

**WE ARE
MACMILLAN.
CANCER SUPPORT**

**FACING
THE FIGHT
ALONE**

Isolation among cancer patients

February 2013

Foreword



How important is the support of family and friends in the fight against cancer? In 2006, a study by US epidemiologist Candyce Kroenke and her colleagues suggested that women who were most socially isolated before they were diagnosed with breast cancer were twice as likely to die from the disease as women with the strongest social networkⁱ.

In 2010 a small study led by researchers from the University of Southampton found that some lonely people diagnosed with colorectal cancer produce higher levels of a protein associated with cancer progressionⁱⁱ.

In 2012 research by another team of US scientists suggested that women with ovarian cancer who had the most supportive social relationships lived for at least a year longer on average than those without supportⁱⁱⁱ.

This evidence and more shows that isolation can have a real and negative impact on people living with cancer.

It is all the more concerning to learn that one in four people diagnosed with cancer in the UK will lack the support of family or friends during their treatment and recovery. The figure, revealed for the first time by a Macmillan Cancer Support survey^{iv}, means that more than 70,000 people diagnosed with cancer in the next year could face probably the toughest fight of their lives and face it without the support many of us take for granted.

Almost three in five people who lack support say it's because their family and friends are too busy to help or live too far away. Some have not been visited at home by family or a friend for at least six months.

More than half of those who are isolated have skipped meals or not eaten properly because of lack of support at home. More than one in six have not been able to collect a prescription for their medication and more than one in 10 have missed a hospital or GP appointment. The numbers go on and on.

At Macmillan Cancer Support, we believe no-one should face cancer alone. We understand that people deal with cancer in different ways, but for every person who copes better by themselves there will be many more who simply have no-one to turn to.

For the first time, we can see the true scale of isolation among cancer patients. We can offer a range of services that can help. One example is the Macmillan Support Line, which took over 132,000 calls in 2011. Another is our online community of 65,000 people.

Working together, our team at Macmillan will find better ways to help those in need. But we need everyone's support if we are to reach each person living with cancer. This new survey shows how much more there is to be done. Being diagnosed with cancer is bad enough. Facing it in isolation is worse.

A handwritten signature in dark green ink that reads "Ciarán Devane". The signature is fluid and cursive, with a long, sweeping tail on the final letter.

**Ciarán Devane, Chief Executive
at Macmillan Cancer Support**

Executive summary

Every day people affected by cancer share their experiences with the Macmillan team. From these conversations we hear first-hand how important it can be to have the support of family and friends in the fight against cancer.

And we also hear how hard it can be for people who feel isolated – whether that means receiving their cancer diagnosis on their own, having to cook their own meals after surgery or making their own way to hospital every day during radiotherapy. But despite this wealth of anecdotal evidence, we didn't know the full scale of the problem. To find out, we launched the first-ever research into the number and profile of isolated cancer patients in the UK. We surveyed more than 1,700 people living with cancer^{iv} and more than 150 healthcare professionals who treat cancer patients (GPs, oncologists and cancer clinical nurse specialists)^v about the amount of support patients receive during their treatment and recovery, and what effect this has on their physical and emotional wellbeing. The findings are summarised below:

- One in four people (23%) diagnosed with cancer in the UK will lack support from family or friends during their treatment and recovery – that represents more than 70,000 people each year^{vi}.
- More than half (53%) of healthcare professionals say patients have decided to skip treatment altogether because they have no support from family or friends.
- Almost three-fifths (58%) of those who lack support during their treatment and recovery say it's because their family and friends are too busy to help or live too far away.
- Women are twice as likely as men to say a lack of support has left them feeling isolated, although slightly more men than women experience a complete lack of support.
- For some, isolation is a direct result of their cancer diagnosis – just over one in six (18%) of those who lack support say they lost touch with family or friends because of their diagnosis, while four in five (80%) say the financial cost of cancer means they can't afford to see their family or friends as much.
- People living in London and the East of England are more likely to lack support than those in other regions of the UK.
- More than a third of healthcare professionals (37%) do not always ask if a patient has support from family or friends; this increases to almost half (47%) of GPs.

