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CANCER'S HIDDEN PRICE TAG

Revealing the costs behind the illness

Northern Ireland



Research co-funded by our partner the RBS Group

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Foreword

Cancer is the toughest fight most of us will ever face. Its impact lasts long after treatment has ended. But while everyone anticipates the cost to health, few understand the financial impact of cancer. Our new research reveals the sheer scale of the financial burden faced by people living with cancer.

In Northern Ireland, three out of four people are worse off as a result of a cancer diagnosis, due to a reduced income and increased expenses. On average, cancer patients are £290 a month worse off. Higher household fuel bills, which affect most cancer patients because they struggle to keep warm as a result of treatment, are a particular problem in Northern Ireland. On average, patients have to spend an extra £18 a month to keep warm after diagnosis, while the average for the UK is just £8.

Shockingly, financial issues such as higher fuel bills resulted in nearly 40% of cancer patients in Northern Ireland not being able to keep their home adequately warm in winter. And more than 10% of people with cancer in Northern Ireland missed paying at least one fuel bill in the previous 12 months. Thirty six per cent of cancer patients in Northern Ireland also said they constantly struggled or fell behind with bill payments, and one in five had missed a payment on a household bill in the last 12 months.

The financial impact of cancer is something Macmillan has long been aware of. We already have specialist benefits advice services in Northern Ireland's four cancer units and cancer centre, to help cancer patients access vital financial support. In the past six years, our services have helped NI cancer patients claim in excess of £20 million in benefits. And over the same period of time, we have awarded over £3 million in Macmillan grants to people with cancer who were struggling to cope financially.

The NI Assembly also recognises the importance of making sure people with cancer receive financial advice. We were delighted to accept funding from the Department of Social Development Innovation Fund to test new models of service delivery that aim to provide financial support to even more people affected by cancer. The NI Executive has also recognised the specific problem of fuel poverty among cancer patients. In February 2012, it gave a £100 fuel payment to all people with cancer going through treatment. People who received it told us the payment had been a 'lifeline'.¹

In March 2013, we called on the NI Executive to commit to repeating the payment, using just a fraction of the millions left unspent by government departments at the end of each financial year. This year this money totalled a massive £42 million. Just one sixtieth of this amount would have been enough to repeat the cancer fuel payment in 2013, allowing people

going through cancer treatment to turn on the heating without fear. We want the Executive to commit to using its unspent millions to fund this payment. We also know from a recent Ipsos Mori poll that the public overwhelmingly back this payment, with 88% of over 1,000 people in Northern Ireland saying it should be repeated.²

The health service also has an important role to play in tackling cancer poverty. We need clinical staff to direct patients to financial advice services as early as possible in their cancer journey. It's vital they tell patients about schemes such as those that will allow them to claim back travel costs for medical appointments and access free parking. Clinical staff must also fulfil their responsibility of completing the new Employment Support Allowance form for patients, so they can be fast-tracked to the right benefits group and receive financial support earlier.

We also need employers to work with us to make sure people with cancer are given the time they need to go through treatment and recover afterwards. Employers must also provide the right support to help people with cancer remain in or return to work, if they wish to do so.

So far, our work with the NI Executive, Department for Social Development, Social Security Agency and the health service, has been vital to helping people with cancer

access the financial help they need. However, our new research shows much more still needs to be done, particularly at a time when welfare reform is increasing demand for our services. We need the support, ideas and influence of our partners to make sure that in the future all cancer patients can focus on their health without having to worry about how they'll pay their next heating bill.

Heather Monteverde
General Manager of Macmillan
Cancer Support in Northern Ireland

Thank you to the RBS Group
Macmillan would like to take this opportunity to thank the RBS Group for helping us pilot our financial guidance service and for part-funding this valuable research. Their backing and recognition of this important issue is much appreciated.

Mario's story

Mario was running an Italian restaurant when he was diagnosed with non-Hodgkin lymphoma. He became too ill to run his business and that's when the financial impact of cancer hit him.

'I lost my income. The insurance company said that because cancer was an illness not an accident, I wasn't covered, so I lost everything. I couldn't carry on paying the rent and ended up losing my home. It's very scary, especially when going through chemotherapy.

'When I went to see the benefits adviser, I was in there for no more than 10 minutes [before] being told there was nothing they could do.

'The financial implications of cancer, costs which weren't budgeted for, it's a lot of money. We're talking in the hundreds. Where is it going to come from?'



'I lost everything. I couldn't carry on paying the rent and ended up losing my home. It's very scary, especially when going through chemotherapy.'

Mario, diagnosed with non-Hodgkin lymphoma.

Executive summary

Macmillan wants to make sure that no one faces cancer alone, and this includes helping people deal with the unexpected financial consequences of a cancer diagnosis. We talk to people every day about their money worries and know that cancer brings with it the risk of financial hardship. We commissioned this research to shed new light on the scale and scope of this problem.

