relief after speaking to Macmillan and accessing some financial support.'

Chris is a welfare rights adviser on the Support Line at Macmillan. His responsibilities include providing advice on all aspects of social security benefits, financial support, grants or anything that a cancer patient might be eligible for.

Macmillan's services

In 2015 we helped more than 123,000 people affected by cancer to cope financially.

Macmillan Support Line financial help teams

The Macmillan Support Line contains a team of expert benefit advisers, as well as financial guides, who help equip people affected by cancer to make informed decisions about mortgages, insurance and pensions. Our team of energy advisers, supported by npower¹², offer support and advice with energy bills. These can quickly add up since many people affected by cancer feel the cold more, and they also have to spend more time at home. Through an established partnership, we also refer people affected by cancer who require specialist debt advice to StepChange Debt Charity.

Macmillan Grants

Every week, more than 600 people with cancer receive a grant from Macmillan to help cover the costs of essential items, such as white goods, fuel bills, clothing or travel costs. In 2015, we distributed £11.7 million in grants, to almost 33,000 people.

Face-to-face benefits advisers

We also deliver specialist face-to-face benefits advice to people affected by cancer. We work in partnership with local services like Citizens Advice, the NHS and local authorities to help people identify and apply for benefits for which they become eligible following diagnosis. We have more than 120 services across the UK, many of which offer support in acute hospital settings.

Recommendations

Financial information, guidance and advice

Governments and health bodies across the UK should ensure that:

- 1** holistic needs assessments – which include a focus on identifying and meeting financial needs – are embedded in health and social care systems
- 2** health and social care staff are equipped with the skills and knowledge they need to have effective conversations with patients about their financial concerns.

Governments, local authorities, the NHS, relevant health bodies and health and social care staff themselves should ensure that:

- 3** there is renewed recognition of the importance of financial wellbeing in maintaining and improving health.

The benefits system

Governments across the UK should ensure that:

- 4** the key benefits for people with cancer are processed in an acceptable time frame
- 5** the relevant departments, including the Department for Work and Pensions, expand the publication of average processing times beyond Personal Independence Payment (PIP)
- 6** ongoing welfare reform – including the roll out of Universal Credit – does not lead to administrative issues or delays for people claiming their benefits.

Governments across the UK, and the wider policy-making community – including charities like Macmillan – should:

- 7** work together to address the challenge of ensuring people affected by cancer of working age get sufficient financial support from the benefits system.

Banking

Banks should ensure that:

- 8** all frontline staff are confident in identifying and helping customers with cancer
- 9** they have the right specialised support in place to support customers with cancer
- 10** their policies and products are developed using accurate, up-to-date information on the financial needs of people with cancer.

The banking sector, the Government and the Financial Conduct Authority should ensure that:

- 11** the needs of those with cancer – and vulnerable customers more widely – remain a priority across the financial services industry.