Macmillan Cancer Support is concerned about the detrimental effects of isolation on the health of people living with cancer:

- One in three people (33%) who have experienced isolation say a lack of support has caused them stress or anxiety.
- More than one in four (28%) say they have experienced depression.
- More than half (53%) have skipped meals or not eaten properly because of a lack of support at home.
- One in four (27%) have been unable to wash themselves properly, and three in five (60%) have been unable to do household jobs such as cleaning.

To improve the outlook for people diagnosed with cancer who lack support, Macmillan makes the following recommendations:

- For people living with cancer who lack support:
 - Recognise that isolation can have a real, negative impact on your health and wellbeing.
 - Be aware that there are alternative sources of support available, such as the Macmillan team, other registered cancer charities and social services.
 - Speak to the healthcare professionals involved with your care to make sure they acknowledge your lack of support and direct you to alternative sources of support.

– If you are not offered an alternative source of support, don't be afraid to ask your healthcare team what's available.

- For family and friends of those affected by cancer:
 - Be aware that talking to someone about their cancer or treatment is unlikely to increase their distress.
 - Make use of resources that can help you talk to loved ones affected by cancer, such as Macmillan's *How to talk to someone with cancer* booklet or call the Macmillan Support Line.
 - If you still find it too hard to talk to someone about their cancer, consider starting with practical ways that you could help them instead.
- For healthcare professionals treating people with cancer:
 - Recognise that isolation can have a real, negative impact on patients' health and wellbeing and how they engage with their treatment.
 - Always ask patients if they have support from family or friends.
 - Make allowances for patients who lack support wherever possible, such as being flexible with appointment times.
 - Be aware of all the alternative support available for isolated patients and make full use of these services wherever possible.

The extent of isolation among cancer patients

One in four (23%) of the 325,000 people diagnosed with cancer in the UK each year could lack the support^{vii} of family or friends during their treatment and recovery, according to a Macmillan Cancer Support survey of people living with cancer.

One in 14 people (7%) diagnosed with cancer – representing around 20,000 people in the UK each year – receive no help whatsoever, facing cancer completely alone. A further one in six (16%) only have support some of the time or occasionally.

Over 90 percent of healthcare professionals have treated cancer patients who do not have any support at all from family or friends. More than half (60%) have seen patients in this situation in the past month.

For some cancer survivors, the isolation goes beyond their initial treatment and recovery. One in six people (17%) who were diagnosed with cancer more than 10 years ago have not been visited at home by a friend or family member for at least six months.

Reasons for isolation

The majority of people who lacked support during their treatment and recovery (60%) told all or most of their family and friends about their diagnosis. Just 6% did not tell any friends or family.

Three in five (58%) say the reason they lacked support is because their family and friends were too busy to help or lived too far away. One in four (23%) say they did not want any support from family or friends in the first place. Some people may prefer to deal with their cancer in isolation – two in five (41%) of those who did not ask anyone else for help say they wanted to handle things on their own. However, just as many didn't know where to turn, thought that there was no-one who could help them or felt too tired or ill to do anything.

Feedback from survey respondents highlights a wide range of reasons why some people with cancer do not seek out help. Some are able to cope by themselves because their cancer treatment is relatively mild. "At the time I didn't really need any support," said one 65-year-old man. "I didn't have treatment other than surgery and tablets, [so] no need for a lot of support," said a 63-year-old woman.

Others, however, may be in more need of help than they realise. “I just thought I was coping,” said one 49-year-old woman. “[I was] too proud to ask,” said a 52-year-old man. And other survey respondents simply did not have the support they needed. “[My family and friends] were frightened of my illness,” said a 53-year-old woman.

More than two-thirds (68%) of people lacking support say they would have found support from family and friends helpful.

A third of healthcare professionals (37%) do not always ask if a patient has support from family or friends; this increases to almost half (47%) of GPs.

Around one in six (18%) people who lack support say they lost contact with family and friends as a result of their diagnosis. The same number have been unable to look after their children or grandchildren because of a lack of support.

Worryingly, the financial cost of cancer makes isolation worse – four in five (80%) cancer patients who lack support say they can’t afford to see their family or friends as much as they did before they were diagnosed.

