



## 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 can be based in a variety of settings eg a Citizens Advice Bureau, a Macmillan information and support centre, a local council, or a hospital setting.

*'It made a big difference. My husband takes 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



The average level of UK household debt in 2014 (including mortgages) stood at **£55,008** per household.<sup>1</sup>



Only **54%** of cancer patients had received information about financial help or benefits they might be entitled to in 2013.<sup>13</sup>

## Reach



It is estimated that for every £1 spent on Macmillan supported benefits advice on average **£19** is claimed back in benefits.<sup>22</sup>



Face-to-face Macmillan benefits identified over **£180m** in benefits for people affected by cancer in 2013.<sup>21</sup>

## Impact



Macmillan welfare rights services can help to free up hospital and social work staff, reducing the resource cost of best meeting patients' needs.<sup>11</sup>

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](http://www.macmillan.org.uk/impactbriefs)



Guildford Welfare Rights Service's referrer feedback found that **95%** of referrers felt that the service was either 'crucial' or 'very important' to them in helping relieve some of their workload.<sup>34</sup>

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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**  
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.
- **Debt**  
Debt can be a major problem during illness, causing deteriorating mental and physical health. The effect on carers can also be substantial.
- **Benefits advice**  
People affected by cancer often struggle to access generic benefits advice provision. First, the symptoms of cancer and side effects of treatment mean that it can be very difficult for people to access advice via conventional channels. Second, if people affected by cancer 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 missed.
- **Cancer specific benefits advice services leading to increased income can be associated with improvements in psycho-social aspects of health such as levels of energy and tiredness and improved mental health. The income generated as a result of benefits advice enables people to afford necessities and additional items that were required as a result of a diagnosis of cancer.**
- **Inadequate guidance**  
Although nurses, doctors and other patients sometimes offer valuable guidance many people affected by cancer do not receive it at the right, best or most effective time.

# DETAILED FINDINGS

## 1. What is the issue?

### Why do cancer patients struggle with financial issues?

In the current economic climate many people are experiencing financial difficulties. According to the Money Charity, the level of UK household debt (including mortgages) at the end of August 2014 stood at £55,008 per household.<sup>1</sup> There is a link between income and health, people with a higher disposable income also tend to have better health. According to the OECD around 88% of UK adults with a disposable income in the top 20% rate their health as 'good' or 'very good' compared to about 69% for those with a disposable income in the bottom 20%.<sup>2</sup>

Further to a cancer diagnosis people may face new or increasing debt as a result of their change in circumstances. 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. Examples include increased heating and general domestic bills, increased travel costs to and from hospital and a change in dietary or clothing requirements.<sup>7</sup>

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. Additional 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.<sup>3</sup>

Cancer patients and their carers who were interviewed as part of a study on the effect of specialist benefits advice services made the following statements about their increase in financial burden<sup>4</sup>

*'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.'*<sup>4</sup>

**Carer of cancer patient**

*'He had lost an awful lot of weight so we had to buy new clothes. New sheets, laundry bills, washing powder and conditioner.'*<sup>4</sup>

**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.'*<sup>4</sup>

**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 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.'*<sup>4</sup>

**Cancer patient**

### **What is the knock-on impact on health and wellbeing of this financial burden?**

In general, debt problems can lead to anxiety and stress, depression, self-harm and suicidal thoughts, strain on personal relationships and self-esteem and social exclusion.<sup>5</sup>

Research has shown 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'.<sup>6</sup> One of the people interviewed commented that financial difficulties were '*more of a worry than the cancer.*'<sup>7</sup>

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.'<sup>8</sup>

### **Under claiming of eligible financial benefits**

Despite 83% of cancer patients' household incomes being negatively affected 'as a direct result of cancer' there is a wealth of evidence demonstrating significantly low awareness and/or take-up of financial support entitlement.<sup>9,10</sup>

During 2008 Macmillan commissioned an evaluation of a cancer specific welfare rights service in Altnegelvin Hospital Trust. One finding was that without the welfare rights service most of the beneficiaries consulted indicated that they would not have been aware that they were entitled to support.<sup>11</sup> In the case of the Salisbury Macmillan benefits advice service 89% of service users in a 2010 survey would not have known how to get help if the service didn't exist.<sup>12</sup>

The 2013 National Cancer Experience Survey found that 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.<sup>13</sup> In addition, there have been reports from many clients of frustration at being unaware of the support available until late in their illness.<sup>4</sup> There is also a marked difference by age, with older respondents feeling less satisfied about having received financial information. Early provision of benefits advice services could help prevent major financial issues such as debt, bankruptcy and house repossession.