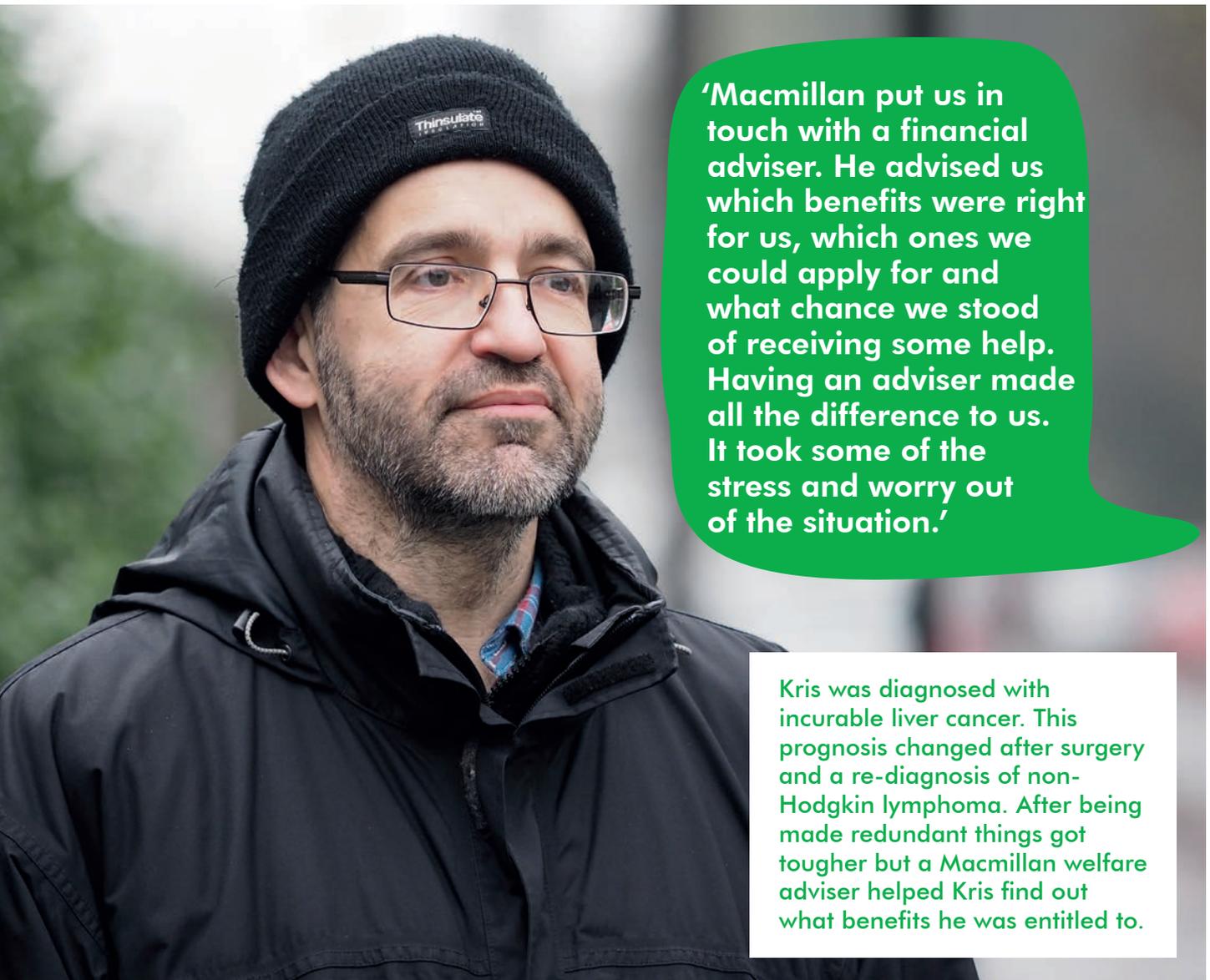
Insurance

The insurance industry should consider what more it can do to ensure people living with and beyond cancer are able to access key insurance products. As a first step the industry should:

- 12** consider how it can use the most up-to-date information about cancer to ensure current pricing systems accurately reflect the level of risk posed by people who are living with and beyond cancer.

Financial information, guidance and advice

It's imperative that people affected by cancer are aware of the financial impact of their diagnosis, and know where they can get the help they need to deal with it. Health and social care staff play a key role in this – they have regular contact with patients and carers and can signpost them to the most appropriate sources of financial information, guidance or advice.



'Macmillan put us in touch with a financial adviser. He advised us which benefits were right for us, which ones we could apply for and what chance we stood of receiving some help. Having an adviser made all the difference to us. It took some of the stress and worry out of the situation.'

Kris was diagnosed with incurable liver cancer. This prognosis changed after surgery and a re-diagnosis of non-Hodgkin lymphoma. After being made redundant things got tougher but a Macmillan welfare adviser helped Kris find out what benefits he was entitled to.

Awareness and assistance

The first step in helping people with cancer deal with the financial impact of their diagnosis is to help ensure they are aware of the impact itself. Our research shows that 45% of people with cancer are unprepared for the effect on their finances.¹³ This leaves them playing catch-up and struggling to come to terms with the financial reality of their situation. Recent qualitative research carried out by Macmillan found that many of those who don't receive support until later in their cancer journey end up with large debts, while those who don't receive any support at all may never be able to make a full financial recovery.¹⁴

We know that when people receive help early – be it in the form of information, financial guidance or specialist benefits advice – they are better able to access the right support and manage the financial impact of cancer, and they are less likely to fall into financial hardship.¹⁵ Despite this, many people with cancer are not getting access to this help when they need it. Macmillan research shows that nearly half (46%) of the people who experience a financial impact of cancer say there are periods following their diagnosis when they need more financial information and guidance.¹⁶ Meanwhile, a fifth of all cancer carers say they are missing out on financial information or advice, including on benefits.¹⁷

The role of health and social care staff

Almost every person affected by cancer comes into contact with members of the health and social care workforce, from clinical nurse specialists or a support worker to GPs, early in their cancer journey. While they should not be expected to have in-depth specialist knowledge, these members

of staff are extremely well positioned to raise awareness of the financial impact of cancer and signpost people to appropriate sources of financial information, guidance and advice. However, this isn't happening as much as it should. The most recent Cancer Patient Experience Surveys from England, Scotland, Wales and Northern Ireland show that, across the UK, many people with cancer were not given information by hospital staff on how to get financial help or benefits even though they wanted it.

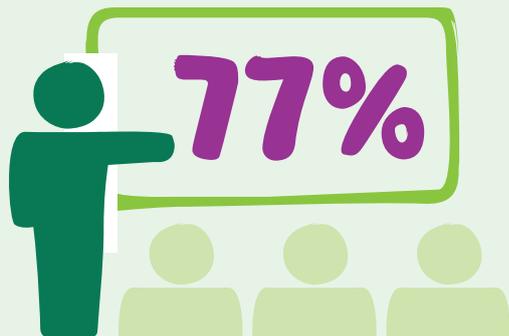
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What's the problem?

