



What are they?

Macmillan helps people living with cancer through the support and funding of Local Benefits Advice Services. Although individuals often face increased costs and reduced income as a result of their cancer diagnosis, many are not aware of the benefits they are entitled to.

Macmillan's benefits advice services are based in a variety of settings, such as Citizens Advice Bureaux, Macmillan Information and Support Services, local councils, or hospitals.

'Receiving the benefit has made a big difference. My husband has to take me here, there and everywhere and petrol is expensive. I feel the cold, especially when I take the wig off so I run the heating more.'

Cancer patient

Need



On average cancer patients are **£570** a month worse off because of a cancer diagnosis.⁸



Only **54%** of cancer patients had received information about financial help or benefits they might be entitled to in 2014.²

Reach



Every £1 we spend on a face-to-face benefits adviser helps people affected by cancer claim **£23.45** in benefits they are entitled to.³



Face-to-face Macmillan benefits advisers identified over **£181m** in benefits for people affected by cancer in 2014.⁴

Impact



Macmillan Welfare Rights Services can help to free up hospital and social work staff, reducing the resource cost of best meeting patients' needs.⁵



Referrer feedback from Macmillan Welfare Rights Service in Guildford found that **92%** of referrers felt that the service was either 'crucial' or 'very important' to them in helping relieve some of their workload.²³

This Impact Brief is part of a suite of Impact Briefs which provide evidence about the impact of Macmillan's direct and indirect services, available at www.macmillan.org.uk/impactbriefs

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LOCAL BENEFITS ADVICE SERVICES

INTRODUCTION

Macmillan helps meet the benefits advice needs of people affected by cancer in a variety of ways including through the support and funding of Local Benefits Advice Services, the production and distribution of high quality printed materials, and directly through our website and telephone helpline (Macmillan Support Line).

SUMMARY OF KEY FINDINGS

- **The financial cost of cancer is acute**
83% of cancer patients suffer loss of income and/or increased costs as a direct result of cancer. The most widespread cost facing cancer patients is the cost of travel to, and parking at, hospital.
 - **Financial debt causes problems**
Debt can be a major problem during illness, causing a deterioration of mental and physical health. The effect on carers can also be substantial.
 - **Benefits advice is often hard to access**
People affected by cancer often struggle to access generic benefits advice provision. The symptoms of cancer and side effects of treatment mean that it can be very difficult for people to access advice via conventional channels. When they are able to access this advice they often find that, whilst the advisers have an expertise in benefits advice issues, the lack of understanding of cancer and its treatments means that some of the available financial help can be missed.
- Benefits advice leads to better patient outcomes**
Cancer specific benefits advice services leading to increased income can be associated with improvements in psychosocial aspects of health. Better mental health, higher levels of energy and reduced tiredness are just some examples. The income generated from benefits advice enables people to afford necessities and additional items that were required as a result of a diagnosis of cancer.
- **Guidance is often given at the wrong time**
Although nurses, doctors and other patients sometimes offer valuable guidance many people affected by cancer do not receive it at the right time.

DETAILED FINDINGS

1. What is the issue?

The cost of cancer

In the current economic climate many people are experiencing financial difficulties. According to The Money Charity, the level of UK household debt in 2015 stood at £28,442 per adult (as of May 2015). During the same period, households spent on average £3.10 on water, electricity and gas every day. Which equals to £1,131.50 per year.¹

Health and income are also significantly linked, with people with a higher disposable income tending to have better health. According to the OECD, around 89% of UK adults with a disposable income in the top 20% rate their health as 'good' or 'very good', compared to around 64% for those with a disposable income in the bottom 20%.⁷

Further to a cancer diagnosis people may face new or increasing debt as a result of their change in circumstances.⁸ Loss of income, reduced savings, short or long term unemployment, reduced occupational pension and additional costs associated with cancer treatment are the main financial consequences of a cancer diagnosis.⁹ Examples include increased heating and general domestic bills, increased travel costs to and from hospital and a change in dietary or clothing requirements.¹⁰

