

What are they?

Macmillan helps meet the information and support needs of people affected by cancer in a variety of ways including through the production and distribution of high quality information and advice materials, and digitally through our website.

'I got the leaflets from the clinic when diagnosed, including Macmillan's. I went away and then also browsed the internet including Macmillan website'

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



87% of people affected by cancer want to know more about their disease.⁵



43% of cancer patients would like more information than they are given.⁶

Reach



In 2014 Macmillan reached an estimated **3.4 million** people affected by cancer through our Macmillan printed information resources.¹⁷



Macmillan's website provides high quality, up to date information. It is written and reviewed by specialists to ensure it is of the highest standard.¹⁶

Impact



Almost **90%** of those affected by cancer would recommend Macmillan information resources.¹



Accessing appropriate information resources leads to a reduction in anxiety and improved ability to cope during all stages of a patient's cancer journey.¹⁸

www.macmillan.org.uk/impactbriefs

INFORMATION RESOURCES

INTRODUCTION

Macmillan provides a wide range of information resources for people living with cancer, their family and friends. Information is available in a range of formats and in both print and online versions, allowing individuals to access information in the way that is most suitable for their needs.

Macmillan produces and distributes a wide range of publications that are available free of charge, for people affected by cancer and the professionals and volunteers who work with them. Information and support is also offered through our website at www.macmillan.org.uk, and through our free telephone helpline, the Macmillan Support Line.

SUMMARY OF KEY FINDINGS

- **Information requirement**
The vast majority of cancer patients would like to be informed about their illness; as a cancer diagnosis can lead to feelings of fear, uncertainty and loss, having appropriate information can help to alleviate some of these feelings.
- **Benefits for patients**
Timely information can reduce anxiety, increase patient involvement in decision about their care, lead to increased confidence and a more positive outlook. Information resources have a significant impact on people's quality of life, both in the immediate and long term.
- **Resource formats**
Macmillan produces over 1,000 award-winning free printed resources, including leaflets, booklets, books as well as audiovisual materials on cancer.
- Internet use by patients at all stages of cancer care is now widespread, so the provision of reliable and trusted online information sources is increasingly important. The Macmillan website provides high quality up-to-date information written by specialists.

DETAILED FINDINGS

1. What is the issue?

Cancer information is very important for people affected by cancer, throughout their patient journey. Timely information can have a significant impact on people's quality of life, both in the immediate and long term.¹

The vast majority of patients would like to be informed about their illness; as a cancer diagnosis can lead to feelings of fear, uncertainty and loss; having appropriate information can help to alleviate some of these feelings.² Providing cancer patients with adequate information is also important for patient health, wellbeing and satisfaction.³ Regardless of the stage at diagnosis, those people with cancer have a high need for information and this need also continues into post-treatment stages.⁴

Research into cancer patient's information needs found that those patients who took a more active role in decisions related to their treatment had a greater need for information than those who did not take an active role.⁴

87% of cancer patients want to know more about their disease.⁵ Most people affected by cancer who want information receive it from healthcare professionals at the point of initial diagnosis. However various 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 all and 43% would like more information than they are given.⁶

Cancer patients receive the majority of the information at the time of diagnosis – and not at other stages along their care pathway. However it is best practice to ensure information is provided across all stages of the patient pathway. It is also vital to ensure that people understand the information that they are given. In the 2014 National Cancer Patient Experience Survey, 72% of patients said they were given easy to understand written information about the type of cancer they had, whilst this is up from 66% in 2010, there is still room for improvement on this key information need.^{7, 8}

Having access to a wide range of information and receiving support to understand it means that cancer patients are less likely to seek information from unreliable internet sources and are more able to make informed decisions.⁸

The internet is increasingly being used to access health related information. In 2007 approximately only one in five adults (18%) used the internet to access health information, however by 2013 this proportion increased to 43%. The figure was even higher amongst those aged 25 to 34, the rate of use for this age group increased to nearly 6 in 10 (59%) in the same period.⁹

Cancer patients and their carers use the internet for a wide range of information and support needs, many of which are unlikely to be met through conventional healthcare.¹⁰ Internet use by

patients at all stages of cancer care is now widespread, from early investigations to follow-up after treatment.¹¹ As such the provision of reliable and trusted online information sources is increasingly important.

An advantage of accessing online health information means the need to

*'I was real, real sick and I was desperate for information. Driving was out of the question. I was able to get what I needed off the internet.'*¹¹

Cancer patient

Speak to someone face to face about issues which people affected by cancer may feel uncomfortable or embarrassed about can be alleviated. The internet particularly appeals to young men, who are worried about their health but can be reluctant to visit the doctor.¹²

2. What is Macmillan doing to address the issue?

In 2014 Macmillan reached an estimated 3.4 million people affected by cancer through our printed Macmillan information resources.¹³

i) Printed resources

Macmillan has developed and produced more than 1,000 award-winning resources leaflets, booklets, books and audiovisual materials on cancer. The booklets can be displayed and accessed in cancer environments and used to support discussions with patients on a variety of topics from symptom awareness to the emotional effects of cancer. Booklet displays were found at hospitals, clinics, and Macmillan information centres.¹ These are also available to download or order, free of charge at be.macmillan.org.uk¹⁴

