What are they?

Cancer information and support services provide people affected by cancer with the chance to ask questions and talk through their concerns with specialist staff and trained volunteers. They provide information and support on a wide variety of cancer types, financial, practical, physical and emotional support. Many of these services have benefits advisers and some even offer complementary therapies.

Cancer information and support services are located within hospitals, hospices, libraries and other community settings.

‘I was given lots of complex information in a folder but then Macmillan explained things to me. They answered my questions clearly and directly and told me what I needed to know.’

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.¹

50% of cancer patients forget most of the information given to them within minutes of their consultation.¹⁰

Reach

There are 187 Macmillan cancer information and support services across the UK, helping 274,868 unique people affected by cancer.¹⁶

Around £100,000 could pay for a new small Macmillan information and support centre.³³

Impact

For every £1 spent on encouraging self-care, there could be £1.50 of cost benefits to the health service.³⁰

Information and support provision raises awareness of available financial practical and emotional support. This improves peoples’ ability to recover and self-manage living with cancer, which can reduce the use of statutory services.
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 cancer information and support services
- the production and distribution of high quality information and advice materials
- directly through our website, http://www.macmillan.org.uk
- directly through our telephone helpline, Macmillan Support Line (0808 808 00 00 – Monday to Friday 9am – 8pm)

We ensure our online and telephone information services, as well as our Macmillan supported services, work to the same high standards and use common resources. Where appropriate, we also refer to other relevant local support services, to ensure that people’s needs are met.

KEY FINDINGS

- **Personalised information and support**
  87% of cancer patients want to know more about their disease, however many do not receive the right kind of information when and how they need. There are particular gaps in the provision of information addressing emotional, financial and social concerns.

- **Improved quality of life**
  The provision of local 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. There is evidence linking improved quality of life to faster recovery, earlier discharge from hospital and to a reduction in the use of statutory services.

- **Funding local cancer information and support services**
  Macmillan has helped to fund and run over 180 local cancer information and support services around the UK, working in partnership with a range of organisations including the NHS and the voluntary sector. These Macmillan-supported services provide personalised, high-quality, and accurate information to people affected by cancer, alongside appropriate support to understand and act on it.

  In 2014, the Macmillan Information and Support Services were visited 452,829 times, reaching 274,868 unique people affected by cancer through our UK.

- **Unmet information and support needs**
  Despite the support available, there are still significant levels of unmet information and support needs for people affected by cancer across the UK.
**DETAILED FINDINGS**

## 1. What is the issue?

There are **four main issues** with the current provision of cancer information and support in the UK:

### i) Some people with cancer receive limited or no information at all about their diagnosis and/or living with the disease

87% of cancer patients want to know more about their disease.¹ Most people affected by cancer receive information from healthcare professionals at the point of initial diagnosis. Various studies have shown that a significant minority (16%) do not receive any information, despite they would want to.⁹ Also, 43% of cancer patients would like more information than what they are given.²

People affected by cancer find it harder to get the information, advice and support they need during the early stages of the cancer journey. Providing the right kind of information following a cancer diagnosis can help reduce many financial, emotional and physical needs.⁷

Yet, the National Audit Office report *Tackling Cancer: Improving the patient journey* shows that 77% of people with a cancer diagnosis were given no financial information during the cancer journey.³

In addition, many people living with cancer are not receiving information about the practical and emotional needs or available support to address them.⁴

Cancer patients are often reluctant to ask questions around non-clinical needs and concerns to health professionals. Clinicians are considered too busy and lacking capacity to provide this kind of support, as well as being primarily focussed on clinical care. Often, cancer patients also think their needs are poorly understood by healthcare professionals.⁷

UK health policy recognises the importance of providing health information to patients. Yet evidence shows that investments in the development and delivery of health information are often uncoordinated and in many cases absent. Information provision is also problematic, with reported lack of consistency.⁵

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### ii) Some people with cancer are overloaded with information, often solely focussed on their physical condition

A study of cancer patients in Wales carried out by Macmillan shows that, although widely available, information is often found overwhelming and irrelevant by patients. Also it is often poorly promoted and not always up to date.⁷

Evidence also suggests that information is often predominantly focussed on physical needs. This leaves a significant portion of support needs unanswered, especially in the emotional domain. Research shows that for many people affected by cancer the emotional impact of the disease is the most difficult aspect to deal with.⁹ Despite this, information on how to address this area of need is the hardest to find.⁸

A study found that 58% of people diagnosed with cancer feel their emotional needs are not adequately met.⁹ Out of them, 75% suffered from anxiety, and a significant percentage within those suffering from anxiety (85%) claimed they did not receive any advice, support or treatment for this condition.⁹
iii) Many people with cancer do not understand the information they are given and need additional support

