



## What are they?

Macmillan's online community can be accessed through the Macmillan website. The community allows people to connect with others who have been through a similar experience,

Online support is accessible 24 hours a day, can be used anonymously, in confidence and from the comfort of users' own homes.

*'It's just very good to know that other people have been through this and to kind of share the experience with other people, and you feel much less isolated...'*

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



**43%** of people use the internet to access cancer information.<sup>2</sup>



For people living with something as life changing as cancer, speaking to others in the same position can be a vital way to deal with emotions.<sup>12</sup>

## Reach



Macmillan's online support services helped more than **4 million** people in 2014.<sup>8</sup>

## Impact



**79%** of users spend up to an hour accessing the online community on their visit.<sup>10</sup>



Accessing online communities reduce feelings of isolation and loneliness. It can also alleviate the feeling that you are on your own and nobody else has been through a similar experience.<sup>6</sup>

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



# MACMILLAN'S ONLINE COMMUNITY

## INTRODUCTION

Macmillan helps meet the information and support needs of people affected by cancer in a variety of ways including directly through our website and telephone helpline (Macmillan Support Line)

Macmillan online community provides emotional and peer support for those affected by cancer. The online community can be accessed through the Macmillan website and gives people the opportunity to connect with others who have been through a similar experience, and to be part of an understanding community. In addition to the online support, the website provides signposting to local support groups.

## SUMMARY OF KEY FINDINGS

- **Internet use**  
83% of UK households have internet access, with 73% accessing the internet every day. The internet is increasingly being used to access health related information, with almost half of UK adults using the internet for this purpose.
- **Advantages of online support**  
Online support is accessible 24 hours a day, can be used anonymously, in confidence and from the comfort of users' own homes. Cancer patients who are confined to their home or struggle to discuss issues face-to-face find this particularly appealing.
- Online communities and networks provide emotional support from others who have similar experiences and can understand this, in turn can lead to reduced anxiety, stress and depression.
- **Macmillan online support**  
The Macmillan website features high-quality cancer information, an online community where people can chat and support each other, and information on how Macmillan and other organisations can provide emotional, practical and financial support. In 2012, these support sections of the website helped more than 4.6 million people.

# DETAILED FINDINGS

## 1. What is the issue?

With an ageing population, and cancer survival rates rising, the number of people living with cancer in the UK is set to reach 4 million by 2030. This will bring a proportional growth in need for emotional support services, and additional pressures on the NHS. Online peer support communities like Macmillan's will continue to play a growing role in combating isolation and helping people cope with the emotional impact of cancer.<sup>1</sup>

### Increased internet usage

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.<sup>2</sup>

### Advantages of online support

US support group NCCN highlights the advantages of effective online support. They state that effective online support groups offered by knowledgeable, skilled staff from reputable organisations can be especially helpful for people in rural areas, those who are too ill to attend a meeting in person, or those who without access to transportation. Online support groups also have the advantage of providing anonymity and 24-hour availability, as well as bringing together individuals from different geographic areas. Also because they are Internet-based, members can easily share resources such as links to websites, information, and news through emails and posts, providing a venue for knowledge exchange and review.<sup>3</sup>

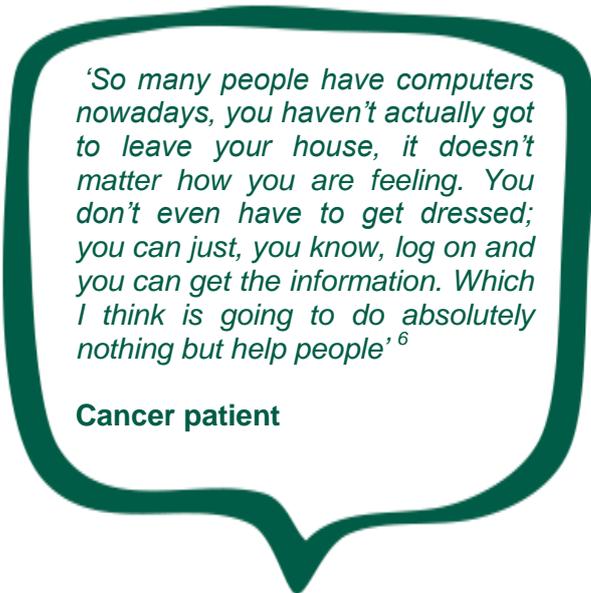
For some people the internet is their only means to communicate with the outside world.<sup>10</sup>

One HIV patient who was made housebound made the following comment: (see right)<sup>4</sup>

Cancer patients are often confined to their homes as a result of their cancer and its treatment and as such this is likely to also be applicable to them.