There is evidence to suggest that patients, particularly the elderly and disabled, lack knowledge about accessing benefits and would not have been able to claim without assistance.<sup>14,15,16</sup> People with cancer, especially the elderly get very tired and often give up seeking help if it is difficult.<sup>17</sup>

In addition, people struggle with making claims, finding the forms complicated and difficult to understand.<sup>18</sup> 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.<sup>19</sup>

Cultural and social barriers also prevent many people from making claims. For example older people are reluctant to accept what they perceive as charity if it is not delivered in a sensitive way. There is also evidence to suggest that even those who are seriously ill, and life-time tax payers, feel stigma in claiming financial help.<sup>18</sup>

## 2. What is Macmillan doing to address the issue?

### Benefits advice

Although nurses, doctors and other patients sometimes offer valuable guidance many people affected by cancer do not receive it at the right, best or most effective time. Although general practitioners are skilled in detecting need, and their practice is enhanced by specialist support, further resource and support is needed to provide the advice which cannot be met by clinical consultation.<sup>20</sup>

One study indicates that finances are not a priority at diagnosis and there is a lack of help in hospital. There is also evidence to suggest that health and social care staff do not have sufficient knowledge of financial support issues and vice versa experts in benefits advice know little about cancer.

To combat these issues Macmillan has developed a number of benefits advice services in partnership with the NHS, local authorities and Citizens Advice Bureaux among others. These services provide specially trained benefits advisers who can promote and support people to access appropriate financial help. A Macmillan benefits advisor can offer specialist advice such as advice on entitlements to benefits, tax credits and grants. These services also understand the specific needs of people with cancer and are able to help them to access the support they are entitled to in order to remain as independent as possible.

In 2013, our national network of face-to-face Macmillan benefits advisers reached around 130,000 people affected by cancer, identifying over £180m in benefits for people affected by cancer.<sup>21</sup> 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: (i) advising people about their entitlements; (ii) assisting with claims; (iii) dealing with the complexities that surround the benefit system; and (iv) answering questions that people did not, or felt they could not, ask of their health professionals.<sup>23,29,37,39</sup>

It is estimated that for every £1 spent on Macmillan supported benefits advice on average £19 is claimed back in benefits.<sup>22</sup>

In addition Macmillan provides benefits advice over the phone and on line to anyone in the UK on 0800 808 00 00 or via [www.macmillan.org.uk](http://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 2013, the Macmillan Support Line benefits advice experts reached 31,827 people affected by cancer across the UK, identifying around £44m in benefits.

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

### i) Impact on the financial burden

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 diagnosis of cancer. 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.<sup>19</sup>

People living with cancer may face new or increasing debt as a result of their change in circumstances. Effective debt advice can lead to improvements in health and reduction in relationship breakdown and time spent worrying about debt problems.<sup>24</sup>

## CASE STUDY: LANARKSHIRE FINANCIAL ADVICE AND SUPPORT SERVICE<sup>25</sup>

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 the physical and mental wellbeing of people living with cancer

There is good evidence pointing to the importance of dedicated benefits advice services or welfare rights services in helping people affected by cancer negotiate the complex welfare benefits system by providing expert knowledge<sup>26</sup>, thereby reducing stress and anxiety.

There is a positive knock-on effect to health and well-being from being able to resolve debt and ease financial burden.

As a consequence of receiving help and advice from Citizens Advice Bureau, clients described improvements in their health. They felt better; were less anxious, less stressed and less worried about money.<sup>27</sup>

*'It made a big difference. My husband takes 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.'*<sup>4</sup>

**Cancer patient**

People affected by cancer are often unaware of health/cancer related benefits advice services, yet many experience considerable stress around financial issues.<sup>11</sup> Once the financial stress is removed, they are more able to deal with their illness and treatment.

*'The advisor made being diagnosed with cancer easier as I didn't have to worry about finances as well.'*<sup>29</sup>

**Cancer patient**

*'These advisors 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.'*<sup>29</sup>

**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.<sup>28</sup>

In the Macmillan welfare rights service in Guildford 66% of service users felt less stressed about their situation after speaking to an advisor.<sup>29</sup> Another study reported that all patients claimed that benefits received as a result of benefits advice services funded by Macmillan helped to reduce stress levels, which can in turn aid recovery.

Clients with dependent children also reported improved relationships with their children in that they were more relaxed around them.<sup>30</sup>

Overall accessing benefit entitlements increases capacity to cope with many of the wider consequences of cancer<sup>18</sup>

*'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 her [the Macmillan advisor] as I couldn't and didn't know how to answer the questions on benefits.'*

**Cancer patient**

### iii) Potential savings for health services due to effective benefits advice

In 2010 the cost to the NHS of cancer and tumour related costs was estimated to be as much as £5.13 billion.<sup>31</sup> Evidence suggests that lack of financial stability and/or social support can reduce an individual's ability to maintain a stable home care status, leading to admission to hospital as a safety net.<sup>32</sup>

Around 20% of all cancer patients suffer from depression,<sup>33</sup> and there is evidence that debt-related mental health issues impose considerable costs onto health, social care and other services<sup>34</sup>. There is consistent evidence that benefits advice can help prevent anxiety and stress, and 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.<sup>23,29,39,37,25</sup>