Macmillan works closely with health and social care staff across the UK. Many tell us that they feel ill-equipped to broach and address money issues with their patients and lack the time to have such conversations. A recent Macmillan survey of healthcare staff¹⁹ found that 61% think there is a lack of knowledge amongst professionals about the financial impact of cancer, while 77% would like more training or support to help them to have money-related conversations. Around the same proportion of healthcare staff are unaware of the available local and national sources of information, guidance and advice to which they can signpost people. Our survey found that 74% of staff surveyed felt that healthcare professionals don't know what specialist services are available. More fundamentally, our survey also showed that 31% of healthcare staff did not see it as their role to have money-related conversations with people living with cancer at all.

A recent survey of healthcare staff found that **77% would like more training or support to help them have conversations with people about the financial impact of cancer**



What more can be done?

It is imperative that health and social care staff make sure people with cancer, and those caring for them, are aware that their diagnosis is likely to have a financial impact and signpost them to the appropriate financial information, guidance or advice.

As a first step, Macmillan believes that governments and health bodies across the UK should ensure that:

- **Holistic needs assessments – which include a focus on identifying and meeting financial need – are embedded in health and social care systems.** Health and social care staff do not need to have specialist knowledge on financial matters, but it is vital they are equipped with the right tools to enable them to discuss money issues with their patients and guide them towards the appropriate level of specialist support. Holistic needs assessments are a key component of the Recovery Package, a series of interventions designed to ensure people get practical, physical and emotional support that meets their individual needs both during and after treatment. Macmillan welcomes the commitments across England, Scotland and Wales to ensure people with cancer receive holistic needs assessments and a tailored care plan. We look forward to working with the relevant health bodies to ensure this is rolled out.²⁰
- **Health and social care staff are equipped with the skills and knowledge they need to have effective conversations with patients about financial concerns.** At present, health and social care staff don't routinely receive specific training to help them

broach financial issues. Macmillan welcomes the recognition in the UK Government's work, health and disability green paper of the need for employment issues to form part of the training and professional approach of the health and social care workforce.²¹ We believe the important role that health and social care staff play in supporting people with financial wellbeing should also be included. In England, Health Education England's strategic review into the cancer workforce – as recommended by the England Cancer Strategy²² – provides an excellent opportunity for this work to be taken forward.

Of course, the ability of health and social care staff to signpost effectively is dependent on the existence of appropriate sources of financial information, guidance or advice. While Macmillan provides specialist support through our website, helpline and face-to-face advisers, it's imperative that other sources are also maintained. Continued pressure on local authority and health budgets means that the funding landscape for specialist advice services is increasingly challenging. Macmillan is keen to work with local authority partners, the NHS and others to consider what more can be done to ensure specialist advice is available to everyone with cancer.

A shift in attitudes

As this report outlines, Macmillan's research shows that the financial impact of cancer can have significant detrimental effects on physical and mental health. If we are to ensure that the health and social care workforce do all they can to help alleviate this impact, financial issues need to be a higher priority across the health and social care sector.

Macmillan believes we need **renewed recognition from governments, local authorities, the NHS, relevant health bodies and health and social care staff themselves of the importance of financial wellbeing in maintaining and improving health.**

Make Money One Less Worry

In addition to our services, Macmillan has also launched Make Money One Less Worry – an ambitious new public-facing campaign designed to ensure no one is unduly financially disadvantaged by a cancer diagnosis. Through online, radio and media activity we are raising awareness of the financial impact of a cancer diagnosis amongst those most at risk, and then signposting them to our support offer. We are also working with affiliated health and social care staff to develop useful resources that support them to have money-related conversations with people affected by cancer.

The benefits system

Tens of thousands of people affected by cancer rely on the benefits system to provide vital funds when they need them most. It's crucial that the system provides financial support which is both readily accessible and set at an adequate level. All too often, this isn't the case.



'I really started to worry after the first three months when my salary was reduced and I had to exhaust my savings. I spoke to Fiona, a welfare rights adviser. She literally changed my life. I discussed my financial situation and the difficulties that I was experiencing and she advised me about the benefits I might be entitled to.'

When Shola had to give up work to have treatment for thymoma, a tumour affecting her thymus gland, she soon encountered financial problems. Fiona, a Macmillan benefits adviser, helped her apply for Personal Independence Payment, as well as helping Shola when there was a lengthy delay in receiving the benefit.



The importance of welfare support

When the benefits system works properly, it can help people with cancer to avoid falling into financial hardship and suffering the associated effects on physical and mental health. Wider research shows that the financial support provided by benefits can help to lower stress, improve diet and raise levels of physical activity.²⁴

However, we know from speaking to people with cancer that the system often doesn't work as it should. To begin with, the benefits system in the UK is complex and difficult to navigate. Every year Macmillan's benefits services receive thousands of enquiries from people affected by cancer who need help in negotiating their way through the system and gaining access to their entitlements. Sometimes the complexity of the system can even put people off

claiming altogether. Previous Macmillan research on the process of claiming Personal Independence Payment (PIP) found that some people with cancer gave up their claim due to the process being too time consuming, too difficult or too upsetting.²⁵

'Horrendous and very, very stressful. The whole thing took around 18 months during which time I had zero income and was entirely dependent on my wife. Apart from my physical illnesses, I also have a history of depression which was triggered by the stress of this ordeal.'

