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CANCER SUPPORT

# LOCAL INFORMATION AND SUPPORT SERVICES

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

## Need



**87%** of people affected by cancer want to know more about their disease.<sup>1</sup>



**50%** of cancer patients forget most of the information given to them within minutes of their consultation.<sup>10</sup>

## Reach



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



Macmillan invests **£148,000** per year in Local Information and Support Services.<sup>31</sup>

## Impact



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



Information and support provision raises awareness of available financial practical and emotional support and in turn improves peoples' ability to recover and self-manage living with cancer, which in turn can reduce use of statutory services. <sup>1</sup>

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



# LOCAL CANCER INFORMATION AND SUPPORT SERVICES

## 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, [www.macmillan.org.uk](http://www.macmillan.org.uk)
- directly through our telephone helpline, Macmillan Support Line (0808 808 00 00 – Monday to Friday 9am – 8pm)

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 client'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 information at the right time in the right way. 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 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, along with appropriate support to understand and act on it.  
  
In 2013 Macmillan achieved 401,965 interventions with people affected by cancer through our UK network of Macmillan information and support services.
- **Unmet information and support needs**  
Despite this there are still a significant number of people affected by cancer across the UK with unmet information and support needs.

# 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.<sup>1</sup> Most people affected by cancer who want information receive it from healthcare professionals at the point of initial diagnosis. 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<sup>9</sup> and 43% would like more information than they are given.<sup>2</sup>

People affected by cancer find it harder to get the information, advice and support they want and need during the early stages of the cancer journey.<sup>27</sup> Many of the financial, emotional and physical problems people with cancer face could be reduced if they are provided with the right information to help them.<sup>7</sup>

The National Audit Office report *Tackling Cancer: Improving the patient journey* showed that 77% of people with a cancer diagnosis were given no financial information during the cancer journey.<sup>3</sup>

In addition many people with cancer are not receiving information about the practical and emotional support they need, or told where they can go for help.<sup>4</sup>

Cancer patients are often reluctant to bother health professionals with questions about non-clinical needs and concerns as they deem them to be too busy, lacking capacity and more focussed on clinical care. In addition, cancer patients often think their needs are poorly understood by the medical and nursing profession.<sup>7</sup>

*'GPs don't seem to know the full extent of the information you need.'*<sup>6</sup>

**Cancer patient**

Although UK health policy recognises the importance of providing health information to patients, a report by the Patient Information Forum found that investment in the development and delivery of health information is often uncoordinated and in many cases absent. There is also a lack of consistency in information given to patients; the report evaluation describes this as 'a lottery'<sup>5</sup>

### 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 a wide range of information is available to the majority of people at the point of diagnosis it is often overwhelming and irrelevant. It is also the case that where information is available it is often poorly promoted and not always kept up to date.<sup>7</sup>

A study of over a thousand people affected by cancer found that the emotional impact of cancer is the most difficult aspect for people to deal with.<sup>9</sup> Despite this, information on how to deal with emotions, relationships and social situations is the hardest to find.<sup>8</sup> 58% of people diagnosed with cancer feel their emotional needs are not adequately looked after.<sup>9</sup>

The same study found that 75% of this group suffered anxiety, and of these, 85% did not receive advice, support or treatment for this condition.<sup>9</sup>

### iii) Many people with cancer do not understand the information they are given and need additional support to interpret it

Macmillan funded research has shown that 37% of people with cancer found the whole cancer support system confusing and would benefit from structured support and guidance on managing their condition.<sup>9</sup>



*'I find information leaflets a bit frightening. I would rather have information explained directly to me.'*<sup>6</sup>

**Cancer patient**

Seven million adults in the UK (20% of the adult population) 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.<sup>10,11</sup>

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

Evidence 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.<sup>12</sup> 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.<sup>10</sup>

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 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.

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

One study showed that at least 50% of cancer patients forgot most of the information provided to them within minutes of their consultation.<sup>10</sup>



*'When my chemotherapy and radiotherapy stopped I felt pushed out into the cold, or as if I was walking the plank...isolated from qualified and informed support.'*<sup>15</sup>

**Cancer patient**

Many cancer patients do not receive information at the most effective time.<sup>13</sup> In addition many people affected by cancer are frustrated at being unaware of the support available until late in their illness.<sup>14</sup>

Cancer 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.<sup>7</sup>

## 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 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 are able to help people affected by cancer access the information they need, signpost and connect them to services in their local area and offer support in an accessible, trusted, familiar and informal environment. In 2014, Boots Macmillan Information Pharmacists helped around 55,000 people affected by cancer across the UK.<sup>16</sup>

#### **Specialist staff and information provision**

A visit to a cancer information and support centre provides people affected by cancer with 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 available to help and some offer complementary therapies too. Macmillan also funds the design, construction and furnishing of hospital and community-based cancer information and support centres. In 2014, Macmillan achieved 452,829 interventions with people affected by cancer through our UK network of Macmillan information and support centres.<sup>16</sup>

#### **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 78,559 people affected by cancer across England, Wales and Scotland.