*'The Booklet was a better format for me - I wanted to be able to pick up and put down, and keep.'*¹

**Cancer patient -
Benefits and financial support
booklet**

Local Cancer Information and Support Services

Macmillan has helped to fund and run 187 Local Cancer Information and Support services across the UK in partnership with a range of organisations including the National Health Services of the four UK Nations, local authorities, and the voluntary sector. These offer access to Macmillan's information resources, and are staffed by Macmillan cancer information and support specialists.¹³

Mobile Information and Support Services

Macmillan also provides Mobile Information and Support Services tour the UK throughout the year, with information leaflets to take away, and offering free, confidential and tailored information and support to people in their communities. In 2014, the four Macmillan Mobile Information and Support Services reached a total of 78,559 people affected by cancer across England, Wales and Scotland.

Cost of printed Macmillan information resources^{15*}

Macmillan invests in high quality, up-to-date printed cancer information. Typical 2014 costs of a Macmillan information and support centre stocked with all the information resources it needs to support people affected by cancer for 2014 are shown below.

Item / Time period	Cost of keeping an information and support centre stocked with printed information
A copy of our <i>Help with the cost of cancer</i> booklet.	50p
A copy of <i>The cancer guide</i>	52p
1 Day	£14
1 Week	£69
1 Month	£300
1 Year	£3,600

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

ii) Online resources

The Macmillan website provides high quality, up to date and reliable information for cancer patients, families and carers. It also meets financial, support and emotional needs, offers access to online communities, signposting to support groups and access to financial advisers. The information provided on the website is written and reviewed by specialists to ensure it is of the highest standard.¹⁶

We ensure both our virtual 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 across all types of information provision to ensure the customers' needs are met.

The reliability and accuracy of the health information found on the internet more globally is highly variable. Cancer patients searching for information may come across potentially dangerous drugs, treatments that cannot be financed on the NHS, unethical or unproven alternative treatments and information that could be damaging to their mental well-being.¹⁷ The importance of quality assured online information provision is therefore paramount.


Macmillan's website in contrast provides high quality, up to date information for cancer patients, families and carers. The information provided on the website is written and reviewed by specialists to ensure it is of the highest standard.¹⁶

Macmillan's website contains a wealth of information covering over 56 different cancer types, causes and risks, treatments, tests and screening, how to cope with living with cancer, as well as information on end of life care and supportive information for carers and family members.¹⁶

Information on financial assistance in the form of grants and benefits is also provided online, allowing cancer patients to determine whether they might be eligible for disability living allowance and directing them towards Macmillan's benefits advice helpline and grants team. In addition there is signposting to external sources of financial advice and support such as the Citizen's Advice Bureau.¹⁶

In addition, the Macmillan website also has an online community for social networking and gaining support and advice from fellow cancer patients, families, carers and Macmillan professionals.¹⁶

In a recent evaluation of Macmillan information resources, the majority (three-fifths) of those questioned read the information for between half an hour to one hour. A higher proportion of those reading hard copy booklets to read the information for over an hour compared to an online user reading time of between 15-30 minutes.¹



*'I was given books etc, but online was better: it is easier to understand, less frightening.'*¹

Breast cancer patient

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

Benefits for cancer patients

When cancer patients have access to appropriate information, this leads to an increase in patient involvement in decision making and greater satisfaction with treatment choices. Other benefits include an improved ability to cope during the diagnosis, treatment and post treatment phases of the cancer journey, as well as a reduction in anxiety and improved communication with family members. In fact it has been demonstrated that information seeking plays a critical role in individual's efforts to cope with the disruption in quality of life associated with cancer diagnosis and treatment.¹⁸

Individual information requirements

The amount and type of information wanted by those living with cancer varies according to individual's unique information needs and other factors such as the stage in their cancer journey, as well as a person's age, culture and beliefs. Published data (in the western world at least) demonstrates unequivocally that patients with cancer want and need information about their condition.

Format preference

People affected by cancer use a range of information formats and access a number of information and support sources. Some of those questioned for a Macmillan evaluation indicated that they accessed Macmillan information resources in a combination of formats eg. reading a booklet triggered a search for more information online, and vice versa, a website or telephone line was used to order booklets. Some did prefer one format over the other but relatively few (15%) showed a very clear preference.¹



'I got the leaflets from the clinic when diagnosed, including Macmillan's. I went away and then also browsed the internet including Macmillan site'¹

Breast Cancer patient

Timeliness of access

Only around 20% of cancer patients feel they received information too late, with the preferred time to be immediately after diagnosis for treatment information. Online information was almost always received at the right time as the person affected by cancer is more likely to seek information independently.¹

Use of the information

Information resources are used by people affected by cancer for general information, to understand what was happening to themselves or a friend or relative and to seek advice on what they needed to do next. Information had been used to prepare for meetings with health professionals to help inform discussion. Information was also used to answer specific questions and to meet emotional needs, providing peace of mind.¹