Person affected by cancer on the experience of claiming PIP.

'I had to wait ages to receive the PIP payment which was ridiculous as you have needs almost immediately after you become ill enough to qualify. Why should you have to wait so long to get it paid?'

Person affected by cancer on the experience of claiming PIP.

As well as being difficult to navigate, we also know that the benefits system can be subject to administrative delays. Following the introduction of PIP in England, Scotland and Wales in 2014 and Northern Ireland in 2016, many people with cancer faced significant delays in receiving their payments due to administrative issues in processing claims. For some, the effects of this were devastating. A survey of those who had experienced delays found that 51% felt under increased emotional strain as a result, while 40% were left unable to heat their homes. At the time, Macmillan consistently called on the Government to reduce these delays and ensure that average waiting times were no more than 11 weeks – the time it typically took for Disability Living Allowance (the benefit which PIP replaced) to be processed and paid.

Since 2014, real progress has been made on PIP processing, with the average waiting time currently standing at 10 weeks.²⁶ However, our benefits advisers tell us that a number of people with cancer still face delays in claiming their benefits. For example, Macmillan is aware of cases where

people with cancer are waiting longer than they should to receive Employment and Support Allowance (ESA) – a vital benefit for those who are too ill to work.

It is unacceptable that people with cancer should face delays in accessing the benefits to which they are entitled. Not only do such delays affect their access to crucial benefits, but they can have knock-on effects on those around them. For example, Carers Allowance, which provides vital funds for many people caring for those with cancer, is linked to the receipt of PIP.

Macmillan therefore believes that more should be done to ensure the system operates smoothly and effectively in the future.

What more can be done?

The UK Government and – where responsibilities for welfare provision are devolved – administrations in the nations, have a duty to guarantee that people with cancer can quickly and reliably access the support they are entitled to from the benefits system.

In the first instance, Macmillan believes that **governments across the UK should ensure that key benefits for people with cancer are processed in an acceptable timeframe**. It is imperative that the average processing times for PIP claims do not rise above 11 weeks, or seven days for those who have a terminal diagnosis. Similarly, people with cancer should not have to wait longer than 13 weeks to be assessed for Employment and Support Allowance – the target for processing times set out in the design of the benefit itself. When a person with cancer appeals a decision on their eligibility for a particular benefit,

for example through a mandatory reconsideration, this should be completed in a timely, transparent way.

In order to ensure benefits claims are processed in a timely manner, Macmillan believes that **relevant departments, including the Department for Work and Pensions, should expand the publication of average processing times beyond PIP** to include other key benefits accessed by people living with cancer. These should include ESA and Attendance Allowance (the equivalent of PIP for those of pensionable age) and the figures should feature breakdowns of any regional variations in processing times.

More widely, **governments across the UK should ensure that ongoing welfare reform – including the roll out of Universal Credit – does not lead to administrative issues or delays for people claiming their benefits.** The Department for Work and Pensions – and equivalent departments in the devolved nations – should be open to working with health and disability charities, such as Macmillan, to ensure the experiences of those interacting with the benefits system are integral to the development of Universal Credit. This should include identifying issues or delays as they arise and, where needed, making changes to the claiming process to ensure people living with cancer and others are getting the support they are entitled to.

An adequate level of support

As well as making sure that the benefits system operates in an effective and timely manner, governments across the UK need to ensure that the benefits paid to people affected by cancer

provide them with an adequate level of financial support. Macmillan welcomes the UK Government's commitment to not making any further welfare savings in the current Parliament. We also welcome the Government's previous commitment to place cancer patients waiting for, undergoing or recovering from treatment directly into the Support Group of ESA without the need for a face-to-face assessment.

However, we believe that more should be done to ensure people affected by cancer can access sufficient support from the benefits system.

Working age benefits

Macmillan's research shows that people of working age experience a particularly severe financial impact of cancer. They are more likely to face a substantial loss in income due to having to give up or cut down on work, plus they tend to have significant financial commitments, such as paying a mortgage or supporting dependent children.²⁷

Despite this, the level of financial support available to people with cancer of working age has not been immune from successive governments' focus on reducing the cost of working age welfare. For example, from April 2017 new ESA claimants placed in the Work Related Activity Group (WRAG) or the limited capability for work element of Universal Credit will receive nearly £30 per-week less than at present – a change which Macmillan strongly campaigned against. In addition, the main component of ESA is currently subject to the benefit freeze, affecting tens of thousands of people with cancer – including those in the Support Group.

Supporting those who are able to

remain in or return to work is crucial. Government has a central role to play in this through ensuring it takes a joined-up approach and recognises that people affected by cancer need appropriate support and healthcare to do so.

Until now, most government programmes have been primarily focussed on supporting people who are currently out of work to gain employment. While the Department for Work and Pensions' Fit for Work service provides information and telephone-based occupational health advice to help people to remain in work, many people living with cancer require more joined-up and personalised work-focused healthcare along with support in the workplace to retain employment.