Macmillan research shows that the financial implications of cancer are extremely high. 83% of cancer patients suffer loss of income and/or increased costs as a direct result of cancer. On average patients are £570 a month worse off because of a cancer diagnosis. People may stop working or be forced to work reduced hours due to ill health and so face a loss of income, whilst also having to cope with additional cancer related costs. Further financial burdens include regular trips to medical appointments and spiralling household bills - including increased heating costs, as a person living with cancer often feels the cold more. The most common additional costs faced by people living with cancer is getting to and from hospital, or making other healthcare visits.⁸

'He had lost an awful lot of weight so we had to buy new clothes. He spent more time in bed, which meant new sheets, laundry bills, more washing powder and conditioner.'

Carer of cancer patient

Evidence also suggests that the cost of cancer is higher for people in specific groups. Patients who are working at the time of their cancer diagnosis are heavily impacted financially.²¹ Other groups include younger and older people, people with dependent children, as well as with low income and/or savings.²⁰

'I spend more on special foods for him because he can't swallow a lot of things. He was in hospital in Glasgow so travel costs for me to visit were expensive.'

Carer of cancer patient

'We went to the hospital every day and the bus works out quite expensive. It must have been about 300 times back and forth on the bus.'

Carer of cancer patient

'I have increased electricity and gas bills because I can't take heat nor cold. If it is too hot I have to have a fan on, if it is too cold I have to have the heating on. Because I cannot reach the washing line since having surgery I have to tumble dry the washing.'

Cancer patient

The impact on health and wellbeing

Research shows that the financial impact of cancer is often overlooked when considering the direct implication of the illness on people's lives. Cancer patients themselves claim that they had not generally considered financial consequences of cancer before being diagnosed.³³

In general, between 49% and 75% of people living with cancer feel depressed or anxious.¹¹ Financial problems can exacerbate these issues, leading to severe anxiety and stress,

depression and self-harm, as well as strain on personal relationships, low self-esteem and social exclusion.^{12,34}

Research shows that the stress and anxiety caused by the financial implications of living with cancer can have a negative impact 'almost worse than the disease itself'.¹³

For people affected by cancer, the financial difficulties arising as a result of a diagnosis can be even more worrying than the cancer itself.¹⁰

Furthermore, anxiety resulting from the financial consequences of a cancer diagnosis appear to be stronger for people in more deprived areas. A study on anxiety and support in breast cancer stated that 'more affluent women are better informed and less likely to suffer from anxiety after treatment for breast cancer than less privileged women and deprived women reported greater anxiety about money'.¹⁴

Inequalities in accessing financial support

Evidence suggests that a major problem in the context of financial support for cancer patients is not the lack of services themselves, but rather that existing services fail to reach the right people at the right time.³⁵

Current service provision appears to target specific groups of people, which are considered to have higher financial needs. These include younger people of working age and people with lower financial income. Yet, different people are affected by cancer in a different way. This suggests that a single policy can hardly be effective for all people affected by cancer, calling for a more tailored kind of financial support.³⁵

Income is not the only factor to influence financial impact of cancer in people's lives. Savings, work situation, distance from hospital (and related travel costs) are just some of the many other aspects that need to be considered, as they can significantly contribute to a financial worse off following a cancer diagnosis.

Furthermore, work is needed to fully understand the financial implications of cancer in BME and minority groups.³³ These groups are particularly affected, as levels of reported income tend to be lower and deprivation higher. Also, minority groups might have to deal with other barriers to accessing financial support, like the limited knowledge of English.³⁶

Claiming financial benefits

83% of cancer patients are financially affected 'as a direct result of cancer'. Despite the clear link between a cancer diagnosis and being financially worse off, there is a wealth of evidence demonstrating significantly low awareness and/or take-up of financial support entitlement.⁸

A 2008 Macmillan commissioned evaluation has found that without the welfare rights service most of the beneficiaries would not have been aware that they were entitled to financial support.⁵

In another case study, 89% of users of Macmillan Local Benefit Advice Services claimed they would not have known how to get help if the service had not existed.¹⁵

