

WE ARE
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CANCER SUPPORT

MACMILLAN SUPPORT LINE

What is it?

The Macmillan Support Line (MSL) is a free, multilingual telephone service available from Monday to Friday from 9am to 8pm.

The MSL is staffed by cancer support specialists who can provide high quality and up-to-date cancer information and support for everyone affected by cancer. Callers particularly value the anonymity and confidentiality offered by the MSL.

0808 808 00 00

'I had no idea where to turn for help until a friend suggested I call the Macmillan Cancer Support Line. Thanks to Macmillan, I've discovered that a lot of the fear I felt when I was first diagnosed was just fear of the unknown.'

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

Need



43% of cancer patients would like more information about their disease than they are given.³



Macmillan invests **£3.2m** a year to provide the MSL for those affected by cancer free of charge.²⁵

Reach



The MSL helped responded to **149,312** advice and information requests in 2014.²²



Benefits advice experts on the MSL identified over **57m** in benefits to help callers with the financial cost of cancer in 2014.²²

Impact



91% of callers were satisfied with their overall experience of MSL.³²



The MSL is particularly beneficial for those who are too ill to leave the house, live in more remote areas, have no means of transport or simply want an anonymous and confidential conversation.²⁶

www.macmillan.org.uk/impactbriefs

INTRODUCTION

Macmillan helps meet the information and support needs of people affected by cancer in a variety of ways including:

- through the support and funding of local and mobile cancer information and support services
- the production and distribution of high quality information and advice materials
- directly through our website
- directly through our telephone helpline (Macmillan Support Line).

We ensure both our website and telephone information services and our Macmillan supported services work to the same high standards and use common resources. We also enable referral to local support services where appropriate, to ensure the client's needs are met.

SUMMARY OF KEY FINDINGS

- **Gaps in cancer information provision**
87% of cancer patients want to know more about their disease, however many do not receive the right information at the right time in the right way. There are particular gaps in the provision of information addressing emotional, financial and social concerns. In addition evidence suggests that over half the population are unlikely to understand cancer information brochures routinely used in hospital settings. Therefore there is a need, not only for information provision, but also for a comprehensive explanation of it.
- **Telephone line service and timings**
The Macmillan Support Line is a free, multilingual telephone service available from Monday to Friday from 9am to 8pm, and is free to call from UK landlines and mobiles. People affected by cancer particularly value the anonymity and confidentiality offered by the Macmillan Support Line.
- **Specialist support and information**
- The Macmillan Support Line is staffed by cancer specialists who are trained to offer practical, medical, emotional and financial advice and who have immediate access to high quality and up to date cancer information. Callers to the Macmillan Support Line are also signposted to appropriate local Macmillan and non-Macmillan services.
- The provision of effective cancer information and support can make a real difference to a patient's quality of life by helping to improve their physical and mental health, their financial situation and their ability to manage living with cancer.

DETAILED FINDINGS

1. What is the issue?

The need for cancer specific information and support

Access to information

87% of cancer patients want to know more about their disease.¹ Studies have shown that a significant minority of cancer patients (16%) who would like to receive information about their condition do not receive any at all² and 43% would like more information than they are given.³ A quarter of cancer patients feel they have no-one to talk to about their cancer and treatment.²

A cancer patient's information needs are complex and vary over time.⁴ People affected by cancer find it particularly hard to get the information, advice and support they want and need during the early stages of the cancer journey.⁵ Cancer patients also often feel abandoned by the health system once their treatment is finished due to lack of information and support about next steps in their cancer journey.⁶

Health literacy

Health literacy levels are a major barrier to accessing information for people affected by cancer.⁷ 7 million adults in the UK (20% of the adult population) cannot read or understand simple instructions such as those found on medicine labels or locate the expiry date on a driving licence.^{7,8} Evidence suggests that over half the population are unlikely to understand cancer information brochures routinely used in hospital settings.⁷

Evidence also suggests that functionally illiterate adults (as described above) suffer from higher morbidity and mortality than the population as a whole and are less likely to adopt positive cancer avoiding behaviours.⁹ They are less likely to seek medical advice with early symptoms and as such they are therefore more likely to present with cancers at a later pathological stage.⁷

This means that those most in need of interventions and information are those that are the least likely to be able to find, interpret and absorb such information without support. This therefore suggests that there is a need not only for the provision of information but also a need for information to be explained and delivered in a way which is appropriate to the individual.