Three in four people with cancer in Northern Ireland were financially affected as a result of their diagnosis. On average, cancer patients were £290 a month worse off.

Our research findings show the financial impact of cancer can be extremely hard. In Northern Ireland, a massive three out of four people with cancer were worse off as a result of their cancer diagnosis. On average, cancer patients were £290 a month worse off.³ Worryingly, this led to over a third (36%) of cancer patients in Northern Ireland struggling to keep up with their financial commitments,⁴ with 16% using an unauthorised overdraft in the past 12 months, 11% failing to pay an instalment on a loan in the past year, and 10% missing a minimum payment on a loan or credit card. Our research also revealed 7% of respondents had missed a payment of their rate bill in the past 12 months.

Increased household fuel costs were a particular problem in Northern Ireland. Over half (51%) of cancer patients spent more on fuel because of their diagnosis, with £18 a month being the average extra cost for everyone surveyed. But if we were to only look at the average cost for those affected by this issue, the average figure would be much higher.

In comparison, looking at the UK as a whole, only a third of people (33%) had to spend extra on fuel. The average extra cost was also much lower compared to Northern Ireland, with respondents having to pay an extra £8 a month on average. Our research also found that in Northern Ireland 11% of people had missed a fuel payment in the past year, and more than one in three (38%) weren't able to keep their home adequately warm in winter.

We believe fuel poverty is a particular problem in Northern Ireland because fewer people have access to mains gas and many are still dependent on costly oil and coal heating.

We know that for many cancer patients of a working age, losing the ability to work has a major impact on their finances. Across the UK, almost one in three (30%) people living with cancer experienced a loss of income as a result of their diagnosis, and a third of respondents to our survey (33%) stopped working permanently or temporarily. This loss of income comes at a time when patients are facing additional costs across a wide range of areas, for example, travel costs to medical appointments and spiralling household bills.

High travel costs also hit NI cancer patients hard, with 67% of patients having to pay for travel to medical appointments. People surveyed spent, on average, £76 a month on such costs. Just under a third (31%) had to pay for new clothes as a result of their illness. The average cost for new clothes for everyone surveyed was £13 a month. Forty four per cent of people paid someone to help them around the home or garden. The average cost for this type of help for everyone surveyed was £19 a month. Fourteen per cent couldn't afford to replace a major electrical appliance because of their illness, and 30% said they couldn't afford to keep their home in an adequate state of decoration.

This report provides an overview of our research and highlights a significant and complex problem. Over the coming months, we intend to explore the implications of this research further and aim to develop detailed policy solutions. We want to work with the NI Executive, the health service, local government and local businesses to do this.

However, we also know from the work we have already carried out in this area that action can be taken now that will immediately help to ease the financial burden many people affected by cancer have to cope with.

NI Executive

We call on the NI Executive to:

- commit to giving the £100 winter fuel payment to people going through cancer treatment every year the government identifies an underspend in the January monitoring round
- develop a long-term costed plan with key milestones to help tackle the fuel poverty many people with cancer in Northern Ireland face
- help people affected by cancer claim and receive vital welfare support as a core part of their treatment and care
- make sure people affected by cancer are protected from any future cuts to the welfare budget
- help people living with cancer return to or remain in work by providing return to work support, including vocational rehabilitation.

Health service

We call on the health service to:

- make sure people with cancer are directed to financial support and information at key points during their cancer journey, including diagnosis, treatment and end of life
- make sure clinical staff fulfil their responsibility of completing the section on cancer on the new Employment Support Allowance application form
- make sure staff tell people with cancer about schemes that allow them to claim back hospital travel costs and access free parking.

Business

We call on employers to improve their policies and practice to make sure all staff affected by cancer can remain in or return to work, if they wish to do so and are well enough.

We call on the financial services industry to work with us to make sure:

- customers affected by cancer receive specialist support from the industry so they can manage their financial commitments and maintain their financial wellbeing throughout their cancer journey
- financial products designed to alleviate the impact of serious illness are accessible, transparent and consistently deliver promised support when it is needed.

Energy companies

We want all energy companies to work closely with Macmillan to improve service standards for customers with cancer and to help them manage their costs. This will allow us to reach and support more people living with cancer who have worries about energy costs.