The 2014 National Cancer Experience Survey found that in England only 54% of patients living with cancer said they had received information about financial help or benefits they might be entitled to. 46% of patients who would have liked information did not get any.² In addition, there have been reports from many clients of frustration at being unaware of the support available until late in their illness.²⁵

Age also seems to play an important role, with older respondents feeling less satisfied about the financial information they received.² There is evidence to suggest that patients find the process of receiving financial support too difficult and would not have been able to claim without assistance.¹⁷ People with cancer, especially when older, get very tired and often give up seeking help if they perceive it as difficult.¹⁶

In addition, people struggle with making claims, finding the forms complicated and too hard to understand.¹⁷ Those under state pension age (SPA) and in work can experience greater problems in obtaining benefits because the process of making a claim is often more complex than for those above SPA.¹⁹

Early provision of benefits advice services could also help prevent major financial issues such as debt, bankruptcy and house repossession.¹⁰

Implications for health professionals

In the current context, it is important that patients are aware about the possible financial impact of cancer in their lives and the support available as early as possible in their cancer journey.³³

Yet, although nurses and doctors sometimes offer valuable guidance on financial benefits available for people with a cancer diagnosis, many people affected by cancer do not receive it at the right time.¹⁷ General practitioners often provide initial support with questions around benefit entitlement and financial relief services, but specialist advice is needed to help people affected by cancer with practical financial support that cannot be met during clinical consultation.

Financial guidance often does not seem to be a priority at diagnosis, which leads to a lack of help available in hospital for people financially impacted by cancer. Health and social care staff often do not have sufficient knowledge of financial support issues. At the same time, experts in benefits advice often know too little about cancer.

Therefore, it seems to be increasingly difficult for people diagnosed with cancer to access a service that is expert on both financial support and their condition.

2. What is Macmillan doing to address the issue?

Benefits advice

To fight these issues Macmillan has developed a number of benefits advice services in partnership with, among others, the NHS, local authorities and Citizens Advice Bureaux. These services provide specially trained benefits advisers who can promote and support people to access appropriate financial help for people affected by cancer.

A Macmillan benefits adviser can offer specialist advice on entitlements to benefits, tax credits and grants. These services Macmillan offers understand the specific needs of people with cancer and are able to help them to access the support they are entitled to throughout their cancer journey.⁶

Recently, Macmillan has reviewed face to face benefits advice provision and is now in a position to move towards a more consistent and cost effective model of provision. By redesigning benefits

advice, Macmillan hopes to fulfil a core ambition: that poverty is not a consequence of a cancer diagnosis. Macmillan is intending to shift to a model of strategic investment and delivery that ensures we have a consistent minimum level of provision across the UK and a standard service specification has been developed to facilitate a strategic shift towards earlier, high impact, low cost interventions.

Macmillan face-to-face benefit advisers

In 2014, our national network of face-to-face Macmillan benefits advisers reached around 122,600 people affected by cancer, identifying over £181.4m in benefits.⁴

These services provide compelling evidence, through commissioned external evaluations, client satisfaction surveys and routine feedback forms, about the high quality of service on offer, in terms of

- advising people about their entitlements
- assisting with claims
- dealing with the complexities that surround the benefit system
- answering questions that people did not, or felt they could not, ask of their health professionals.^{22,23,24,28}

Every £1 Macmillan spends on a face-to-face benefits adviser helps people affected by cancer claim £23.45 in benefits they are entitled to.³

Additional Support

Macmillan Support Line (MSL)

In addition Macmillan provides benefits advice over the phone and online to anyone in the UK on 0800 808 00 00 or via www.macmillan.org.uk.

The Macmillan Support Line has a specialist team of phone-based Macmillan benefits advice experts who offer specialist advice to help ease money worries for people affected by cancer, including providing information on benefits, tax credits, grants and loans.