Macmillan-funded research shows that 37% of people with cancer find the whole cancer support system confusing and would benefit from structured support and guidance on managing their condition.9

Seven million adults in the UK (20% of the adult population) are functionally illiterate. They cannot read or understand simple instructions, such as those found on medicine labels, locate the expiry date on a driving licence or find page reference numbers in the yellow pages.10,11

In addition, over half the population are unlikely to understand cancer information brochures routinely used in hospital settings.10

Evidence suggests that functionally illiterate adults suffer from higher morbidity and mortality rates than the rest of the population. They are also less likely to adopt healthy lifestyles and behaviours, which can prevent or reduce the risk of cancer.12 Furthermore, they are less likely to seek medical advice with early symptoms, therefore being more likely to present with cancers at a later pathological stage.10

This means that those with higher information needs are the least likely to have the ability to find, interpret and absorb it without support.

This suggests that there is a need not only for information provision in general, but also for information to be explained and delivered in an appropriate and tailored way.

iv) Information is often not provided at the optimum time in a person’s cancer journey

Evidence shows that half of cancer patients are likely to forget most of the information they receive within minutes of their consultation.10

Information often does not reach people affected by cancer effectively. Many cancer patients do not receive it at the right time,13 and they are frustrated at being unaware of the support available until late in their illness.14

Information after cancer treatment is also reported as lacking. Patients 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.7
2. What is Macmillan doing to address the issue?

i) Through local cancer information and support services
Macmillan has helped to fund and run 187 local cancer information and support services across the UK, working in partnership with a range of organisations – including the National Health Services of the four UK Nations, local authorities, and the voluntary sector. In 2012 Macmillan introduced cancer information and support services on the high street in local Boots stores nationwide. As part of this new provision, Boots Information Pharmacists help people affected by cancer access the information they need in an accessible, trusted, and informal environment. They are signposted and connected to services in their local area, as well as receiving direct support. In 2014, Boots Macmillan Information Pharmacists helped around 55,000 people affected by cancer across the UK.16

Specialist staff and information provision
A visit to a cancer information and support centre gives people affected by cancer the chance to ask questions and talk through their concerns with specialist staff and trained volunteers. Macmillan information professionals working in these centres answer questions and talk to people affected by cancer about their concerns. The centres hold booklets and leaflets about cancer and information on financial support. Many centres have benefits advisers and some also offer complementary therapies. Macmillan also funds the design, construction and furnishing of hospital and community-based cancer information and support centres. In 2014, Macmillan recorded 452,829 interactions with people affected by cancer through our UK network of Macmillan information and support centres.16

Mobile information services
Macmillan Mobile Information and Support Services tour the UK throughout the year, offering free, confidential and tailored information and support to people in their communities. The services are staffed by Macmillan cancer information and support specialists. In 2014, the four Macmillan Mobile Information and Support Services reached a total of 78,614 people affected by cancer across England, Wales and Scotland.16

Size and location
Macmillan information and support services vary in size and location, as well as in the type of service delivered. Small services can be run during timed slots in community locations (e.g. libraries), which might occur every fortnight for a couple of hours. They can also be offered via a home visit to someone who is unable to travel to a centre. The large support services can include, among others, facilities for benefits advisers, complementary therapists, and meeting rooms for self help and support groups. These support services can be based in libraries, hospices, hospitals or other acute settings.

Whatever their size or setting, a Macmillan cancer information and support service is able to deal with all levels and types of enquiry. Information and support offered depends on the needs of the client. It can range from simple information provision – where the enquirer wants a specific piece of information such as a leaflet or contact details – to complex support. In these cases, the enquirer may be in crisis and have more severe needs which need to be thoroughly unpicked.

Our services use a combination of appropriate environment, quality resources, and skilled staff to help people affected by cancer to identify and express their concerns and needs. The services provide personalised high-quality information and support on areas ranging from condition-specific enquiries to practical issues such as how to obtain travel insurance.
When needed, Macmillan information and support services also signpost or refer to other relevant clinical, social care or supportive services which best meet the identified needs of clients. In addition, many support services are able to offer complementary therapies, as well as access to benefits advisers or other specialist services. Macmillan professionals and volunteers are also there to provide immediate face-to-face advice and support.

The service has a very important role in the community and hospital settings. It acts as a resource for staff, patients and carers in a counselling, listening and advisory capacity.17 45% of users of the Renfrew Macmillan cancer information and support service stated that they would not know where to go if the service were not available.18

ii) Through Macmillan health and social care professionals
Macmillan supports a range of health and social care posts, providing information directly to people affected by cancer or signposting them to other appropriate sources. Examples of these posts are Macmillan information and support managers and officers. Macmillan clinical nurse specialists (CNSs) are also active in providing supported information, alongside their other responsibilities.