‘Living alone, I had nobody to support me while I was having my radiotherapy. I didn’t have the energy to do anything at home, so I just lived on ready-made meals. There were times when I was going to bed having had nothing more than a glass of milk and a biscuit because I was too exhausted to cook anything else.’

Lis, aged 66, from Surrey

Differences between men and women

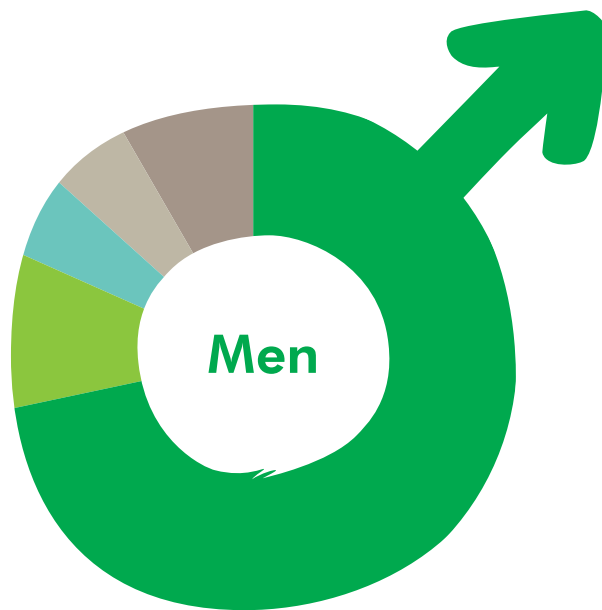
Overall, women are more likely to be isolated than men. Almost three-quarters of men with cancer say they are fully supported during their treatment and recovery, compared with only just over half of women (71% compared with 53%). Women are twice as likely as men to say that a lack of support has left them feeling isolated, lonely or abandoned (47% compared with 23%).

However, slightly more men than women are completely isolated (8% compared with 6%). Men are also more likely than women to be told they have cancer without having any family or friends with them – only one in five men (22%) have a loved one present when they hear their diagnosis, compared with almost two in five women (37%). Almost half of women who received their diagnosis alone would have preferred to have someone with them, compared with just 15% of men.

Of people who lack support, women are more likely than men to say they would have found more support helpful – 77% of women would have preferred more support from family, compared with 60% of men, and 79% would have preferred more support from friends, compared with 55% of men.

The gender divide

How often people had support from family and friends during their treatment and recovery