In 2014, the Macmillan Support Line benefits advice experts reached 20,117 people affected by cancer across the UK, identifying around £57m in benefits.⁴

Macmillan Financial Guidance Service

Macmillan Financial Guidance Service provides information and advice to people affected by cancer on different issues, from helping people to make informed decisions about their mortgage, pension or insurance to explaining financial jargon and assisting with financial planning.

In 2014, the service provided 4,682 people affected by cancer with advice in the UK, identifying £2.9m in financial gains.

3. What is the impact of effective benefits advice services?

i) Impact on finances

The income generated as a result of benefits advice enables people to afford necessities and additional items that are required as a result of a cancer diagnosis. Examples include higher travel and parking costs, heating bills and altered dietary and clothing requirements. In addition the extra income can help to lessen the impact of a loss of earnings and provide a safety net giving the individual time to arrange other sources of finance.¹⁹

People living with cancer may face new or increasing debt as a result of their change in circumstances.⁸ Successfully applying for welfare benefit has an important impact on general finances, resulting in a median increase in income of around £70 per week.²⁵

Case Study: Macmillan Lanarkshire Benefits Advice and Support Service²⁸

A 72 year old widow diagnosed with breast cancer had surgery and was just coming to the end of her course of chemotherapy. After contact with the service her income increased by **£101.45** a week. This allowed her to keep her heating on without worrying about being able to afford it.

ii) Impact on physical and mental wellbeing

Dedicated benefits advice services or welfare rights services help people affected by cancer negotiate the complex welfare benefits system by providing expert knowledge.⁹

These services have a positive effect on the health and wellbeing of people living with cancer. Stress and anxiety are reduced and claimants move steps forward towards resolving debts and easing financial burden.

'Receiving the benefits made a big difference. My husband has to take me here, there and everywhere and petrol is expensive I feel the cold, especially when I take the wig off so I run the heating more.'

Cancer patient

'These advisers are there for the people who need their help when they need it most. I am so grateful for the burden and stress they have taken off my shoulders.'

Cancer patient

The benefits of receiving financial support are widely acknowledged. Clients of the Citizens Advice Bureau reported improvements in their health and wellbeing as a consequence of receiving financial help. 81% said they felt less stressed, depressed or anxious after receiving support.²⁶

People affected by cancer are often unaware of health and/or cancer related benefits advice services, yet many experience considerable stress around financial issues.²⁵ Once they are relieved from stress related to financial difficulties, they are able to focus their mental and physical energy on their illness and treatment.

'The adviser made being diagnosed with cancer easier as I didn't have to worry about finances as well.'

Cancer patient

Cancer specific benefits advice leading to increased income can be associated with improvements in levels of energy and tiredness, impacting on the ability to carry out day to day tasks.¹⁹

In the Macmillan Welfare Rights Service in Guildford, 84% of service users felt the advice they received helped them feel less stressed about their situation.²³ Another study reported that all patients claimed that benefits received as a result of Macmillan-funded Benefits Advice Services helped to reduce stress levels, which can in turn aid recovery.⁵

Clients with dependent children also reported that receiving financial benefits following Macmillan advice made them feel more comfortable at home. This feeling improved the relationship with their children, as they were more relaxed around them.

Overall accessing benefit entitlements increases capacity to cope with many of the wider consequences of cancer.

'I feel I could not do without this service. It is a huge benefit to both me and patients'.

Healthcare professional

'The form I had would never have been filled in without the Macmillan adviser, as I couldn't and didn't know how to answer the questions on benefits'.

Cancer patient

iii) Impact on health services

In 2013, the NHS spent on cancer and tumour related costs was estimated to be as much as £5.8 billion.²⁷ Evidence suggests that lack of financial stability and/or social support can reduce an individual's ability to maintain a stable home care status. This can in turn lead to considering hospital admission as a safety net. An elevated number of hospital admissions, though, means increasingly high costs for NHS, using funds that could potentially be redirected to improving services for people affected by cancer.