Macmillan supports the development of professionals and volunteers. Through Macmillan e-learning programme, they are able to develop skills and expertise to provide the most appropriate support to people affected by cancer.

iii) Through Macmillan website and Macmillan Support Line
Macmillan provides information and support directly over the phone and online to anyone in the UK on 0808 808 00 00 or via www.macmillan.org.uk. The website gives people affected by cancer the opportunity to access information and support 24 hours a day, anonymously and in confidence.

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

i) Impact on the emotional and mental wellbeing of people living with cancer
Having access to the right information, alongside the support to understand it, promotes feelings of improved wellbeing. This also enables people affected by cancer to feel more in control, less anxious and less stressed about their condition.

Macmillan-supported cancer information and support services are staffed with trained professionals and volunteers with a wide range of skills. They are able to provide relevant information and help people to fully understand it. This means that people affected by cancer are able to fully benefit from the information they receive. We believe this model of supported information provision is key to meeting people’s needs.

People affected by cancer who are in contact with Macmillan are more likely to get information, support and advice about the physical, emotional, social and financial aspects of living with cancer than those who do not have this contact.19

‘Coming to the cancer information and support service has improved the quality of my life. I’m not sure that I would be here but for this service’.6

Cancer patient
Macmillan publications are considered to be well produced, highly respected and of excellent quality. Therefore, they are deemed more reliable than other external sources available to people affected by cancer.  

Receiving unreliable information can be detrimental for people affected by cancer. Having access to such a wide range of information (as well as the support to understand it) means that cancer patients are less likely to seek information from potentially untrustworthy sources, such as general internet searches. Unreliable information can lead to incorrect self-diagnosis and/or increased feelings of anxiety and stress. Contrarily, when cancer patients are well informed they tend to experience less anxiety and are more likely to better cope with their illness. They are also able to have a more active role in consultations with health professionals, understanding and participating in decision-making around their care. With the right information and support, patients can look after themselves more efficiently and their quality of life is improved.

Besides improving self-management, evidence from the Patient Information Forum shows that access to appropriate information also has an impact in reducing healthcare costs. So investing in high quality consumer health information and support is highly recommended from an ethical, financial and clinical perspective.

In 2012 Macmillan rolled out cancer information and support service drop-in services in Glasgow Libraries, known as GlasgowLife. An interim evaluation report shows that Macmillan information points are seen as a helpful addition to libraries, being informative and comfortable areas for people to access cancer information and support.

Cancer patients are able to speak openly about the impact of cancer on themselves and their family, which helps to maintain strong relationships

Cancer patients find it difficult to talk about their condition. They do not always know who to talk to, or how to talk to them. Evidence shows that 25% of participants to a study broke up with their partner as a result of their cancer. In addition, 36% of carers felt an enormous strain on relationships following cancer and its treatment. Receiving information and support helps to ease this pressure. Research has also shown that, upon receiving information, patients are more likely to be open about their condition when interacting with a confidant.

‘I was given loads of complex information in a folder but then Macmillan explained things to me. They answered my questions clearly and directly and told me what I needed to know’. Cancer patient

‘I felt so much better to be able to talk about things openly. It was an immense relief. I was able to talk about everything and I cried. I no longer felt hemmed in’. Cancer patient

‘To be able to talk about my husband and his reaction to cancer and the treatment but also my feelings and how I was struggling to cope was really important to me’. Cancer patient

‘The Macmillan representative was so helpful, informative and sympathetic and the hidden seating area at the rear is a great help not only from a confidentiality standpoint, but for privacy when upset’. Cancer patient
An evaluation of Macmillan information and support services in Wales found that 81% of those using the centres interacted with a Macmillan coordinator. Service users commented that the coordinator provided ‘a friendly face to chat to’, was ‘kind and sympathetic’ and ‘a tower of support’ for their needs.

- 70% of respondents gained further information directly from the coordinator
- 68% used the information and support available from the leaflets and DVDs
- 27% received help from the coordinator at the centre to complete forms.

Similar international studies found that 80% of cancer patients feel better after talking to someone on a one-to-one confidential basis. In addition, having access to information and support helps people feel better informed, encouraged, confident and empowered.

Creating the right environment and personalised service promotes feelings of wellbeing

In the context of information provision, hospital-based services are very important as they have the potential to reach a large number of people. In addition, Macmillan cancer information and support services in hospital settings are developed to be informal, friendly and welcoming environments. This helps improve patient experience, by making them feel more at ease.