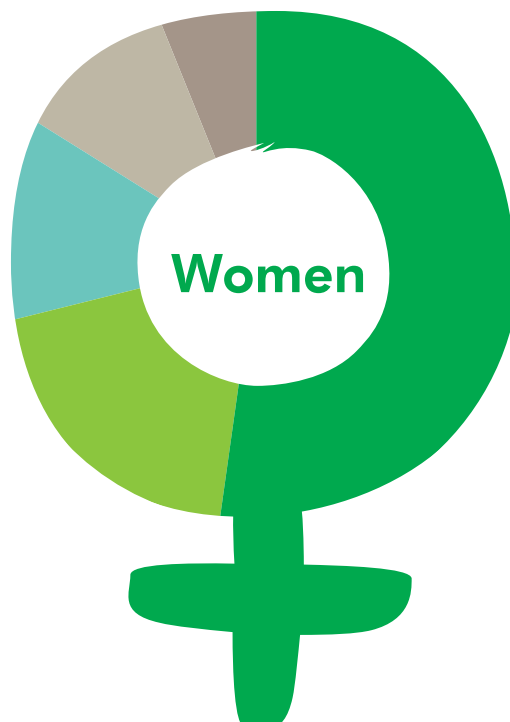
All of the time
71%

Most of the time
10%

Some of the time
5%

Occasionally
5%

Never
8%



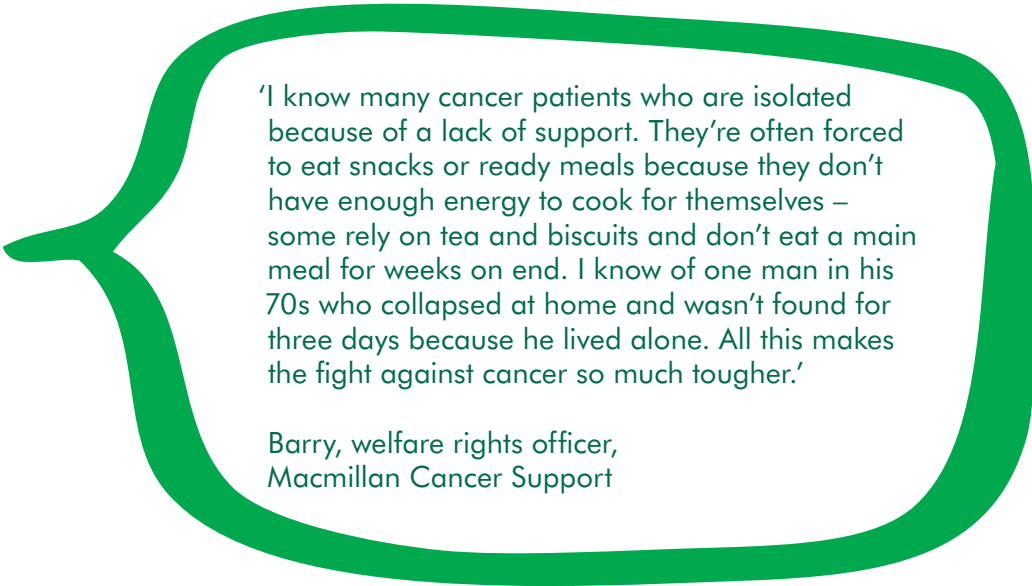
All of the time
53%

Most of the time
19%

Some of the time
13%

Occasionally
10%

Never
6%



'I know many cancer patients who are isolated because of a lack of support. They're often forced to eat snacks or ready meals because they don't have enough energy to cook for themselves – some rely on tea and biscuits and don't eat a main meal for weeks on end. I know of one man in his 70s who collapsed at home and wasn't found for three days because he lived alone. All this makes the fight against cancer so much tougher.'

Barry, welfare rights officer,
Macmillan Cancer Support

The role of age and wealth

People with cancer aged between 35 and 55 are least likely to have support at all times – fewer than half (48%) say they are fully supported during their treatment and recovery, compared with two-thirds (66%) of those aged 55 or over.

Compared with those in higher socioeconomic groups, people in lower socioeconomic groups have slightly lower overall levels of support, are more likely to feel stressed or anxious because of a lack of support (41% of those in the C2DE group compared with 28% of those in the ABC1 group) and are more likely to have not been in touch with their family and friends before their diagnosis (9% compared with 3%).

Regional variations

Cancer patients in London and the East of England are the most isolated in the country. People living with cancer in these regions are more likely to lack support from family and friends than those in the North, Midlands or South of England. Only 54% of Londoners say they are fully supported during their treatment and recovery, compared with 68% of those in the Midlands. And one in eight (12%) of those in London are facing cancer completely alone – three times the proportion in Scotland (4%) and double the proportion in the North and South of England (6%).

Londoners are also more likely to reject support from their family and friends – 29% of those living in the capital who lacked support said the reason was that they didn't want any, compared with just 16% in the rest of the South of England.