1 Methodology

In early 2012, Macmillan commissioned the University of Bristol's Personal Finance Research Centre and TNS BMRB to research the financial impact of cancer on people across the UK and answer the following questions:

- **What, if any, are the additional financial costs that are associated with cancer?**
- **How and when do these costs arise?**
- **How do these costs impact on the financial and wider wellbeing of adults with cancer and their households?**

The purpose of the research was to provide an up-to-date picture of the financial impact cancer is having on people across the UK. Macmillan's previous research in 2006 concluded that families affected by cancer were living with a 'huge financial burden'.⁵ Recent research in Wales has also demonstrated that financial pressure is an increasing issue for people affected by cancer.⁶

The research

Our research was undertaken in two phases. First, in-depth interviews were conducted with 24 people living with cancer to explore and understand the range and nature of financial issues affecting them. This concluded in spring 2012.

Then the interviews informed the structure of a postal survey that over 1,600 people responded to, and which was conducted between August and October 2012.

The postal survey captured people's self-reported expenditure across a wide range of areas over six months. These included inpatient and outpatient costs, other healthcare costs, clothing, equipment for and modifications to their home, and day-to-day living costs. Costs that respondents would find difficult to quantify, such as increased insurance premiums as a result of their cancer diagnosis, were excluded. In addition, costs that were not identified in the in-depth interviews as having a main impact, for example, costs associated with eye care and spectacles, were also not included.

People's income before and after their diagnosis was captured to calculate any loss of income as a result of cancer.⁷ These figures were adjusted in-line with inflation.

Research participants

Participants were recruited from across the UK, and included visitors to Macmillan's information and support centres and callers to the Macmillan Support Line. A response rate to our survey of 37% was achieved. Results were weighted to be representative of age, gender, cancer type and UK country. Participants had a wide range of cancer types and had been diagnosed within the past month to several decades ago.

The vast majority (88%) had been diagnosed within the last five years and most (96%) had received some form of cancer treatment in the past six months. The household income of respondents varied. However, over half (52%) had household incomes of less than £16,000 per year.

Most participants (61%) did not receive health-related benefits. And out of our 1,610 respondents, 1,096 lived in England, 196 in Scotland, 174 in Wales and 144 in Northern Ireland.

2 The financial impact of cancer

As well as being the toughest fight most people will face, cancer is expensive. From filling up the car with fuel for regular trips to hospital, to keeping the heating on because your cancer makes you feel the cold more, to taking a pay cut because you're too ill to work, the costs really add up.

Across the UK, four in five (83%) people with cancer are, on average, £570⁸ a month worse off because of their cancer diagnosis. This figure is made up of reduced income and increased costs across the following categories: inpatient and outpatient costs, other healthcare costs, clothing, equipment for and modifications to the home, and day-to-day living costs.

£570 is comparable to the monthly mortgage payment most people pay in the UK.⁹

Because of the way we have calculated costs incurred by people with cancer in Northern Ireland, we can't state a comparable figure.¹⁰ Although we do know that the average extra cost to all the NI cancer patients who responded to our survey was £290 a month. Also, we know many people with cancer in Northern Ireland experience real financial hardship and some costs, particularly fuel bills, are considerably higher in Northern Ireland compared to other areas of the UK.

Across all of the UK, the financial impact of cancer has serious knock-on effects to the wellbeing of people affected by cancer. It places a huge amount of additional pressure on people at a time when they should be focusing on their treatment and recovery.

Struggling to keep up with bills and payments is a common theme. Almost a third of people living with cancer (31%) were affected in this way, from time to time. And, worryingly, almost a fifth (18%) faced a 'constant struggle' to keep up with the payment of bills as a result of their cancer.

One in five (17%) respondents did report that they incurred no loss of income or additional costs as a result of cancer. Although this may be the case, it must be remembered that our research only captures their expenditure over a six-month period. Cancer can have a financial impact on people long after a diagnosis has occurred and the size of the impact will change at different points in time. Also, costs incurred by others, such as family and friends, were not included in the research.

An unequal burden

Our research shows the financial impact of cancer is high, but the burden does not fall equally on everyone affected. The costs reported by individuals ranged widely: large numbers of people experienced low costs, while a significant minority of people incurred much higher costs.

Out of the four in five people living with cancer who faced a reduced income and/or increased costs, some were more affected than others. Key factors that influence the financial impact of cancer include people's age, where they are in their cancer journey, their employment status and income.

People aged under 60 who were in work at the time of the survey were particularly affected by the financial impact of cancer, both in terms of the number of people affected and the costs they incurred. This suggests a cancer diagnosis affects the earnings of those who continue in or return to work. A substantial part of this impact was loss of income, although this group also experienced higher expenses. Those with dependent children and mortgages were also more likely to be hit hard financially by cancer.

People who had undergone chemotherapy or surgery in the past six months had to cope with a higher than average impact. More than a third (37%) of respondents had undergone chemotherapy and 31% had received surgery in this period.¹¹ Whilst undergoing treatment, people may make many trips to the hospital, feel the effects of the cold more and have to stop working, all of which can increase the financial impact of cancer.