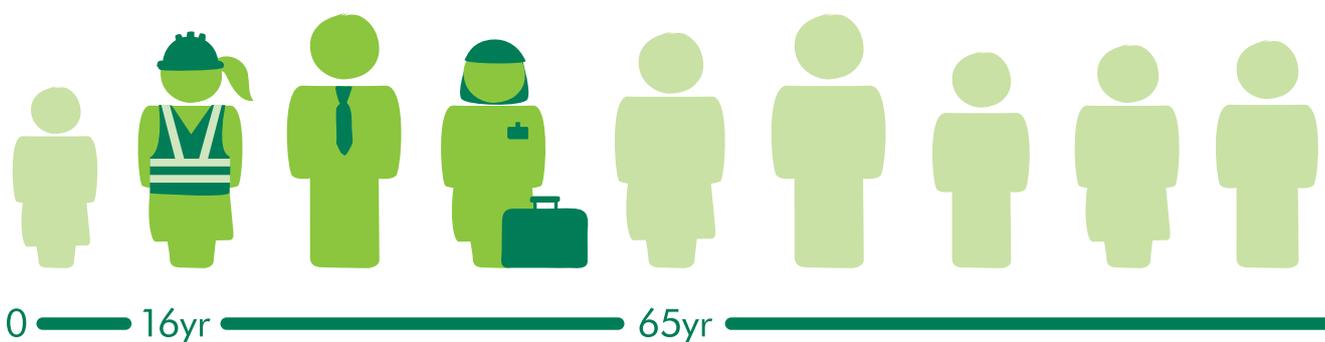
The UK Government's green paper on work, health and disability represents a welcome opportunity to make sure that people with cancer have the support they need to remain in and return to work if they are ready and able.²⁸ For example, the availability of and access to vocational rehabilitation services for people with cancer and other long-term conditions needs to be improved. These services should include an assessment of needs, rehabilitation to build physical, social and work skills, and liaison with employers to negotiate a phased return to work.

Macmillan provides a range of support to help people with cancer remain in or return to work. For example, through our Macmillan at Work Programme, we work with employers to create supportive workplaces, develop skills and capacities of HR and line managers and to implement appropriate policies and practices to manage cancer in the workplace. We also campaign to raise awareness amongst people affected by cancer of their rights and how they can manage cancer at work. What's more, we provide advice and support on work and cancer through our helpline and information services.

However, the need to support those who can work to do so must be balanced with government's duty to ensure that those who are unable to maintain an income through work – be it temporarily or permanently – are provided with adequate financial support.

Macmillan believes **that governments across the UK, and the wider policy-making community – including charities like Macmillan – should work together to address the challenge of ensuring people affected by cancer of working age get sufficient financial support from the benefits system.**

Approximately one in three people living with cancer in the UK **are of working age**



Working age estimated based on those living with a cancer diagnosis aged 15-64 in 2015. Prevalence under the age of 64 based on Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010- 2040. Br J Cancer 2012; 107: 1195-1202. Projections scenario 1 and the assumption that in 2015, 99% of those aged 64 or under are aged 15 or over. The 99% is based on 20-year prevalence in 2010 derived from Macmillan Cancer Support and Public Health England's NCRAS. 2014. Segmenting the cancer survivor population. Available at: http://www.ncin.org.uk/about_ncin/segmentation

Banking

Banks are in a unique position to help their customers cope with the financial impact of a cancer diagnosis. However, the experiences of people with cancer vary greatly depending on their banking provider. Despite some excellent examples of good practice across the industry, the available support is not always embedded or consistent.

A portrait of Patrick, a Black man with short, dark, curly hair, wearing red-rimmed glasses and a dark grey jacket. He is looking slightly to the right of the camera with a neutral expression. The background is a blurred green, suggesting an outdoor setting with foliage.

'My bank, Nationwide Building Society, helped me by not putting undue pressure on me and allowing me to get a temporary overdraft when I needed it. The one most important thing about this was that I did not have to keep repeating myself, as from the very start they were understanding and compassionate.'

Patrick, who was diagnosed with skin cancer in 2000, prostate cancer in 2003, leukaemia in 2007 and bowel cancer in 2013.

People with cancer's experiences of the banking industry

In 2014, Macmillan published *Counting on Your Support*, a report which provided a unique insight into people with cancer's experiences of the banking sector. Based on evidence from our Financial Guidance Service and a wide-ranging survey of people who had received a cancer diagnosis, the report showed that, at the time, many were not getting the support they wanted or needed from their bank.

Of those surveyed, less than 5% of people used financial services firms as a source of information and support, despite 43% saying they were aware that they could have sought financial information from their bank. Of those who did get information from their financial provider, 16% were dissatisfied with what they received. When we asked those who didn't make contact with their bank what had stopped them, 27% said they felt banks either didn't have a role to play in helping 'people like them' or that their bank would not, or could not help them.²⁹

What can banks do?