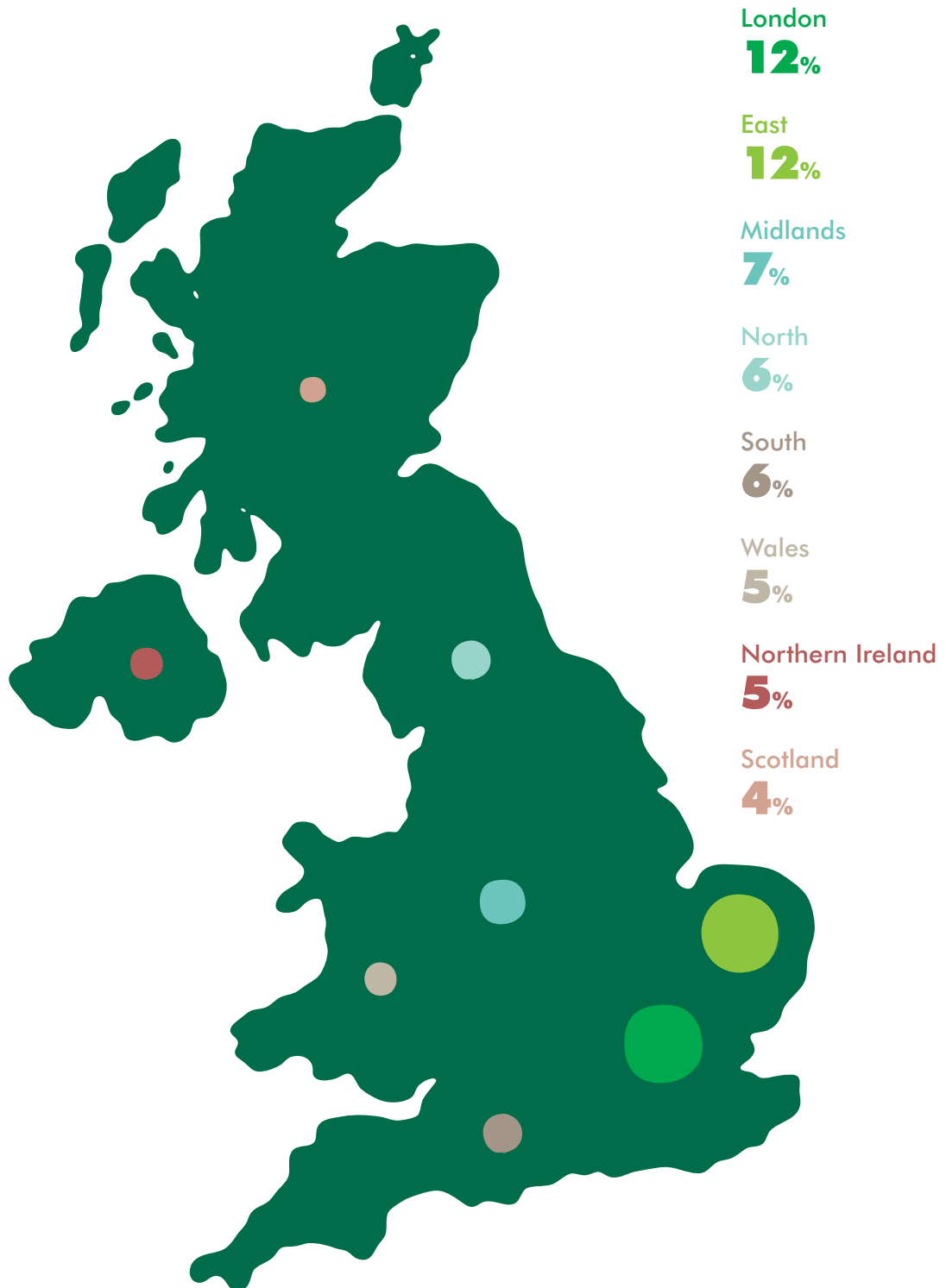


'One in three of our local population lives alone without family within one hour of travel. This places a great burden on patients and clearly influences their [treatment] decisions.'

Survey response from healthcare professional

All the lonely people

The proportion of people in UK who are completely isolated during their cancer treatment and recovery



Impact of isolation on health

More than half (53%) of isolated cancer patients have skipped meals or not eaten properly because of a lack of support at home, with one in three (33%) often or sometimes not getting enough to eat. Among women, this rises to almost one in two (45%). Four percent are concerned they are malnourished because of a lack of support, and three-quarters (75%) have cut back on what they spend on food.

One in four (27%) of those experiencing isolation are not always able to wash themselves properly, and three in five (60%) have been unable to do household jobs such as cleaning. One in four (26%) say they have not been able to exercise^{viii} because of a lack of support; among women, this rises to one in three (33%). A third (33%) say a lack of support has caused them stress or anxiety, and more than one in four (28%) say they have experienced depression.