A 2013 survey of health information producers showed that most believe all health information resources should be clear, simple and straightforward in order to meet a wide range of health literacy needs. The vast majority also recognised that health literacy levels were important and relevant for everyone, and not just for specific groups of people.¹⁰

The need for benefits advice for people affected by cancer

Financial implications of cancer

A cancer diagnosis can result in new or increasing debt due to changes in circumstances.¹¹ Macmillan research shows that the financial implications of cancer are very 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 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 people living with cancer face is getting to and from hospital, or making other healthcare visits.¹²

A Macmillan report found that people living with cancer were often unaware of sources of financial information, advice or support. A lack of help could intensify feelings that life is a struggle and impact on the patients' well-being.¹³ In the 2013 Cancer Patient Experience Survey, 54% of people living with cancer said they had been given information about how to get financial help or benefits they might be entitled to by hospital staff and 46% responded that they did not get any of this information but would have liked some.¹⁴ There is also a marked difference by age, with older respondents feeling less satisfied that they had received financial information.¹⁵

Many cancer patients express frustration at being unaware of the support available until late in their illness.¹⁶ Some cancer patients, in particular those who are elderly or disabled, lack knowledge about accessing benefits and would not have been able to claim without assistance.^{17, 18, 19}

Cultural and social barriers also prevent many people from making benefits claims. For example older people are reluctant to accept what they perceive as charity if it is not delivered in a sensitive way.¹⁸ In general, people struggle with making benefits claims, finding the forms complicated and difficult to understand.²⁰

A high proportion of callers to the Macmillan Support line are concerned with the financial aspects of living with cancer. The need to establish and maintain financial security in the face of uncertainty of a cancer diagnosis is a primary source of anxiety for callers. The complexity of the benefits system and bureaucracy that goes with it heightens this anxiety.²¹

2. What is Macmillan doing to address the issue?

High quality information and advice

The Macmillan Support Line service is just one part of a range of services aimed at meeting the information and support and financial advice needs of people affected by cancer. We offer high quality information and financial advice directly through our website and an array of over 1,000 leaflets, booklets, books and audiovisual materials. We fund local information and support centres in hospital and community settings and also offer additional support in hard to reach or rural communities through our Macmillan Mobile Information and Support Services.

The Macmillan Support Line (on 0808 808 00 00) is available Monday to Friday from 9am to 8pm and is free to call from UK landlines and mobiles.²¹ An interpretation service is available for those whose first language is not English and a text phone service for those who are deaf or hard of hearing.²¹

The Macmillan Support Line is staffed by cancer support specialists. They are there for everyone affected by cancer, whatever they need. They can answer questions about cancer types and treatments and provide practical, medical, emotional and financial support to help people live with cancer. Upon phoning, the caller is directed to the most appropriate expert to deal with the enquiry.^{21,22}

The Macmillan Support Line responded to over 149,312 phone calls, emails and letters in relation to information, support and financial advice issues in 2014. This is an average of over 2,800 per week. During 2014 Macmillan additionally sent out 79,487 letters and emails to callers. In 2014, the Macmillan Support Line benefits advice experts reached 20,117 unique people affected by cancer across the UK, identifying around £57m in benefits.²²

The Macmillan Support Line and Mobile Information and Support Services were awarded the Contact Centre Association (CCA) Global Standard Award in December 2013, strongly demonstrating key principles within the health information industry and commitment to our customers.²³

Caller demographics

In 2014 69.5% of callers were women and the most common age ranges of callers were of late working age (40-69 years). There were very few callers below the age of 20 or over the age of 80.⁴³

Cancer patients make up just over half of all callers. Friends, relatives, carers, health and social care (SCP) professionals and employers make up the remainder.⁴³ Macmillan research shows that the helpline is being used by significant numbers of people from harder to reach groups such as older people and those from low income backgrounds.²⁴ By being able to speak about their concerns they feel better able to cope and look after their loved one. It may help ease their worries and increase confidence.