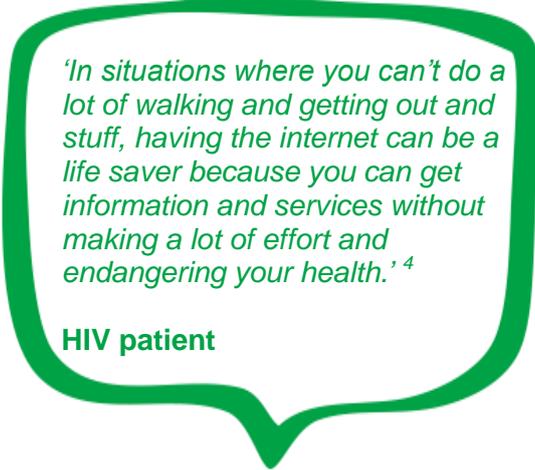
For some a lack of mobility, financial difficulty caused by an illness or the responsibility of caring for a child or elderly family member reduces the ability to leave the house and places a bigger reliance on the internet. One study found that online support groups were particularly popular with women from rural locations who did not have ready access to other forms of support.<sup>5</sup>

The internet alleviates the need to speak to someone face to face about issues which people affected by cancer may feel uncomfortable or embarrassed about.



*'So many people have computers nowadays, you haven't actually got to leave your house, it doesn't matter how you are feeling. You don't even have to get dressed; you can just, you know, log on and you can get the information. Which I think is going to do absolutely nothing but help people'*<sup>6</sup>

**Cancer patient**



*'In situations where you can't do a lot of walking and getting out and stuff, having the internet can be a life saver because you can get information and services without making a lot of effort and endangering your health.'*<sup>4</sup>

**HIV patient**

This particularly appeals to young men, who are worried about their health but reluctant to visit the doctor. <sup>6</sup>

### Why those affected by cancer use online communities

Cancer patients use the internet for a wide range of information and support needs, many of which are unlikely to be met through conventional healthcare. <sup>6</sup> Internet use by patients at all stages of cancer care is now widespread, from early investigations to follow-up after treatment. <sup>7</sup>

For people living with something as life-changing as a cancer, speaking to others in the same position can be a vital way to help them deal with their emotions. <sup>1</sup>

Although support from the medical professionals is of course essential, this support is likely to be focused on the cancer first and the emotional wellbeing of the patient second. Resources for professional emotional support are not infinite, and can never be constantly available. <sup>1</sup>

Whilst friends and family can help, not everyone has a good support network. In addition, those living with cancer may be reluctant to open up, for a range of reasons, from not wanting to worry people, to fearing they will not understand. In some cases there is no substitute for talking to someone else who has been in the same position, someone who instinctively 'gets it.' This type of support is known as 'peer support', and it's something that people are increasingly accessing online. <sup>1</sup>

One survey of people affected by cancer listed a number of the key reasons for accessing the internet, many of these include the use of online communities. Some of the reasons given are detailed below:

- To raise awareness about cancer through instant communication with a large numbers of people



*'I know there are other people out there and we can get something done.'* <sup>10</sup>

**Cancer patient**

- To seek support from peers



*'It's not just the medical information aspect; it's just a kind of support, moral support, which is very, very important when you've had a diagnosis of cancer.'* <sup>6</sup>

**Cancer patient**

An added benefit of the internet for this purpose is the ability to access support when needed rather than having to wait until a scheduled meeting time.<sup>19</sup>

- To make social connections

*'People log on because they've either got something to say or else an ear to lend to those who do.'*<sup>10</sup>

**Cancer patient**

*'There are friendships and camaraderie that you get from the internet. There's a community of us who are always on the internet. Nine times out of ten, I'm closest to people who are on the internet.'*<sup>10</sup>

**Cancer patient**

- To tackle isolation

*'It's just very good to know that other people have been through this and to kind of share the experience with other people, and you feel much less isolated...'*<sup>6</sup>

**Cancer patient**

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

The Macmillan website features high-quality cancer information, an online community where people can chat and support each other, and information on how Macmillan and other organisations can provide emotional, practical and financial support. In 2014, these support sections of the website helped more than 4 million people.<sup>8</sup>

On average there were 56,000 unique visitors to Macmillan's website every month in 2013. In 2014 this is up to almost 73,000 to date, with almost half this number being new to the site.<sup>9</sup>