Over half (51%) of respondents were in full or part-time work at the time of their diagnosis. These people were more likely to have to contend with a greater financial burden, for example where they are unable to continue working or need to reduce their hours. Level of income is also a major factor in predicting the financial impact a cancer diagnosis will have on individuals. Those on middle to high incomes were most likely to incur additional costs. Like most of the UK,¹² these people may not necessarily be able to manage their finances adequately but their income provides a buffer against lack of financial capability. This is until an experience such as cancer causes an 'income shock'.

People on the lowest incomes – less than £100 a week – were also more likely to report a loss in income. This is because they were already in the lowest income group and their income had dropped further, or because they were in the middle or high income group and the impact of cancer was so substantial that they had dropped to the lowest income group.

Key factors that influence the financial impact of cancer include people's age, where they are in their cancer journey, their employment status and income.

Differences between UK countries

Macmillan seeks to influence governments on behalf of people affected by cancer in each of the four UK countries. Our research into the financial impact of cancer looked at the costs incurred by households living with cancer in England, Scotland, Wales and Northern Ireland.

Differences in the average financial impact people were hit by were not statistically significant.¹³ There are, however, some areas in which differences in costs are of interest.

Proportionately, people living with cancer in England tend to be more affected by the cost of parking for outpatient appointments than people in Scotland, Wales or Northern Ireland. A major factor in this is likely to be that many hospitals in England are still not adhering to Department of Health guidance that they provide concessionary or free parking. Hospital car parking is largely free in Scotland and Wales, and people undergoing chemotherapy and radiotherapy in Northern Ireland are eligible for free parking.

Our research shows that heating the home is an extremely pressing issue for people living with cancer in Northern Ireland, who face the highest level of extra costs in the UK. A smaller gas network than other countries may explain this, with 68% of households in Northern Ireland relying on oil for heating, which can be more expensive than gas or electricity.¹⁴

In Scotland, people living with cancer were also more likely to face higher overall household fuel costs, compared to those in other UK countries. As with Northern Ireland, a significant number of households in Scotland still use oil as a source of energy.¹⁵

In Wales, fewer people faced the cost of hospital parking than in England, but their cost of travel to outpatient appointments was particularly high. Previous Macmillan research has highlighted the complex nature of cancer treatment in Wales and the geographical spread of cancer centres.¹⁶

Reduced income

Reduced income can contribute heavily to the financial impact of cancer. Thirty per cent of people with cancer experience a loss of income as a result of their cancer, with those affected losing, on average, £860 a month.¹⁷

A third (33%) of respondents to our survey stopped working permanently or temporarily, and 8% worked reduced hours or took unpaid leave. This emphasises that a significant number of people with cancer stop work when undergoing gruelling cancer treatment or recovering from it.

It is extremely important that people affected by cancer can claim and receive vital benefits at a time when they need them the most and which will ease this loss in income.

In 2011, the UK government announced the biggest shake-up to the benefits system for 60 years. Macmillan campaigned to 'Put the fair into welfare', and the government agreed that many people with cancer require unconditional help from the welfare system.¹⁸ This means they should not face stressful face-to-face assessments or have to take steps to get back to work when applying for Employment and Support Allowance (ESA).

We were delighted that the government listened to our calls by introducing a 'light-touch process' for people awaiting, undergoing or recovering from cancer treatment when applying for ESA and hope they will continue to do so.

We want the UK government to make sure welfare support is maintained and people affected by cancer are protected from any future cuts to the welfare budget.

But people with cancer don't just need welfare support. If they need or want to remain in or return to work, they should be supported so they can do this. Macmillan believes far more can be done in this area, something that would significantly help to stem the financial hardship suffered by those who have to leave work.

Thirty per cent of people with cancer experience a loss of income as a result of their cancer, with those affected losing, on average, £860 a month.

We know vocational rehabilitation services can improve work and health outcomes for people with cancer and help them return to or remain in work.¹⁹ In fact, Macmillan has developed a three-level model of work-related support and vocational rehabilitation. However, there has been little progress at a UK-wide level in this area since a 2008 review of vocational rehabilitation commissioned by a group of stakeholders that included the UK government.

It is vital more progress is made.

Governments must help people living with cancer return to or remain in work by providing return to work support including vocational rehabilitation.

Employers must improve their policies and practice to make sure all staff affected by cancer can remain in or return to work, if they wish to do so.

Increased costs

Outpatient and inpatient costs

The most common cost that people living with cancer face is getting to and from their outpatient²⁰ and inpatient appointments. People undergoing treatment for cancer have frequent hospital appointments. They may also need to visit a range of other healthcare professionals for treatment, rehabilitation and follow-up care. Because of reduced immunity, public transport is often unsuitable, forcing them to rely on travel by car or taxi.