The most common queries from callers are with regards to treatment (33%) followed by welfare rights enquiries (27%) and financial and psychological issues (both at 10%).⁴³

Cost of running the Macmillan Support Line^{25*}

Macmillan operates the Macmillan Support Line and invests significant amount in keeping the service running. Typical costs for 2014 are shown below.

Time period	Cost
1 Day	£20,542
1 Week	£102,708
1 Month	£445,068
1 Year	£5.3 million

*For more detailed costs of these and other Macmillan services visit be.macmillan.org.uk to download The Cost of Macmillan's Services fact sheet.

3. What is the impact of effective telephone information and support services?

i) The Macmillan Support Line is open to everyone

People affected by cancer can phone from anywhere and have a private conversation at a time that suits them. For those who are too ill to leave the house, or live in more remote areas and have no means of transport the phone line is particularly beneficial.²⁶ There are no call charges so our phone line doesn't discriminate against people from lower socio-economic backgrounds.²¹

People affected by cancer can access support through the Macmillan Support Line when needed rather than having to wait until a scheduled meeting time.²⁷ More affluent people, who have been shown to be more likely to put off going to the GPs because they are too busy, may also find telephone support particularly appealing.²⁹

In a study looking at the reasons people delay coming forward with cancer symptoms, reasons given included practical barriers such as a lack of time and not having anyone to take them to the doctors. People also substituted professional support for self-diagnosis e.g. online search engines. These results point to the real need for accessible and reliable cancer information services.²⁸

Unlike most health literature in the UK a comprehensive interpretation service for over 200 languages is available via the Macmillan Support Line to reduce language barriers.²¹

ii) The Macmillan Support Line is anonymous


Almost 40% of British people would put off going to their GP with cancer symptoms because they feel that they do not want to bother the doctor and waste his/her time. They would also delay making an appointment because they were too embarrassed, scared or worried about what their doctor might find.²⁹

The Macmillan Support Line allows people affected by cancer to ask questions and discuss issues openly that they may find too uncomfortable or embarrassing to talk about face to face.

This particularly appeals to young men, who are worried about their health but reluctant to visit the doctor.³⁰

iii) Our phone line is a fast and reliable source of information

The information given out is high quality, up to date and tailored to the caller's specific needs, and can be accessed immediately. In 2013 the British Medical Association awarded Macmillan with two prizes for the high quality of its patient information leaflets and booklets.²³ Macmillan Support Line staff are cancer specialists and highly experienced so they are effective at identifying underlying problems and then help to find a solution. If the problem is an emotional one the specialist can offer advice and comfort directly, refer on to counselling or help find local support groups.



*'I have spoken to you a few times and am very grateful for all the help, support and clear information I get each time I call. Just being able to talk to someone makes such a difference.'*³¹

Cancer patient

iv) The Macmillan Support Line meets the needs of callers

89% of callers were satisfied with their overall experience of the Macmillan Support Line.³²

v) The impact of effective information provision

Patients who have a better knowledge and understanding of their cancer and treatment are found to be more positive and less depressed.³³ Conversely, research has found that patients who are dissatisfied with the information they receive are much more likely to be depressed and are potentially more likely to be anxious.³⁴

In addition, cancer patients who are well informed are better able to understand and participate in their health care plan, experience less anxiety and are more likely to cope with their illness.³⁵ They are also

better equipped and prepared with questions for consultations with health professionals.³⁶