Macmillan believes that banks have an unrivalled reach which gives them a unique opportunity to help people with cancer deal with the financial impact of their diagnosis. For example, for many people, a mortgage is the single biggest financial commitment they have. Mortgage lenders – such as banks – are therefore extremely well placed to help them manage this when facing the financial impact of cancer.

However, some of the experiences highlighted in *Counting on Your Support* suggested this potential source of support was not being fully utilised. In some cases, banks were actually making the problem worse. The report therefore included recommendations on the steps banks could take to better support their customers with cancer.

Counting on Your Support – Macmillan’s vision for the banking industry

Firstly, **banks should ensure that all frontline staff are confident in identifying and helping customers with cancer.** Staff should be confident in having sensitive conversations with customers with cancer and equipped with the skills and knowledge to refer those customers to more specialised support. This is crucial in ensuring people with cancer are treated with empathy, but also that they get access to the available support quickly and efficiently.

When people with cancer are referred on by front-line staff, **banks should have the right specialised support in place.** This support will often come in the form of specialist vulnerable customer teams and these teams must have the right level of training, resource and authority to properly identify and respond to customers’ needs.

Crucially, **banks also need to ensure that their policies and products are developed using accurate, up-to-date information on the financial needs of people with cancer.** The reality of what it means to live with cancer is changing – someone diagnosed with cancer is likely to have varying financial needs at diagnosis, treatment and beyond. It’s imperative that the products on offer from banks, as well as their policies and procedures accurately reflect these needs.

Progress to date

Since *Counting on Your Support* was published in 2014, Macmillan has welcomed the commitment from the banking industry to improve outcomes for people with cancer. In February

2015, the Financial Conduct Authority (FCA) published an Occasional Paper on Consumer Vulnerability. This report highlighted the urgency of improving support to customers affected by cancer and outlined the industry’s intention to make change happen. In the same month, Macmillan collaborated with the British Bankers’ Association (BBA), the Stroke Association and the Royal College of Psychiatrists to publish a briefing outlining best practice for banks in helping customers with long-term conditions such as cancer. Individual banks, such as Lloyds Banking Group, are also working alongside us to further enhance the service they offer to people with cancer. Another excellent example of this is Nationwide Building Society’s Specialist Support Service. Developed in partnership with Macmillan and piloted in late 2015, the service demonstrates one way in which banks can practically apply the guiding principles set out in *Counting on Your Support*.

More to be done

Although some banks have made improvements to the services they offer, Macmillan still believes that the sector as a whole could – and should – do more to ensure that people diagnosed with cancer have consistently positive experiences, no matter who they bank with. We’re currently conducting research into whether people with cancer’s experiences of banks have changed or improved since 2014. We’ll be publishing our findings later this year, highlighting areas where progress has been made, as well as where more needs to be done. In the meantime, **it’s imperative that the Government, the Financial Conduct Authority and the banking sector ensure that the needs of those with cancer – and vulnerable customers more widely – remain a priority across the financial services industry.**

Nationwide Building Society – Specialist Support Service

Macmillan has worked in partnership with Nationwide Building Society to develop and deliver a Specialist Support Service which provides free, tailored and confidential support for Nationwide members affected by cancer.

The service, run by Nationwide employees trained by Macmillan, provides personalised support that responds to the wide range of needs people affected by cancer may experience. There is a focus on helping people understand their choices so that they are able to make informed decisions, and on providing tangible support that minimises the financial impact of their change in circumstances. Central to the success of the service is a single point of contact, meaning that each time a customer calls they speak to a member of the team who knows and understands their personal circumstances.

Since the launch of the service, more than 1,800 Nationwide members have been supported and nearly 350 members have been referred to Macmillan, benefitting from further financial guidance. This has led to more than £230,000 worth of additional benefits and grants being accessed by Nationwide members. Nationwide’s service has now expanded to support other customers in vulnerable circumstances including those with lifelong and life-limiting conditions, and it will soon be supporting customers living with mental health problems and dementia.

Macmillan recommends that banks should ensure that ...

...all frontline staff are confident in identifying and helping customers with cancer.



...specialist support is available when and where people need it.



...policies and products are developed using accurate information about the financial needs of people with cancer.



Insurance

People who have received a cancer diagnosis can face a range of difficulties both in accessing and in claiming insurance. As a result, many people find themselves without the financial safety net provided by mainstream insurance products. Macmillan believes there is more the insurance industry could do to support people with cancer.

A widespread issue

Through our specialist financial support services, Macmillan hears directly from people with cancer about their experiences of the insurance industry. The frequency of requests for digital and print information about insurance, the annual volume of calls to the Macmillan Support Line, and the nature of cases dealt with by our Financial Guidance Service (FGS) all demonstrate the scale of the issues they face. Between August 2015 and August 2016, the FGS provided guidance on insurance more than 3,000 times, our insurance web pages had more than 110,000 unique views, and travel insurance was the second most searched for term on our website.