Macmillan-supported cancer information and support services deliver personalised activities to all cancer patients, regardless of gender, race or religion. Evidence shows that tailored, easily accessible information increases patient understanding.

ii) Impact on the financial burden
Cancer patients are often unaware of the financial benefits they are entitled to and under-claiming of welfare benefits by those eligible is widespread. There is considerable evidence that financial issues are a key concern for cancer patients, often leading to significantly increased levels of stress. Once financial concerns are addressed, patients are more able to focus on their illness and treatment.

A 2010 study of the economic benefit of the Salford Macmillan information and support centre showed that, out of the 1,586 enquiries made to the centre in 2008-2009, the largest recorded proportion related to the financial implications of living with cancer.

Macmillan information and support services provide a vital signposting activity, referring patients to appropriate financial advice and assistance. Participants in a Macmillan-funded...
research claimed that advice received through Macmillan helped to reduce stress levels, which can in turn aid recovery.  

**iii) Potential savings as a result of effective information and support for people affected by cancer**

Despite the initial set up costs, information and support centres can be run very cost effectively. For example, a 2010 report indicated that, although the Salford Macmillan cancer information and support centre costs £50,000 per annum to run, it generates over £78,000 in tangible benefits for clients i.e. for every £1 spent on the service, patients see a benefit of £1.57.  

In addition, educational interventions which encourage and enhance people’s sense of self-sufficiency can reduce demand for medical intervention – as well as reducing the use of health services – therefore leading to cost savings.  

Also, a study from the Nuffield Trust found that failure to provide full and balanced information to patients about risks and uncertainties can give rise to unrealistic expectations, which in some cases can lead to costly legal action.  

Macmillan cancer information and support centres help free up clinicians’ time. This allows health professionals to focus on their core activities, as well as bringing cost benefits to the system. This is demonstrated through the case study below.

**Case Study: Cancer Specific savings the Renfrew and Sunderland Macmillan cancer information and support services**

Semi-structured interviews with professionals working and people affected by cancer revealed a number of benefits from the services:

- **Reduce workload of CNSs**
  CNSs and District Nurses interviewed stated that the Renfrew service helped to reduce their workload. This was due to more cancer patients visiting the drop-in centre and having their needs addressed there. This helped nurses spend less time in home visits. As a result, a short telephone conversation was often enough for keeping up with their patient’s situation.  
  Health professionals working in the Sunderland trust also commented that centre helped free up CNS time, which allowed them to focus on the emotional complexities and treatment for patients.  

- **Improved communication**
  Professionals working with Renfrew service stated that it facilitated improved communication between the different health and social care agencies working in cancer care in Renfrew and thus improved partnership working.  

- **Improved patient experience**
  All the users interviewed expressed a high level of satisfaction with the information and support they received from the drop-in centre. They stated that it met their expectations, and that it was sensitive and appropriate to their needs. Almost half of service users interviewed said that they wouldn’t know where to go to get information, had the centre not existed. A further quarter of participants said that they would go to their GP.
Cost of running a typical Macmillan information and support centre

Macmillan provides Local Information and Support Services for those affected by cancer and invests a significant amount in keeping the services running. Typical costs for 2014 are shown below.

<table>
<thead>
<tr>
<th>Time period</th>
<th>Large centre cost</th>
<th>Small centre cost</th>
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</thead>
<tbody>
<tr>
<td>1 Day</td>
<td>£360</td>
<td>£201</td>
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<tr>
<td>1 Week</td>
<td>£1,799</td>
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<tr>
<td>1 Month</td>
<td>£7,796</td>
<td>£4,350</td>
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<tr>
<td>1 Year</td>
<td>£93,547</td>
<td>£52,200</td>
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*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.

CONCLUSION

Macmillan information and support services are able to offer the specialist cancer knowledge and expertise that is needed to support people affected by cancer. The non-clinical environment, the inclusion of volunteers, and the skills demonstrated by the information and support manager provides people affected by cancer with the space and time to express and discuss concerns that reflect the whole life impact of the cancer diagnosis.

It is this ability to help the client identify and prioritise their concerns and then to meet this concern with the appropriate information and support that enables Macmillan to provide a tailored personalised service. This is done through understanding and addressing the needs of people affected by cancer and helping them to cope with the physical, emotional and social aspects of their cancer diagnosis.

Despite the work Macmillan has done over the years there are still many people affected by cancer with unmet information and support needs. With the number of people living with cancer estimated to rise to 4 million by 2030 it is vital that action is taken now to ensure everyone has access to the information and support they need in the future.

Macmillan continues to fund and provide Cancer Information and Support Services and urgently needs more charitable donations to keep these services 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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