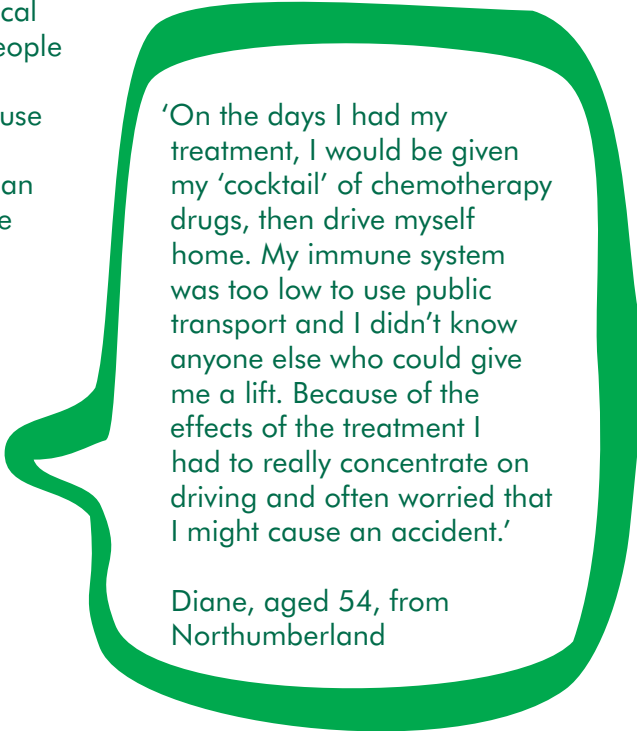
Isolation also makes it harder for people to self-manage their medical care. One in ten (11%) isolated people living with cancer have missed a hospital or GP appointment because of a lack of support, with women affected more than men. More than one in six (18%) have been unable to collect a prescription for their medication; among women this rises to one in four (24%).

Almost half (49%) of healthcare professionals say isolated cancer patients really struggle to get to and from hospital^{ix} – more than four times as many that think non-isolated patients really struggle with this (12%). In addition, more than half of healthcare professionals:

- have seen patients who decided to skip treatment altogether because they have no support from family or friends
- say isolated patients make poorer treatment decisions.

Over 90% of healthcare professionals have patients who they think struggle with the emotional impact of cancer because of a lack of support, with almost a third (30%) saying this is often the case.

Some cancer patients are even forced to take risks with their personal safety because of a lack of support.



'On the days I had my treatment, I would be given my 'cocktail' of chemotherapy drugs, then drive myself home. My immune system was too low to use public transport and I didn't know anyone else who could give me a lift. Because of the effects of the treatment I had to really concentrate on driving and often worried that I might cause an accident.'

Diane, aged 54, from Northumberland

Conclusion and recommendations

Our survey reveals for the first time a comprehensive picture of isolation among people living with cancer in the UK. One in four people diagnosed with cancer will lack the support of family or friends during their treatment and recovery, and more than half of healthcare professionals treating people with cancer have seen patients with no support at all within the past month.

Isolation is having a real, negative impact on people's health: patients are skipping meals, missing medical appointments and even deciding to reject treatment altogether and let their cancer run its course – all because of a lack of support.

We know that many people go the extra mile to support a family member or friend who has cancer. The Macmillan team helps support thousands of cancer patients and their carers each year, through services such as the Macmillan Support Line, our website and online community, support groups and the Connecting Communities pilot programme.

We also know it can be difficult for patients and their loved ones to talk about cancer, and that the amount of support that people with cancer need will vary from individual to individual. But as our survey shows, each year tens of thousands of people diagnosed with cancer do not get as much support as they need: this must change. No-one should face cancer alone.

To improve the outlook for people diagnosed with cancer who lack support, Macmillan makes the following recommendations:

- For people affected by cancer who lack support:
 - Recognise that isolation can have a real, negative impact on your health and wellbeing.
 - Be aware that there are alternative sources of support available, such as the Macmillan team, other registered cancer charities and social services.
 - Speak to the healthcare professionals involved with your care to make sure they acknowledge your lack of support and direct you to alternative sources of support.
 - If you are not offered an alternative source of support, don't be afraid to ask your healthcare team what's available.