Travel insurance: the importance of access

People living with and beyond cancer tell us that they face particular problems in accessing travel insurance. They are sometimes quoted huge premiums which can be more expensive than the cost of a holiday itself, are unable to get cover for their cancer, or are unable even to get insurance at all. This can occur even when people have clearance from their healthcare professional to travel, when they are in remission, or even sometimes many years after they have been given the 'all clear'. Also, we often hear how confusing and distressing the process of searching

and applying for travel insurance can be. Many people are asked blunt and insensitive questions, or complete extensive online applications only to be told that they need to phone the insurer, after which they are subsequently refused cover. Some people have told us that they will set aside a few days to search for cover or ask someone else to do it on their behalf because it is such an exhausting process.

The practical consequence of being unable to access travel insurance is often to limit an individual's ability to make choices about if, where, when and with whom they travel – be it to take a holiday as part of their recovery or to visit loved ones abroad, sometimes for the last time.

Tony,* living with prostate cancer

Tony was diagnosed with prostate cancer 12 months ago. His cancer is controlled by quarterly hormone injections. Tony decided that he would plan a trip of a lifetime to visit his children and grandchildren in Australia. He called six different companies in order to obtain travel insurance – five of them declined to cover him and the final company offered him cover but at the significant cost of £8,000. Tony was unable to afford this and was left with the choice of either taking the risk of travelling without insurance or not seeing his family. In the end, Tony

*Name changed to protect identity

decided the risk was too great and he cancelled his trip. Tony said it would have been the last time he would see his family, and he described the situation as 'very upsetting'. He is now resigned to a situation where he won't see his children or grandchildren again in his lifetime.

Life and protection insurance: access and claims

People with cancer also experience difficulties in accessing life cover and other protection insurance products. Sometimes they are quoted very high premiums or struggle to find an insurer who will offer them cover at all.

The effect of being unable to access mainstream protection insurance products should not be underestimated. Without the protection that such products provide, many people are unable to access the financial safety net that others take for granted. As a consequence, people with cancer can find their life choices significantly restricted, typically at a time when they are recovering and beginning to plan for what their life 'with and beyond' cancer is going to be like. For example, people may feel unable to make major decisions such as moving house if they are unable to find adequate protection insurance for the financial commitments involved. People have told us that these experiences make them feel as though they will never be 'free' of their cancer and, in some cases, that they are being unfairly discriminated against.

Macmillan also has concerns about the experiences that people with cancer have of claiming on insurance products. Through our Financial Guidance Service, we know that many people can find the overall experience of making a claim arduous and even distressing. They may encounter unexplained delays or staff lacking in empathy. This is particularly

concerning given the detrimental impact a delay in paying out on a claim can have on someone's finances. Even more worrying are the cases we see where claims are declined for reasons ranging from having a type of cancer not covered by a particular policy, to disputes over a lack of clarity about what constitutes a terminal diagnosis and whether treatment is palliative or life-prolonging. These experiences can not only have a devastating financial impact but can also seriously affect someone's overall wellbeing. People living with cancer need to be confident that their insurance policy will deliver the financial safety net that was promised when they bought it at the time when they need it most.

What the insurance industry can do

Macmillan believes the industry should consider what more it can do to make sure people who are living with and beyond cancer are able to access key insurance products and have a positive experience of the industry. While we acknowledge there are some providers working to improve the service they offer people affected by cancer – including through reducing delays in paying critical illness claims – this isn't consistent across the sector and more needs to be done. Whatever stage someone is at in their cancer journey, they should be able to access products that are appropriate to their circumstances at a fair price that accurately reflects the risk that is being covered.

Macmillan is currently undertaking research into the extent of the issues outlined above, their root causes and the barriers which insurers face in dealing with them. In the meantime, we believe **the insurance industry should consider how it can use the most up-to-date information about cancer to ensure current pricing systems accurately reflect the level of risk posed by people who are living with and beyond cancer.**

References

- ¹ This includes people who have received a cancer diagnosis, their family members and their carer(s).
- ² Research commissioned by Macmillan Cancer Support, carried out by researchers from the University of Bristol Personal Finance Research Centre in partnership with TNS BMRB, and part-funded by our partner The RBS Group. Figures based on a postal survey of 1,610 adults with a cancer diagnosis, recruited from a database of callers to the Macmillan Support Line and visitors to a sample of Macmillan Information and Support Centres located in hospitals across the UK. The majority (95%) had received cancer treatment within the last six months. Fieldwork took place between August and October 2012. Results were weighted to be representative of all people with a cancer diagnosis in the UK by age, gender, cancer type and country of residence.
- ³ Macmillan Cancer Support/Truth online survey of 955 adults in England, Scotland and Wales who have a cancer diagnosis. Fieldwork was undertaken between 3–21 September 2015. Data has been weighted
- ⁴ Macmillan Cancer Support/YouGov online survey of 2,011 UK adults who have ever been diagnosed with cancer. Fieldwork conducted 7–11 November 2014. Survey data has been weighted by age and gender to match the known profile of people living with cancer (using 2008 cancer prevalence estimates). 36% of people with cancer surveyed reported struggling to keep up with their household bills and credit commitment either entirely or partly due to their cancer diagnosis, which equates to an estimated 400,000 people across the UK.
- ⁵ Macmillan Cancer Support/Truth online survey of 955 adults in England, Scotland and Wales who have a cancer diagnosis. Fieldwork was undertaken between 3–21 September 2015. Data has been weighted
- ⁶ Under pressure: the growing strain on cancer carers, Macmillan Cancer Support, 2016
- ⁷ Estimate based on Macmillan Cancer Support/YouGov online survey of 2,002 people with a previous cancer diagnosis in the UK. Fieldwork was undertaken between 16th and 25th November 2016. The figures have been weighted and are representative of those living with cancer in the UK. The survey found that 7.8% of people with cancer in their 40s and 50s had borrowed money from their parents to cover the additional costs or loss of income associated with cancer. We have applied this to the estimated 390,000 people in their 40s and 50s alive following a cancer diagnosis (between 1971 and 2013) in England as of 2013 to arrive at an estimate of at least 30,000 people across the UK. Estimate