#### **Size and location**

Macmillan information and support services vary in size and location and also in the type of service delivered. The smallest services can be run during timed slots in community locations (e.g. libraries) which might occur once per fortnight for a couple of hours, or be offered via a home visit to someone who is unable to travel to a centre. The largest support services include facilities for benefits advisers, complementary therapists, and meeting rooms for self help and support groups, and there are many different service models in between these two extremes. These support services can be based in libraries, hospices, acute hospitals or other acute settings.

Whatever their size or setting, a Macmillan cancer information and support service needs to be able to deal with all levels and types of enquiry. Effective information and support differs depending on the needs of the client. At one extreme is simple information provision where the enquirer wants a specific piece of information such as a leaflet or contact details. At the other extreme the enquirer may be in crisis and have complex needs which need to be 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 specific problems, concerns and needs. The services then provide personalised, high quality, and accurate information, and support to understand it, on areas ranging from condition specific information to practical information about issues relevant for people affected by cancer such as how to obtain travel insurance.

They 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 and access to benefits advisers or other specialist services. Macmillan professionals and volunteers are also on hand to provide face to face advice, help and support.

The services act as a resource for staff, patients and carers in a counselling, listening and advisory capacity both in hospital and the community.<sup>17</sup> 45% of users of the Renfrew Macmillan cancer information and support service<sup>1</sup> stated that they wouldn't know where to go if the service was not available.<sup>18</sup>

### ii) Through Macmillan health and social care professionals

Macmillan supports a range of health and social care posts, many of who provide information directly or signpost people affected by cancer to other appropriate sources. Example posts include Macmillan information and support managers and officers. Macmillan clinical nurse specialists (CNS) are also active in providing supported information, alongside their other responsibilities

Macmillan offers an e-learning programme to support health and social care professionals and volunteers to enhance the range of skills needed to provide high quality information and support.

### iii) Through Macmillan website and phone 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](http://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 along with the support to understand it promotes feelings of wellbeing, enabling people affected by cancer to feel more in control, less anxious and less stressed.

Macmillan-supported cancer information and support services are staffed by co-ordinated, mixed skilled teams made up of professionals and volunteers who are able to explain the information as well as provide it.

This means that people affected by cancer are able to understand, digest and use the information provided. We believe this model of supported information provision is key to meeting people's needs.

People affected by cancer who have 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 people who do not have this contact.<sup>19</sup>

Macmillan publications are considered to be well produced, respected and of high quality and thus more reliable than other potential sources.<sup>27</sup>



*'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.'*<sup>6</sup>

**Cancer patient**

Having access to such a wide range of information (and receiving support to understand it) means that cancer patients are less likely to seek information elsewhere from potentially unreliable sources such as general internet searches.<sup>20</sup> Unreliable information can lead to incorrect self-diagnosis and/or increased feelings of anxiety and stress.<sup>21</sup>

*'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.'*<sup>6</sup>

**Cancer patient**

In addition, cancer patients who are well informed are better able to understand and participate in their health care plan, experience less anxiety and more likely to cope with their illness.<sup>10</sup> They are also better equipped and prepared with questions for consultations with health professionals.<sup>22</sup> With the right information and support patients can look after themselves more efficiently and their quality of life is much improved.<sup>34</sup>

Further evidence from the Patient Information Forum shows that access to appropriate

information not only allows patients to manage and improve their health but also incur lower costs.

So investing in high quality consumer health information and support is not only the right thing to do from an ethical standpoint but is also a financial and clinical imperative.<sup>5</sup>

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 the addition of the Macmillan information points are seen as a welcome addition to libraries, providing visible, welcoming, comfortable, and useable areas for people to access cancer information.<sup>23</sup>

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

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. One study of over 600 people with cancer found that 25% of the group had broken up with their partner as a result of their cancer. In addition, 36% of carers felt an enormous strain on relationships as a result of the cancer and its treatment. Being given information and support has been shown to help ease this pressure.<sup>9</sup> Research has also shown that patients are more likely to show personalised information to their confidant.<sup>24</sup>

*'It 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.'*<sup>6</sup>

**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'*<sup>24</sup>

**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.'*<sup>18</sup>

**Cancer patient**



An evaluation of Macmillan information and support services in Wales found that 81% of those using the centres talked with the centre's Macmillan coordinator. Service users commented that the coordinator provided 'a friendly face to chat to', was 'kind and sympathetic' and 'a tower of support' 70% gained further information directly from the coordinator, 68% used the information and support available from the leaflets and DVDs and 27% of respondents received help from the coordinator at the centre to complete forms.<sup>25</sup>

An evaluation of a similar 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. In addition, having access to information and support helps people feel better informed, encouraged, confident and empowered.<sup>26</sup> It is reasonable to conclude that this would apply in the UK.