- For family and friends of those affected by cancer:
 - Be aware that talking to someone about their cancer or treatment is unlikely to increase their distress.
 - Make use of resources that can help you talk to loved ones affected by cancer, such as Macmillan’s *How to talk to someone with cancer* booklet or call the Macmillan Support Line.
 - If you still find it too hard to talk to someone about their cancer, consider starting with practical ways that you could help them instead.
- For healthcare professionals treating people with cancer:
 - Recognise that isolation can have a real, negative impact on patients’ health and wellbeing and how they engage with their treatment.
 - Always ask patients if they have support from family or friends.
 - Make allowances for patients who lack support wherever possible.
 - Be aware of all the alternative support available for isolated patients and make full use of these services wherever possible.

As well as the Macmillan Support Line, our website and our healthcare professionals, here are just some of the other ways that the Macmillan team help people living with cancer who lack support:

- We have more than 100 information and support centres across the UK that offer face-to-face support and signposting.
- Our welfare benefits advisors can help people navigate the benefits system and break down the isolation caused by financial worries.
- Thanks to our new partnership with Boots, there are more than |600 Macmillan-trained pharmacists on the high street who can offer advice and direct people to other local sources of support.
- Macmillan supports over 900 independent cancer support groups and organisations across the UK, giving people living with cancer the opportunity to talk to people who understand what they’re going through.

References

- ⁱ Kroenke C H et al. Social Networks, Social Support, and Survival after Breast Cancer Diagnosis. *Journal of Clinical Oncology*. 2006. 24(7): 1105–1111. <http://jco.ascopubs.org/content/24/7/1105.full>
- ⁱⁱ Nausheen B et al. Relationship Between Loneliness and Proangiogenic Cytokines in Newly Diagnosed Tumors of Colon and Rectum. *Psychosomatic Medicine*. 2011. 72(9): 912–916. <http://www.psychosomaticmedicine.org/content/72/9/912.abstract>
- ⁱⁱⁱ Lutgendorf S K et al. Social Influences on Clinical Outcomes of Patients with Ovarian Cancer. *Journal of Clinical Oncology*. 2012. 30(23): 2885–2890. <http://jco.ascopubs.org/content/30/23/2885.full>
- ^{iv} Macmillan Cancer Support/YouGov online survey of 1,794 people living with cancer in the UK. 437 respondents were identified as isolated (i.e. received no support from friends or family during treatment or recovery, or only received support some of the time/occasionally) and completed a follow-up interview. Fieldwork conducted 10–20 July 2012, with additional fieldwork conducted in Northern Ireland 26 November–13 December 2012. Survey results are unweighted.
- ^v Macmillan Cancer Support/ICM online survey of 155 UK health professionals who treat people living with cancer (55 GPs, 50 oncologists, and 50 cancer clinical nurse specialists). Fieldwork conducted September 2012. Survey results are unweighted.
- ^{vi} This estimate represents 23% of the 325,000 people diagnosed with cancer each year in the UK. The 23% comes from Macmillan research and represents the proportion of people living with cancer who say they received no support from friends or family during treatment or recovery, or only received support some of the time/occasionally. Latest UK cancer incidence figures (2010) are sourced from: Office for National Statistics; Information Services Division (ISD) Scotland; Welsh Cancer Intelligence & Surveillance Unit; Northern Ireland Cancer Registry. This estimate assumes that everyone who receives a cancer diagnosis receives cancer treatment, and that only people newly diagnosed with cancer are at risk.
- ^{vii} Defined as having no support at home from family/friends throughout treatment and recovery, or only some of the time/occasionally
- ^{viii} Defined as not getting out and about/not being active
- ^{ix} Defined as health professionals saying that patients are likely to struggle ‘a great deal’

Cancer is the toughest fight most of us will ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The campaigners improving cancer care. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

Our cancer support specialists, benefits advisers and cancer nurses are available to answer any questions people affected by cancer might have through our free Macmillan Support Line on **0808 808 00 00** Monday to Friday, 9am to 8pm.

Alternatively, visit **macmillan.org.uk**
Hard of hearing? Use textphone **0808 808 0121**, or Text Relay.
Non-English speaker? Interpreters available.

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