of people in their 40s and 50s living with a cancer diagnosis in England is based on: Macmillan-NCRAS UK Cancer Prevalence Project, Age breakdown of England Observed Prevalence 1971-2013. Based on unpublished data as of January 31st 2017. This work is part of the Macmillan Cancer Support and Public Health England's NCRAS Partnership Work Plan.

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- ⁹ Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010–2040. *Br J Cancer* 2012; 107: 1195-1202. (Projections scenario 1).
- ¹⁰ Institute of Fiscal Studies: <https://www.ifs.org.uk/publications/7762>
- ¹¹ Comptroller and Auditor General, Financial sustainability of the NHS, Session 2016–17, HC 785, November 2016 & Comptroller and Auditor General, Financial sustainability of local authorities 2014, Session 2014–15, HC 783, National Audit Office, November 2014.
- ¹² As well as supporting our Energy Advice Team, npower helps their customers who are living with cancer through npower's Macmillan Fund. The Fund is available to those who are either in active treatment or the terminal phase of cancer, and caps their energy bills at no more than 10% of their income for two years. Eligibility will also take savings into account. For more information visit www.macmillan.org.uk/keepwarm
- ¹³ Macmillan Cancer Support/Truth online survey of 955 adults in England, Scotland and Wales who have a cancer diagnosis. Fieldwork was undertaken between 3–21 September 2015. Data has been weighted
- ¹⁴ Macmillan Cancer Support/YouGov qualitative study into the long-term financial impact of cancer. The research was conducted in two phases. Phase 1 comprised interviews with 46 people with a cancer diagnosis and who were financially impacted because of cancer. A spread of participants was achieved in terms of the following characteristics: age, gender, social grade, income level, working status, presence of dependents in household, size of household, cancer type and time since diagnosis. Phase 2 comprised follow-up interviews with 10 participants from Phase 1 to explore their experiences in more detail.

- ¹⁵ Ibid
- ¹⁶ Macmillan Cancer Support/Truth online survey of 955 adults in England, Scotland and Wales who have a cancer diagnosis. Fieldwork was undertaken between –21 September 2015. Data has been weighted
- ¹⁷ *Under pressure: the growing strain on cancer carers*, Macmillan Cancer Support, 2016
- ¹⁸ National Cancer Patient Experience Survey 2015, National Results Summary. Quality Health. 2016. <http://www.ncpes.co.uk/index.php/reports/national-reports/2489-cpes-2015-national-report-pdf/file> (accessed December 2016); Northern Ireland Cancer Patient Experience Survey, 2015 All Trusts Report. Quality Health. October 2015. <https://www.quality-health.co.uk/resources/surveys/northern-ireland-cancer-patient-experience-survey/2015-northern-ireland-cancer-patient-experience-survey> (accessed December 2016); Wales Cancer Patient Experience Survey, National Report. Quality Health. January 2014. <https://www.quality-health.co.uk/resources/surveys/welsh-cancer-experience-survey/2013-welsh-cancer-perience-survey/wales-cancer-patient-experience-reports-english-language-versions> (accessed December 2016); Scottish Cancer Patient Experience Survey 2015/2016. NHS Scotland. June 2016. <http://www.gov.scot/Resource/0050/00501127.pdf> (accessed December 2016).
- ¹⁹ Macmillan/ICM online survey of 252 UK GPs and Clinical Nurse Specialists (101 GPs, and 151 Clinical Nurse Specialists). Fieldwork was conducted November-December 2016.
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- ²⁶ Department for Work and Pensions. Personal Independence Payment: Official Statistics. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/577399/pip-statistics-to-october-2016.pdf (accessed December 2016).
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When you have cancer, you don't just worry about what will happen to your body, you worry about what will happen to your life. At Macmillan, we know how a cancer diagnosis can affect everything and we're here to support you through. From help with money worries and advice about work, to someone who'll listen if you just want to talk, we'll be there. We'll help you make the choices you need to take back control, so you can start to feel like yourself again.

No one should face cancer alone. For support, information or if you just want to chat, call us free on **0808 808 00 00** (Monday to Friday, 9am–8pm) or visit **macmillan.org.uk**

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