### **Creating the right environment and personalised service promotes feelings of wellbeing in people affected by cancer by helping put them at ease and feel relaxed**

Hospital-based information and support services are seen as important as they have the potential to reach large numbers of people.<sup>27</sup> In addition to being convenient, Macmillan cancer information and support services are informal, friendly and welcoming environments.<sup>18</sup>

*'I like going down to the cancer information and support service and having a laugh, a chat and cup of coffee. People don't talk about cancer most of the time. Peer support is about everyone helping each other but it's not all about cancer.'*<sup>6</sup>

**Cancer patient**

*'There is no need to wait for an appointment. I never feel rushed and always feel at ease.'*<sup>6</sup>

**Cancer patient**

Macmillan-supported cancer information and support services provide a tailored, personalised service for all cancer patients regardless of gender, race or religion.<sup>27</sup> Personalised information broken down into 'bite sized chunks' is shown to increase patient recall and understanding.<sup>10</sup>

#### **ii) Impact on the financial burden**

Cancer patients are often unaware of the financial benefits that they are entitled to and under-claiming of welfare benefits by those eligible for them is widespread.<sup>28</sup> There is considerable evidence that cancer patients experience substantial stress around financial issues.<sup>13</sup> Once the financial stress is removed, they are more able to deal with their illness and treatment.

Macmillan information and support services provide a vital signposting facility, referring patients to appropriate financial advice and assistance services. Macmillan-funded research has shown that all patients claimed that benefits received as a result of welfare advice funded by Macmillan helped to reduce stress levels, which can in turn aid recovery.<sup>29</sup>

*'They were better than my consultant, GP or nurse because they took the time to listen to me – they were just great.'*<sup>6</sup>

**Cancer patient**

*'It's a very personal service – they treat you based on your individual needs.'*<sup>6</sup>

**Cancer patient**

A 2010 study of the economic benefit of the Salford Macmillan information and support centre showed that 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.<sup>30</sup>

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

Information and support centres require an initial investment however they can be run very cost effectively. For example, 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.<sup>30</sup>

In addition there are cost benefits relating to the ability of cancer information and support services to free up health professionals time, enabling them to concentrate on their core roles. 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 with participating agencies of the Renfrew service revealed a number of benefits from the service:

- Cancer Nurse Specialists and District Nurses interviewed stated that the Renfrew service helped to reduce their workload. This was due to cancer patients that they would normally have to visit and spend a significant amount of time with in their homes instead visiting the drop-in centre and having their needs addressed there. As a result a short telephone conversation was often sufficient in keeping up with their patient's situation.<sup>18</sup>
- 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.<sup>18</sup>

*'Having professionals in the same room at set times means that the incentive and the practical possibility of working together is far greater. You don't have to wait as long to get things done.'*<sup>18</sup>

- Health professionals working in the Sunderland trust commented that the Sunderland information and support centre helped free up CNS time, which allowed them to focus on the emotional complexities and treatment for patients.<sup>17</sup>

*'The service has been valuable; I have been involved in complex situations where without the expertise of the Information Manager I would have struggled to deal with the issues.'*<sup>17</sup>

Similar interviews conducted with people affected by cancer showed that:

- 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 had met their expectations, and that it was sensitive and appropriate to their needs. Asked if the drop-in centre didn't exist where they would go to for support and information like that currently provided, almost half of service users interviewed said that they wouldn't know where they would go to and a further quarter said that they would go to their GP.

## Cost of running a typical Macmillan information and support centre<sup>31\*</sup>

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.

Time period	Large centre cost	Small centre cost
1 Day	£360	£201
1 Week	£1,799	£1,004
1 Month	£7,796	£4,350
1 Year	£93,547	£52,200

\*For more detailed costs of these and other Macmillan services see [be.macmillan.org.uk](http://be.macmillan.org.uk) to download The Cost of Macmillan's Services fact sheet.

### Non-cancer specific provision of health related information and support

Educational interventions which encourage and enhance people's sense of self-sufficiency can reduce demand for medical intervention, reduce the use of health services and therefore lead to cost savings.<sup>32</sup>

A 2002 report for the UK Treasury estimated that for every £100 spent on encouraging self-care around £150 worth of cost benefits for the health service could be delivered.<sup>33</sup>

A study for the Nuffield Trust states 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.<sup>34</sup>

## 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 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, successfully meeting 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<sup>35</sup> 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](http://www.macmillan.org.uk/donate) or call 0300 1000 200 to make a donation.

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