### Expert webchats

The Macmillan website allows people to discuss areas of concern relating to cancer. Users can also take part in, or read transcripts of live webchats with Macmillan cancer experts and can access regular blogs which give high-quality information about cancer. There are many chat topics to cater for different user needs, for example by cancer type and related issues of concern such as diet, benefits or pain management.<sup>10</sup>

*'I have just joined the community link and have found the transcripts of the chat lines so helpful and informative. I am still having a difficult time after bowel cancer resection and removal of colostomy bag with numbers of times going to toilet but am persevering with diet and pills. Thanking God for MacMillan.'*

**Leila, cancer patient**

The web chats are well used by those affected by cancer, for example, the chat on skin cancer in May 2014 had 35 active users and attracted 256 unique views of the transcript in two weeks, and the chat on diet in April 2014 had 25 active users and received 228 unique views of the transcript in two weeks.<sup>10</sup>

After taking part in or simply following and benefiting from other users interactions individuals also go on to actively find out more from other sources. In a recent Macmillan survey about the web chat service, as a result of the chat 66.67% of respondents said they intended to go on to look at the Macmillan website, 42.86% to call the Macmillan Support Line, 33.33% intended to contact another organisation recommended in the chat and 14.29% stated they would go on to order Macmillan information or materials.<sup>11</sup>

### Who does Macmillan reach through the online community and when

In a recent Macmillan survey 37% of participants had undergone cancer treatment and 27% were currently undergoing treatment. 77% of users were female. 36% of users were aged between 55-64, 30% between 45-54, 15% between 65-74, and 10% aged between 35-44.<sup>9</sup>

37% of those questioned found out about Macmillan online community through the Macmillan website and 31% through on online search engines; other sources include through their doctors, Macmillan Cancer Specialist Nurse, other health care professionals and through family and friends.<sup>11</sup>

The most popular time to access Macmillan's online support is in the evening between 5-7pm, with 57% of users preferring this evening time, followed by a preference for the afternoon, between 12-4pm. 79% spend up to an hour accessing the online community.<sup>11</sup>

## 3. What is the impact of online communities?

### i) The impact of the website on user satisfaction and experience

81% of users are satisfied with their last interaction with the Macmillan online community, with 85% finding the site easy to navigate.<sup>11</sup>

95% are very or fairly likely to recommend the website to others and 92% are very or fairly likely to re-contact Macmillan in the future.<sup>12</sup>

### ii) The health and wellbeing impact of accessing information and support

Patients who have a better knowledge and understanding of their cancer and treatment are found to be more positive and less depressed.<sup>7</sup>

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>13</sup> They are also better equipped and prepared with questions for consultations with health professionals.<sup>14</sup>

Informed patients take a greater degree of ownership and responsibility for their care and are better equipped to manage their own symptoms.<sup>7</sup> With the right information and support patients can look after themselves more efficiently and their quality of life is much improved.<sup>15</sup> There is evidence that internet usage enables people to enhance their sense of autonomy.<sup>16</sup>

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.<sup>17</sup>

### iii) The health and wellbeing impact of access to social networking sites and online communities offering support and advice

Accessing social networking sites and online communities reduce feelings of isolation and loneliness. It can also alleviate the feeling that you are on your own and that nobody else has been through a similar experience.<sup>6</sup>

One study of the use of the internet to counteract social isolation after breast cancer found that by being able to exchange knowledge and experiences with other internet users the women concerned felt more empowered. The study also found that internet support groups have important potential for aiding rehabilitation.<sup>18</sup> Peer support has also been shown to improve a patient's ability to cope with their disease.<sup>19</sup>

Recent research in the US found that spending time online reduces depression and increases cognitive brain function among senior citizens. Levels of depression were thought to have decreased by as much as 20%. Potential reasons include the fact that internet usage increases cognitive decision making and the ability to make social connections.<sup>20</sup> A second study confirmed these findings stating that cognitive behaviour interventions are effective in reducing and managing psychological distress in cancer patients.<sup>21</sup>

One evaluation of the positive effect of peer support on the well-being of breast cancer sufferers reported improvements for patients on trauma symptoms, emotional wellbeing, confidence and self-belief. It was found that the opportunity for cancer patients to talk through their experience with someone who has gone through a similar experience could have real therapeutic benefits and positive health consequences.