Between 49% and 75% of people living with cancer feel depressed or anxious¹¹ and debt-related mental health issues impose considerable costs onto health, social care and other services. There is consistent evidence that benefits advice can help prevent anxiety and stress. It can also contribute to savings for other local services of between £63,320 and £511,212 per year by preventing debt-related mental health issues. These figures are critically influenced by delivery volume and the profile of service users.^{22,23,24,28}

Evidence shows that Macmillan Welfare Rights Services can help to free hospital and social workers from having to provide benefits advice to patients. This potentially reduces the time and resources health professionals need to invest in such practices, allowing them to concentrate on providing specialist care that meets patients' needs and their core clinical tasks.¹⁵ Trained benefits advisers are also better placed to offer expert advice and assistance about benefits and finances.

'I used to spend long periods of my nursing time helping patients fill in the form and sending it. Now I just refer to a benefit adviser, it's just one phone call'.

Macmillan Nurse

Interviews with medical professionals at the Renfrew Macmillan Cancer Information and Support Service concluded that the service was helpful to their own personal workload, saving time on unnecessary home visits. In addition, the service helps facilitate partnership working and improve communication between health and social care agencies making the whole process more efficient.⁹

The 2014-2015 Macmillan Guildford Welfare Rights Service's feedback survey found that 92% of referrers felt that the service was either 'crucial' or 'very important' to their own work, helping them relieve some of their workload. In addition, benefits advice deliver savings for other local services by preventing debt-related mental health issues. Where benefits advice have tackled cross-cutting issues beyond health and social care, these have resulted in multiplier effects in benefits generated.²³

Our primary research with Cancer Clinical Nurse Specialists (CNSs) found that a benefits advice service to refer to can help save CNSs between 2.1 hours and 5.8 hours per patient, or 3.95 hours on average. This allows them to focus on their clinical workloads and therefore contributes to the NHS 'releasing time to care' initiative.²⁹ Savings in staff time also have direct implications on the costs of running the services.

Case Study – Macmillan Durham Welfare Rights Service³⁷

In a 12 month period during 2009/10 this service provided advice and support to **1,236** service users. This support:

- ✓ Improved the wellbeing and quality of life of those affected by cancer by alleviating stress and anxiety related to financial pressures
- ✓ Created a conservative estimate of **£79,311** in productivity gains by enabling healthcare professionals to concentrate on their core clinical tasks
- ✓ Created savings for wider local services of **£372,476** by preventing debt-related mental health issues
- ✓ Raised **£3,635,399** worth of welfare benefits, grants and compensation for service users

In generating the above benefits, the service:

- Required **£10,638** in set up costs
- Had average annual operational costs of **£166,039**.

Applying a Return on Investment (ROI) calculation to the monetised costs and benefits, shows that on an annual operational basis every **£1** invested in the service generated **£21.89** to service users, **£2.24** to other local services and **£0.48** of monetised benefits to the healthcare system.

Case Study – Glasgow Long Term Conditions and Macmillan Service²⁴

This service provides welfare benefits advice to people in Glasgow, after they are diagnosed with cancer or another long-term condition. In the financial year 2012/13, **2,550** clients were referred to the service. In this period the service achieved:

- ✓ Improved wellbeing and quality of life for those who accessed the service
- ✓ Improved confidence and better control over their lives for clients and carers
- ✓ **£5,306,938** of benefits and grants accessed by **1,684** clients
- ✓ Reduced voids and house repossessions for housing and mortgage providers
- ✓ An average **2.5hr time saving** per patient for the referrers (NHS/hospice/other staff)

Stakeholder satisfaction with the service was very high:

- Clients rated the service **8.8** out of 10, with **79%** of them saying the service was better than expected
- Carers rated the service **8.5** out of 10, with **85%** of them saying the service was better than expected

Applying a Social Return on Investment (SROI) calculation to the monetised costs and benefits shows that on average every **£1** invested in the service generated a return of **£4**, with returns for stakeholders (clients, carers, referrers and housing/mortgage providers) ranging from **£2.25** to **£5.30**.