Time spent reading information

Nearly 60% of those asked, for a Macmillan evaluation, had read all information available on the topic. It is typical to spend half an hour or more reading Macmillan resources. 60% revisited the information, and those who did were likely to do so several times. This was to refresh memory and better understand what would happen next.¹

Satisfaction level

Almost 90% of those affected by cancer would recommend Macmillan information resources, giving them a 7/10 or more, with 60% giving the top mark of 10.¹

Further actions taken

Over two thirds of evaluation respondents said they went on to take further action after accessing Macmillan information resources. A third looked for further information online, a third contacted Macmillan via the helpline. Around a quarter of interviewees clearly felt they would not have taken these steps without accessing a Macmillan information resource first. Almost all of this group went on to contact another Macmillan service. Around 66% of people who had received financial advice had either applied for financial support or intending to do so following access of information. The majority had or were intending to contact a welfare rights or benefits advisor, 70% had contacted the Macmillan Support Line and almost 60% had or planned to contact a healthcare professional.¹

Informed patients

Patients who have a better knowledge and understanding of their cancer and treatment are found to be more positive and less depressed.¹¹ 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.¹⁹ They are also better equipped and prepared with questions for consultations with health professionals.²⁰

Computer based support

One study of the effect of computer support on younger women with breast cancer found that those who used a computer based support system were significantly more competent at seeking information, more comfortable participating in care and had greater confidence when speaking to doctors than those who didn't have access to information and support online.²¹

Impact on desired patient outcomes

A recent evaluation of Macmillan information resources shows the biggest immediate impacts on outcomes for people affected by cancer are around understanding their condition, having all the information they need, having the ability to make the right decisions and knowing what to do next – each receiving a score of 4 or more, where 5 would indicate complete agreement.¹

In the longer term (2 to 3 months after initial access,) the biggest impacts are knowing what to do next, feeling less anxious, feeling more confident, feeling better able to communicate and feeling better able to make decisions. In addition to scoring 4 or more in each of these areas, respondents felt similarly about feeling more in control and feeling less alone. With some of the outcomes rated significantly higher over time, indicating the positive effect of information in the long term.¹

Feeling less anxious

As a result of Macmillan information people affected by cancer felt less anxious, and this feeling increased over time, this was the second highest ranked outcome in a Macmillan evaluation. While many were general in their reasoning, some linked reduced anxiety to increased understanding, and a sense of relaxation coming from having their questions answered. Some also made links to the support that the information is offering, or reduced isolation by promoting that people were not alone in their condition. Without Macmillan information some would not have experienced the reduced anxiety the information brings – they would not have sought this information from a health professional.¹ For example, A respondent suffering from fatigue put her change in anxiety down to the fact that the information had made her realise its acceptable to feel tired and to rest.¹

Increase in confidence

Confidence was increased by the detailed knowledge gained on issues such as prevalence, side effects, coping strategies, treatment and survivorship. Some cancer patients also felt less isolated and alone as a result of this information, contributing to their confidence, or giving them the confidence to let others know when they were facing difficulties.¹

Better decision making

Being better able to make the right decisions was consistently high across the 3 months after initial contact with the information resources. In general terms this was due to having better understanding of their situation or having questions answered and knowing where to go for further information. There were also specific choices influenced by Macmillan information among patients, such as choice of treatment or confidence and awareness of side effects.¹

Feeling in control


Feeling more in control increased with time, although not as much as with reduction in anxiety. Some put this down to the unpredictable nature of cancer, and health professionals having more direct impact. While some felt this way, others felt better knowledge increased their confidence and knowing what to expect next gave them a feeling of control, especially around treatment choices.¹

Improved communication

Better communication, with both friends and family or health and social care professionals, was facilitated by Macmillan information resources. The information enabled people affected by cancer to ask better questions of their health care staff, and participate more in treatment and decision making. Terminology used by health care professionals seems a barrier to some, and the information was useful to “learn the language.” This specifically gave one patient the confidence to tell their doctor a particular medication was not working, and resulted in a more effective one being prescribed.¹

Feeling less alone

Feeling less alone was not as strongly affected by information resources as other outcomes, but did give some the sense of being “one of many” and their being someone there to help should the need arise.¹



‘It was nice to know other people have suffered from some of these things, e.g. the fatigue, nausea due to chemotherapy.’¹

Cancer patient

CONCLUSION

Having access to appropriate information resources is important for those affected by cancer. Information is needed at all stages of a patient’s cancer journey. Macmillan provides information resources in a variety of formats, including printed booklets and online information. While there has been an increase in the number of people accessing health information online, there is a danger of accessing inappropriate advice, so trusted websites such as Macmillan’s provide a valuable information resource. While some people living with cancer prefer either online or printed information, many use a combination of both.

Having access to Macmillan information resources has been shown to lead to positive outcomes for cancer patients such as less stress and anxiety, better ability to make decisions, an increase in confidence and overall improvement of quality of life.

Macmillan continues to fund and provide Information Resources and urgently needs more charitable donations to keep providing these services to support 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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