Users of Macmillan's online community made the following comments about how the service has improved their lives:

*'Macmillan is amazing, I'm a member of the online community and the support when you need to vent your emotions or ask questions is overwhelming. I have Phoned the main line and I cannot say enough how amazing this service is...'*

**Carri-anne via Facebook**

*'Can I also offer praise for your online community. They have been brilliant the last 4 weeks for support and information.'*

**Louise via Twitter**

*'The online community is brilliant. There is always someone on line to give you advice or encouragement.'*

**Judith via Facebook**

*'The neat thing about the internet is that you can actually hook up with people that have gone through the same experiences, that do understand what you're talking about, that have been there.'*<sup>9</sup>

**Cancer patient**

*'Being involved takes your mind off the horror of it, and you immediately begin the process of fighting the disease.'*<sup>6</sup>

**Cancer patient**

*'The site has truly helped me, it has helped me to gain some perspective and make me realise that I am not alone and to enjoy the moment instead of worrying what the next step is or what tomorrow or next week may hold' <sup>15</sup>*

**Cancer patient**

*'Some days I get strength from seeing that people have the same feelings as me and it gives me comfort when I'm feeling like I'm the only person in the world to feel like I do. Other days it picks me up because I can share my feelings and thoughts which will hopefully give others comfort as well.' <sup>15</sup>*

**Cancer patient**

## CONCLUSION

Macmillan's online community gives people affected by cancer the opportunity to connect with experts and with peers who have had similar experiences, with others who understand.

Online support recognises and helps to address the emotional effects of cancer, not always prioritised by medical professionals. Accessing social networking sites and online communities reduce feelings of isolation and loneliness. It can also alleviate the feeling that you are on your own and that nobody else has been through a similar experience.<sup>6</sup>

Macmillan's online community can be accessed 24 hours a day and can be used anonymously. Online support is also of particular advantage for cancer patients who struggle to leave the house due to ill health, or who live remotely where they cannot access other support easily.

Macmillan continues to fund and support people affected by cancer through its online communities and urgently needs more charitable donations to allow this service to continue 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.

## REFERENCES

---

- 1 Guardian.com. <http://www.theguardian.com/living-with-cancer-macmillan-partner-zone/fighting-loneliness-online-cancer-forums> (accessed October 2014).
- 2 ONS. Internet Access Households and Individuals, 2013. [http://www.ons.gov.uk/ons/dcp171778\\_322713.pdf](http://www.ons.gov.uk/ons/dcp171778_322713.pdf) (accessed October 2014)
- 3 NCCN. [http://www.nccn.org/patients/resources/life\\_with\\_cancer/managing\\_symptoms/support.aspx](http://www.nccn.org/patients/resources/life_with_cancer/managing_symptoms/support.aspx) (accessed Oct 2014).
- 4 Reeves P, et al. *How individuals coping with HIV/AIDS use the internet*. Health Education Research. 2001. USA.
- 5 Lieberman M et al. *Electronic support groups for breast carcinoma: a clinical trial of effectiveness*. 2003. USA.
- 6 Ziebland S et al. How the internet affects patients' experience of cancer: a qualitative study. *British Medical Journal*. 2004. UK.
- 7 CancerBACUP. *The cancer information maze. Report investigating information access for people with cancer*. 2005. UK.
- 8 Macmillan Cancer Support. *The Cost of Macmillan Services Factsheet 2013*. 2014.UK.
- 9 Macmillan Cancer Support. *Online community Dashboard Stats 2013*.UK.
- 10 Macmillan Cancer Support. *Online community team. Web Chat Statistics 2014*. UK.
- 11 Macmillan Cancer Support. *Online community Webchat Survey 2013*. UK.
- 12 Macmillan Cancer Support. *Brand awareness campaign report*. 2008. UK.
- 13 Manning, D, Dickens C. Health Literacy: more choice, but do cancer patients have the skills to decide. *European Journal of Cancer Care*. 2006. UK.
- 14 Barnard H, Stone V. *Review of Macmillan cancer information and support services*. 2003. BRMB qualitative.
- 15 Coulter, A. *The Autonomous Patient: Ending paternalism in medical care*. 2002. The Nuffield Trust.
- 16 Theodosio L ,et al. *Emerging challenges in using health information from the internet. Advances in Psychiatric Treatment*. 2003. UK
- 17 Gustafson D, et al, Effect of computer support on younger women with breast cancer. *Journal of general internal medicine*. 2001. USA.
- 18 Hoybye M, et al. Online interaction. Effects of storytelling in an internet breast cancer support group. *Psycho oncology*. 2005. Denmark
- 19 Hoey M, et al. *Systematic review of peer-support programs for people with cancer*. 2007. Patient education and counselling. Australia.
- 20 Ford G, et al. *Internet use and depression among the elderly. Phoenix Centre Policy Paper*. USA. 2009.
- 21 Manne S, et al. Are psychological interventions effective and accepted by cancer patients? *Behavioural medicine*. 2006. USA.