Providing information to cancer patients helps maintain a sense of control. It helps with treatment compliance and self-management because patients can weigh up the pros and cons of different options, make decisions, and know what to expect. It leads towards a more collaborative relationship between patients and health professionals resulting in greater satisfaction with care.³³

Informed patients take a greater degree of ownership and responsibility for their care and are better equipped to manage their own symptoms.³³ With the right information and support patients can look after themselves more efficiently and their quality of life is much improved.³⁷

vi) The impact of effective emotional support provision

Emotional support is very important to people affected by cancer. The stresses of living with cancer can increase their vulnerability to depression, anxiety or a more serious form of psychological distress if support is not available.³⁸ The process of confiding in a trained professional; someone who

understands, emphasises and provides unconditional support has been shown to be valuable to people affected by cancer.³⁸

In a survey of people affected by cancer conducted by Macmillan, respondents particularly liked the fact that they could talk to someone over the phone and responded well to the offer of emotional support. 87% agreed or strongly agreed that Macmillan helps cancer patients get on with everyday life and are not just there for cancer patients but also for their carers, family and friends. 78% of people said that Macmillan is one of the first places they turn to when they or someone close to them has cancer.³⁹ An evaluation of a similar cancer information and support service in Australia has found that 80% of cancer patients feel better after having someone to talk to on a one-to-one, confidential basis.⁴⁰

*'I have spoken to you a few times and am very grateful for all the help, support and clear information I get each time I call. Just being able to talk to someone makes such a difference.'*³¹

Cancer patient

*'I had no idea where to turn to for help until a friend suggested I call the Macmillan Support Line. Thanks to Macmillan, I've discovered that a lot of the fear I felt when I was first diagnosed was just fear of the unknown.'*⁴¹

Cancer patient

Men respond better to one-to-one support and there is evidence to suggest that support in this manner helps to reduce depression and increase self-confidence.⁴² In 2014, just over 30% of those reached by the Support Line were male.⁴³

*'I am very appreciative of the benefits advice I got from the Macmillan Support Line helpline, which I think is the best thing Macmillan has developed. It is a dreadful shame when very ill people have to worry about filling in complex forms to claim money; the helpline does so much to ease these worries.'*⁴¹

Cancer patient

vii) The impact of effective financial advice provision

Cancer patients are often unaware of the financial benefits that they are entitled to and there is widespread under-claiming of welfare benefits by those eligible for them.⁴⁴ There is considerable evidence that cancer patients experience substantial stress around financial issues.⁴⁵ Once the financial stress is removed, they are more able to deal with their illness and treatment.

In addition to providing financial advice directly, the Macmillan Support Line also provides a vital signposting facility, referring patients to appropriate financial advice and assistance services. Macmillan-funded research has shown that benefits received as a result of welfare advice funded by Macmillan helped patients to reduce stress levels, which can in turn aid recovery.⁴⁶

In 2014 the Macmillan Support Line benefits advice experts received 68,769 calls from people affected by cancer across the UK, identifying around £57m in benefits. The experts spoke to 20,117 unique people affected by cancer.²²

CONCLUSION

In 2014 the Macmillan Support Line responded to 149,312 requests for cancer information and support. This shows that there is clearly a need for a comprehensive information and support service that is easily accessible by all people affected by cancer.

The Macmillan Support Line provides immediate access to trained cancer specialist staff who have high quality and up to date information at their fingertips and can also offer support and guidance, signposting to other services where necessary.

There is evidence to suggest that provision of the Macmillan Support line service helps improve the financial position and health and wellbeing of people affected by cancer as well as aiding recovery.

With the number of people affected by cancer estimated to rise to 4 million by 2030 it is vital that Macmillan continues to provide and improve services that strive to reach those with unmet cancer information and support needs.

Macmillan continues to fund and support the Macmillan Support Line and urgently needs more charitable donations to keep the 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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