iv) Impact on local authorities

A Macmillan Local Benefit Advice Service in Manchester provides quality assured legal advice in key areas of social welfare law. Through advisers who provided representation at court or appeal tribunals, or arranged for such representation, the service contributed to yearly savings of £20,000 for the Legal Services Commission. Wider evidence suggests that there are no routinely available services with the expertise to deal with socio-legal issues arising from ill health. The provision of expertise on benefit decisions and assistance with appeals and tribunals has been identified as key for increasing the likelihood of a benefits advice service being successful. Without such specialist advice and representation, service users are unlikely to challenge decisions.⁹

Local authorities are heavily dependent on central government grants. Grants are awarded taking into consideration needs and priorities of each local authority.¹⁸ The underlying formula is complex and controversial, as some council argue that it is not proportioned to their actual need.³⁰

In order to address the controversies around the formula grant, the Business Rate Retention Scheme (BRRS) is being introduced, which is likely to replace the existing system for awarding grants, leaving local authorities more independent from the central government.^{31,32}

Case Study – Macmillan Welfare Rights Service Guildford²³

This service provides advice, information and advocacy to people affected by cancer in Guildford, Waverley and Surrey Heath, as well as advice to terminally ill people outside of these areas. Thanks to the partnership with the Citizens Advice Bureau, the service can provide a holistic support to patients needs, going beyond just benefits advice support. In the financial year 2014/15, the service helped **769** individual clients, reaching **594** more new clients (plus families and carers). In this period the service:

- ✓ Achieved **1,828** total interactions with clients and **1,187** interactions with third parties (e.g. Local Authorities, Health Professionals, other charities, etc.)
- ✓ Generated a total financial gain for clients of **£1,631,382**

Clients feedback on the service were very positive:

- **81%** said they felt more confident about dealing with their financial situation after accessing the service
- **84%** said the service helped them feel less stressed and upset

Referrers' satisfaction with the service was very high:

- **92%** said the service helped them save time in admin tasks
- **77%** found patients less anxious and more able to focus, after accessing the service

The annual running costs for 2014/2015 amounted to **£67,079** which equates to an average cost per client of **£87.22**.

On average, for every **£1** of funding the service generated **£24.32**.

CONCLUSION

There is significant evidence of the need for the provision of timely, specialist benefits advice services to people affected by cancer. A cancer diagnosis often brings people into contact with the financial support system for the first time and its complexity can be quite confusing.

People affected by cancer often struggle to access generic benefits advice provision. The symptoms of cancer and side effects of treatment mean that it can be very difficult for people to access advice via conventional channels. When they are able to access this advice they often find that whilst the advisers have an expertise in benefits advice issues, the lack of understanding of cancer and its treatments means that some of the available financial help is either missed or received when it is too late.

Macmillan has developed a range of services to help deliver these needs including providing advice over the phone, via the website and through specific partnerships with the NHS, Citizens Advice Bureaux and local authorities.

Positive feedback has been received on Macmillan-supported Local Benefits Advice Services from a number of customers, showing that Macmillan really makes a difference to the lives of people living with cancer.

Macmillan has invested in the development of benefits advice services in recognition of the unique challenges faced by people affected by cancer when trying to access financial information and advice.

Macmillan is helping people affected by cancer manage their finances by developing tailored services. We bring together the benefits advice expertise of our specialists and partners with Macmillan's cancer awareness. This is delivered in convenient locations such as hospitals, community centres or through home visits. In doing so, we help people affected by cancer manage the financial impact of their illness.

The receipt of benefits as a result of Macmillan advice helps cancer patients and their carers cope with the increasing costs resulting from cancer diagnosis, such as travel, heating bills, dietary and clothing requirements.

In addition, receiving benefits advice has an impact on health and wellbeing. It leads to reduction of stress and anxiety, as well as increased feelings of being in control and improvements in family relationships.

Macmillan continues to fund local benefits advice services and to provide support to people affected by cancer in financial distress and urgently needs more charitable donations to keep providing this service supporting cancer patients and their families. Go to www.macmillan.org.uk/donate or call 0300 1000 200 to make a donation.

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