Costs associated with outpatient appointments hit almost three-quarters (71%) of people with cancer. The cost of travel to and from appointments affects 69% of people with cancer and costs them, on average, £170 a month. Parking for outpatient appointments affects 38% of people with cancer and costs them, on average, £37 a month.²¹ And over a quarter (28%) of people with cancer incur costs for inpatient appointments. On average, this amounts to £20 a month for those affected.

The cost of travel to and from appointments affects 69% of people with cancer and costs them, on average, £170 a month.

The Healthcare Travel Costs Scheme²² allows patients who are receiving income-related benefits or eligible for the NHS Low Income Scheme²³ to claim a refund for the cost of travel to a hospital or other NHS premises for NHS-funded treatment. The huge cost of travel to and from appointments suggests many people living with cancer may not be aware of available concessionary schemes or are ineligible for such schemes.

Macmillan has campaigned since 2005 to abolish hospital car parking costs for cancer patients across the UK. It is an unfair tax on illness. We have welcomed steps taken in Scotland, Wales and Northern Ireland to make sure free parking is available for cancer patients in most hospitals. In Scotland and Wales, the vast majority of hospitals provide free parking and in Northern Ireland, parking is free for chemotherapy and radiotherapy patients.

However, despite Department of Health guidance stating that hospitals in England should offer free or reduced parking to cancer patients, many still face these costs. This is an unacceptable tax on healthcare.

Where hospital car parking charges remain, we want these hospitals to abolish car parking charges for cancer patients.

Day-to-day living

The cost of day-to-day living can dramatically increase after a cancer diagnosis – a time when people can least afford it. People may spend more time at home and feel the cold more because of their cancer, which can result in energy bills rising. They may also need to change their diets and buy more expensive foods to help them cope with the effects of cancer and its treatment.

If they feel weak following treatment, they may not be able to go out and see people, which may lead to them using the telephone or internet more to keep in touch with family and friends. Household chores may become difficult as well, resulting in them paying for help around the home or garden.

More than half (54%) of people with cancer experience increased day-to-day living costs. These, on average, add up to an extra £63 a month for those affected by this issue.

Costs incurred by respondents to our survey

Cost	% of people affected	Average cost to those affected (£/month)
Food and drink	22%	26
Household items	14%	10
Household fuel bills	33%	24
Telephone or internet bills	28%	13
Travel costs	16%	21
Television or books	18%	17
Help around the home or garden	25%	34
Child care	1%	N/A*
Total	54%	63

*Sample size too low to report.

A quarter (25%) of our respondents incurred costs for help around the home or garden, at an average cost of £34 a month. These additional costs were a direct result of their cancer, emphasising that cancer and its treatment can cause physical difficulties.

One in three (33%) respondents spent an extra £24 a month on their household fuel bills as a result of their cancer and/or its treatment.²⁴ A particularly concerning finding from the research was that over a quarter (28%) of people with cancer couldn't keep their home adequately warm in winter in the past 12 months because of the cost.²⁵ Given people living with cancer tend to feel the cold more, this is an extremely worrying situation and something that could affect their recovery.

Over a quarter (28%) of people with cancer couldn't keep their home adequately warm in winter in the past 12 months because of the cost.

Macmillan knows people living with cancer face increased energy bills as a result of diagnosis and are particularly susceptible to fuel poverty. We have campaigned to raise awareness of this issue, encouraged governments across the UK to take action and worked collaboratively with the energy provider npower to develop the Fuel Management Programme.

By placing an eligible customer affected by cancer on a reduced payment plan and writing off their energy debts, the Fuel Management Programme takes the customer's household out of fuel poverty. This helps to alleviate worry about using more energy and allows the cancer patient to focus on living well during their cancer journey. After 12 months, each customer's situation is reviewed, and they may be offered a further 12 months on the programme.

We want all energy companies to work closely with Macmillan to improve service standards for customers with cancer. This will help us reach and support more people living with cancer who have energy worries.

Other healthcare costs

Healthcare across the UK is free at the point of delivery. As a result, it would be understandable to think that no additional costs would be incurred for healthcare. However, a significant proportion (41%) of respondents incurred costs for other healthcare needs, with the average cost for those affected being £41 a month.

Over a fifth of respondents were affected by costs for over-the-counter or prescription medicines, costing on average £8 a month.

Costs incurred by respondents to our survey

Cost	% of people affected	Average cost to those affected (£/month)
Over-the-counter/prescription medicines	22%	8
Dietary supplements	12%	16
Dressings	10%	7
Private treatment or healthcare	4%	112
Dental surgery or care	11%	28
Nursing care provided in a person's home	1%	N/A*
Personal care provided in a person's home	5%	56
Total	41%	41

*Sample size too low to report.