Studies have shown that a Macmillan welfare rights service can help to free hospital and social work staff from having to provide this advice and therefore potentially reduces the resource cost of best meeting patients' needs. Their time can be concentrated on their core clinical tasks.<sup>11</sup> Trained benefits advisors are also better placed to offer expert advice and assistance about benefits and finances.<sup>51</sup>

In particular, 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

*'I used to do it myself...help them fill in the form, send for the forms and help them fill it in and now I just refer, it's like one phone call.'*<sup>41</sup>

**Macmillan Nurse**

making the whole process more efficient.<sup>35</sup>

The 2010-2011 Guildford Welfare Rights Service's referrer feedback survey found that 95% of referrers felt that the service was either 'crucial' or 'very important' to them in helping 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.<sup>23,29,39,37,25</sup>

Our primary research with Cancer Clinical Nurse Specialists (CNS) found that a benefits advice service 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.<sup>36</sup> Savings in staff time also have direct implications on the costs of running the services.

### SEMI-STRUCTURED CASE STUDY – DURHAM WELFARE RIGHTS SERVICE<sup>37</sup>

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
- Has 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 **£0.48** of monetised benefits to the healthcare system, **£2.24** to other local services and **£21.89** to service users.

## CASE STUDY: THE FINANCIAL INCLUSION SERVICE – GLASGOW<sup>39</sup>

During December 2009 – December 2010 this service provided advice and support to 1,694 cancer patients. This support:

- ✓ Improved the wellbeing and quality of life of those affected by cancer by alleviating stress and anxiety related to financial pressures.
- ✓ Prevented individuals and families reaching crisis point.
- ✓ Achieved **£108,434** in productivity gains by enabling healthcare professionals to concentrate on their core clinical tasks
- ✓ Achieved efficiency savings for the healthcare system of **£9,108** by ensuring more appropriate use of psychology services
- ✓ Achieved **£602,000** in savings to other local services by preventing tenancy failures
- ✓ Achieved savings for wider local services of **£511,212** by preventing debt-related mental health issues
- ✓ Raised **£4,691,690** worth of welfare benefits and grants for service users

In generating the above benefits, the service:

- Required **£25,000** in set up costs
- Has average annual operational costs of **£252,911**

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 **£0.46** of monetised benefits to the healthcare system, **£4.40** to other local services, and **£18.55** to service users.

### iv) Potential savings for local authorities due to effective benefits advice

The Manchester service provided 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 savings of £20,000 for the Legal Services Commission in a year. 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 being important in increasing the likelihood of a benefits advice service being successful<sup>38</sup>. Without such specialist advice and representation, service users are unlikely to challenge decisions.

In the case of another service, advisers provide face-to-face debt and housing advice and prevented 14 individuals/families from losing their homes, and 13 from having their utilities disconnected. Based on a conservative estimate, by preventing 14 tenancy failures, the Glasgow service contributed to savings for other local services of around £602,000 in a year. Tenancy failure is not simply a housing issue but has implications for health and wellbeing, criminal justice, community relations and more.<sup>39</sup>

Local Authorities are heavily dependent on central government grants. The underlying formula is complex but essentially the greater the need in a local authority area the higher the amount of 'formula' grant awarded to that area.

Therefore, for each local person claiming a particular benefit (capped at a certain level) the local authority receives some additional funds from central Government. This can bring in many thousands of pounds for the local authority.<sup>40</sup> This is especially significant as government budgets and the grants received by local authorities continue to be cut in 2014.<sup>41</sup>

The impact of increased benefit take-up may also bring about a positive knock-on effect for the wider community as this additional income is usually used to purchase of local goods and services.<sup>42</sup>

The theory behind the 'local multiplier tool' (an economic model for measuring local economic impact) is that an increase in spending power, including that generated by a benefits advice service, has a knock on effect, increasing spending power even more. The overall benefit in financial terms is even higher as money is spent and re-spent.

## CONCLUSION

There is significant evidence of the need for the provision of timely, specialist benefits advice services to those 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 bewildering.

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

Macmillan has pro-actively 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 and local authorities.

Positive feedback has been received on Macmillan supported benefits advice services from a number of customers showing that Macmillan really does make a difference to the lives of those living with cancer.

Macmillan has invested in the development of benefits advice services in recognition of the unique challenges which people affected by cancer face in accessing financial information and advice.

By developing tailored services bringing together the benefits advice specialism of our advice partners with Macmillan's cancer awareness and delivered in convenient locations such as hospitals or through home visits, we are helping people manage the financial impact of cancer.

The receipt of benefits as a result of benefits advice has been proven to help cancer patients and their carers cope with the incremental costs of cancer such as increased travel costs, heating bills, dietary and clothing requirements.

In addition, ancillary benefits to an individual's health and wellbeing from receiving benefits advice include reduction in stress, anxiety, increased feelings of well being and control, and improvements in family relationships.

Macmillan continues to fund benefits services and to provide advice to cancer patients in financial need and urgently needs more charitable donations to keep providing this service supporting cancer patients and their families. Go to [www.macmillan.org.uk/donate](http://www.macmillan.org.uk/donate) or call 0300 1000 200 to make a donation.

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