The most common healthcare cost incurred by respondents to our survey was for over-the-counter or prescription medicines. Over a fifth of respondents were affected by costs for over-the-counter or prescription medicines, costing on average £8 a month. Since 2005, Macmillan has campaigned across the UK to end prescription charges for people living with cancer, and we're delighted the UK's governments listened to us. In Scotland, Wales and Northern Ireland, prescription charges were abolished completely. In England, cancer patients are eligible for free prescriptions but must first complete an application form provided by their doctor.

That people are still incurring costs for over-the-counter and prescription medicines suggests that there is still work to do in raising awareness of free prescriptions among people living with cancer. The National Cancer Patient Experience Survey reveals 27% of patients who would have liked information about their eligibility for free prescriptions did not receive it from hospital staff.²⁶

The in-depth interviews carried out as part of this research support this finding, with people sometimes finding out they are eligible for free prescriptions belatedly. Patients may also not realise that after treatment they are still entitled to free prescriptions for over-the-counter items.

The NHS must ensure that people with cancer can access support and information on finances and work at the earliest opportunity.

Just over one in ten (11%) of people were hit by dental costs, at an average of £28 a month. There are significant health benefits to maintaining good oral health before, during and after chemotherapy treatment to lower the risk of infection. This is particularly true for people diagnosed with cancer of the lip, mouth, pharynx and larynx, who are more likely to need dental treatment and, therefore, more likely to incur additional healthcare costs. Eligibility for free dental checks and treatment varies across the UK. However, similar proportions of respondents from all four countries incurred costs.

Private healthcare and personal care provided in people's homes were less commonly paid for, with 4% and 5% of people incurring costs, respectively. But when costs were incurred, the amount was significant. Those who turned to private healthcare paid, on average, £110 a month, and people who required personal care in their homes faced an average cost of £56 a month.

Clothing, equipment and modifications

The effects of cancer and its treatment can last a long time and require people to make significant changes to be able to remain independent and retain dignity. During or after treatment, people may find their clothes no longer fit and have to be replaced. They may need wigs or head coverings after chemotherapy or fabric supports after surgery, for example, surgical bras. Or they may require modifications to or specialist equipment for their home, to allow them to remain independent.

Over a third (37%) of respondents incurred costs for clothing, specialised equipment and home modifications, with those affected paying, on average, £70 a month.

Almost a third (29%) of people had to pay for replacement clothing as a result of their cancer treatment. Weight loss is a common symptom of cancer, and certain chemotherapy drugs, steroids and hormonal therapies can cause weight gain, meaning clothes need to be replaced.

Costs incurred by respondents to our survey

Cost	% of people affected	Average cost to those affected (£/month)
Wigs, hairpieces, head coverings	10%	23
Fabric supports	5%	14
Clothing	29%	31
Modifying the home	4%	326
Specialist equipment for home or care provided in a person's home	6%	28
Total	37%	70

One in ten (10%) of our survey respondents paid, on average, £23 a month for wigs, hairpieces or head covers. This may reflect the high costs of NHS wigs, with a full, bespoke human hair wig costing £250 – something that may often need replacing. Some groups are eligible for free wigs.²⁷ However, the fact that these costs are incurred by a significant number of people living with cancer suggests that such schemes may not be meeting demand or people are ineligible for such schemes.

The vast majority of respondents did not have to modify their homes as a result of their cancer. However, costs that were incurred were significant. One in 25 people (4%) paid for modifications to the home as a result of their cancer. The average monthly cost to those affected was £326. This figure is driven by a small number of people experiencing very high costs, sometimes several thousands of pounds. This may indicate that people are unaware of schemes at local authority level to assist with home modifications, or that the eligibility criteria for most schemes is too stringent for people living with cancer.

3 Advice

Macmillan wants to make sure no one faces cancer alone. However, over two-fifths (42%) of people with cancer who replied to our survey did not receive money or debt advice following their diagnosis. This is broadly comparable with the National Cancer Patient Experience Survey, which found that 48% of cancer patients were not given information by healthcare professionals on how to get financial help or benefits.²⁸

Over two-fifths (42%) of people with cancer did not receive money or debt advice following their diagnosis.

We know it's best for people to have conversations about finances and work soon after diagnosis. This can help them take appropriate steps to prevent and manage any potential problems. Discussions about finances and work should be included in care pathways used by clinicians when providing care to people with cancer.

We want the NHS to make sure people with cancer can access support and information on finances and work at the earliest opportunity.

Our research found that Macmillan is the most common source of financial advice for people living with cancer, with over half (53%) of our respondents turning to our services. However, this may be because our respondents were recruited through Macmillan information and support centres and our Macmillan Support Line, and were, subsequently, aware of the financial support we provide.

Less than one in ten (8%) people with cancer turned to their bank, building society or another financial services provider for help. Experiences with different sources of financial or debt advice varied, with the financial services industry seen as the least helpful source of advice. Less than two-fifths (39%) described the advice they received from a financial services organisation as fairly or very helpful.

This suggests that the financial services industry could do more to help its customers with cancer before they get into financial difficulties. Macmillan is working with the industry to identify ways to improve the support provided to customers with cancer. This includes raising awareness among staff who come into direct contact with customers about the issues customers with cancer face and increasing access to specialist support for vulnerable customers.

We are calling on financial services organisations to work with us to make sure that:

- **customers affected by cancer receive the specialist support they need to manage their financial commitments and maintain their financial wellbeing throughout their cancer journey**
- **financial products designed to alleviate the impact of serious illness are accessible, transparent and consistently deliver promised support when it is needed.**

4 Wider context

The financial burden of cancer comes against a challenging backdrop of welfare reform, rising inflation and austerity.

The Welfare Reform Act, passed in March 2012, sets out the most radical reform of social security provision since the Beveridge report in 1942. Many existing entitlements will be abolished and replaced by new benefits that have tougher eligibility criteria.

Macmillan successfully campaigned for significant changes to Employment and Support Allowance. This now means the vast majority of people with cancer will be placed in the Support Group (which provides unconditional support for people who are unable to work or look for work) without a stressful face-to-face assessment. We were delighted the UK government listened to us, and we hope they will continue to do this as a number of other reforms are introduced which have the potential to negatively impact on people affected by cancer.

Meanwhile, inflation has continued to rise and is not expected to return to the Bank of England's target (2%) until 2016.²⁹ The prices of essential items such as food, gas and electricity have risen even faster, adding to the real cost of living for everyone.

The NHS is also tasked with achieving 'efficiency savings' of up to £20 billion by 2015. This means it will need to change the way health services are provided.³⁰

People living with cancer are already facing a huge burden. It is essential that in this period of austerity they are not allowed to fall further behind financially. We will continue to monitor the impact of the current financial climate on people affected by cancer and strive to make sure they do not lose out.

5 Conclusion

Across the UK, four in five (83%) people with cancer are, on average, £570 a month worse off as a result of their cancer. Our research emphasises that the make-up of the financial impact of cancer is complex and multi-faceted. The solutions cut across a number of stakeholders. We are already working with a wide range of organisations to solve the financial problems cancer causes. However, we need to do more.

Macmillan calls on all UK governments, the NHS and the private sector to offer financial support and information as early as possible. We want them to join us in eradicating financial hardship and money worries for people living with cancer.

We call on governments across the UK to:

- make sure people affected by cancer can claim and receive vital benefits when they need them most
- make sure welfare support is maintained and people affected by cancer are protected from any future cuts to the welfare budget
- help people living with cancer return to or remain in work by providing return to work support including vocational rehabilitation.

We want the NHS to make sure people with cancer can access support and information on finances and work at the earliest opportunity.

Where hospital car parking charges remain, we want these hospitals to abolish car parking charges for people with cancer, in-line with policy and guidance.

We call on employers to improve their policies and practice to make sure all staff affected by cancer can remain in or return to work, if they wish to do so.

We call on the financial services industry to work with us to make sure:

- customers affected by cancer receive specialist support from the industry so they can manage their financial commitments and maintain their financial wellbeing throughout their cancer journey
- financial products designed to alleviate the impact of serious illness are accessible, transparent and consistently deliver promised support when it is needed.

We want all energy companies to work closely with Macmillan to improve service standards for customers with cancer. This will allow us to reach and support more people living with cancer who have worries about energy costs.

This research is forming the basis of a significant Macmillan campaign. Over the next five months, we will continue to examine the issues highlighted by this research and to develop solutions to ease the financial impact of cancer.

References

1. On behalf of Macmillan Cancer Support, RS Consulting carried out telephone interviews with 15 people with cancer who received the fuel payment from the Northern Ireland Executive. Interviews took place between November 2012 and January 2013.
2. On behalf of Macmillan Cancer Support, Ipsos Mori carried out face-to-face interviews with 1,016 people in Northern Ireland between 31 January 2013 and 13 February 2013. Survey results are unweighted. Question was: Last winter the Northern Ireland Executive made a one-off £100 winter fuel payment to cancer patients to help with heating costs at a cost of £700,000. To what extent do you agree or disagree that this payment should be made annually to cancer patients?
3. All average costs for Northern Ireland are based on the answers of all NI respondents to our survey. This means a number of cases where people incurred no costs have been used to calculate these averages. If we were to only use the average cost of those affected by an issue, as is done for our UK-wide figures, the average cost would be much higher. We adopted this approach to make sure all average costs are based on a minimum of 50 respondents.
4. This includes 29% of people with cancer who keep up with their financial commitments but find it a constant struggle, 4% who are falling behind with some bills or credit commitments, and 3% who are falling behind with many bills or credit commitments. A further 25% of respondents said they keep up with financial commitments but it is a struggle from time to time, and 37% said they keep up with all bills and credit commitments without any difficulty.
5. Macmillan. *Cancer Costs: The hidden price of getting treatment*. 2006.
6. Macmillan. *Counting the cost of cancer*. 2012
7. Steps were taken in estimating a figure to attribute loss of income retrospectively to cancer:
 - a. Mid-points of income bands were taken as a proxy for point estimate of total income; this was done for current income and income prior to cancer diagnosis.
 - b. Respondents rating of the extent to which any difference was due to their cancer diagnosis was used to adjust the calculated absolute change in income proportionately.
8. Three digit figures have been rounded to the nearest 10 to make them more accessible.
9. Average mortgage payment in the UK for someone with a 30% deposit is £580 a month, according to the *Halifax Affordability Review 2013*. www.lloydsbankinggroup.com/media/pdfs/halifax/2013/1901_Housing_Review.pdf (accessed 14 March 2013).
10. All average costs for Northern Ireland are based on the answers of all NI respondents to our survey. This means a number of cases where people incurred no costs have been used to calculate these averages. If we were to only use the average cost of those affected by an issue, as is done for our UK-wide figures, the average cost would be much higher. We adopted this approach to make sure all average costs are based on a minimum of 50 respondents.
11. People are often given more than one type of treatment for their cancer.
12. Financial Services Authority. *Financial Capability in the UK: Delivering Change*. 2005.

13. Statistical testing was undertaken on the data and 'significant' differences, ie those that can be confidently generalised from the sample to the population, are defined as those that are statistically significant at the five per cent level ($p < .05$).
14. Consumer Council NI. *Home Heating Oil*. www.consumercouncil.org.uk/energy/home-heating (accessed 14 March 2013).
15. Consumer Focus Scotland. *Help for households in rural areas to cut the cost of heating oil*. www.consumerfocus.org.uk/scotland/news/help-for-households-in-rural-areas-to-cut-cost-of-heating-oil (accessed on 12 March 2013).
16. Supra note 6.
17. Almost half (49%) of those in full or part-time employment at the time of the survey, over a third (36%) of the total sample, reported a loss in income as a result of their cancer.
18. Department of Work and Pensions. *Benefits rules change to help people with cancer*. www.dwp.gov.uk/newsroom/press-releases/2012/sep-2012/dwp100-12.shtml (accessed on 12 March 2013).
19. Macmillan. *Making the shift*. 2013.
20. Outpatient appointments could include trips to the GP, hospital or clinic, physiotherapist, dentist, counsellor or other practitioners.
21. The high cost of outpatient appointments is driven by a smaller number of people experiencing very high costs, sometimes into the high hundreds and even thousands of pounds.
22. Known as the Hospital Travel Costs Scheme in Northern Ireland. In Wales, people are signposted directly to the NHS Low Income Scheme.
23. Eligibility for the NHS Low Income Scheme is determined by savings, investments or property (not counting the place where you live). Further information can be accessed at www.nhs.uk/NHSEngland/Healthcosts/Pages/nhs-low-income-scheme.aspx
24. The research covers a six-month period over spring–summer 2012; these figures are likely to be even higher over winter.
25. This question was based closely on a larger set of items used by the Department for Work and Pensions to understand levels of material and social deprivation as part of their suite of measures to monitor poverty in the UK. DWP. *Households Below Average Income: An analysis of the income distribution 1994/95–2010/11*. 2012.
26. Department of Health. *National Cancer Patient Experience Survey Report 2011/12*.
27. Wigs are free on the NHS if individuals are 16–18 years old and in full-time education, a hospital inpatient or a war pensioner. People can receive help with the costs if they receive income support, Jobseekers Allowance, Employment and Support Allowance or pension credit, have an NHS tax credit exemption or are named on a HC2 certificate.
28. Supra note 26.
29. Bank of England. *Inflation Report: February 2013*. 2013.
30. National Audit Office. *Progress in making NHS efficiency savings*. 2012

Cancer is the toughest fight most of us will ever face. But no one should go through it alone. The Macmillan team is there every step of the way.

We want to make sure people affected by cancer are able to concentrate on their health, instead of worrying about their finances. So, we offer expert financial guidance and information on our website, through our face-to-face benefits advisers and the Macmillan Support Line.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way call us on

0808 808 00 00

(Monday to Friday, 9am–8pm)

or visit **macmillan.org.uk**

Hard of hearing?

Use textphone 0808 808 0121, or Text Relay.

Non English speaker? Interpreters available.

**WE ARE
MACMILLAN.
CANCER SUPPORT**