

Ymchwiliad i unigrwydd ac unigedd

Inquiry into loneliness and isolation

Ymateb gan: Macmillan Cymorth Canser

Response from: Macmillan Cancer Support



## Inquiry into Loneliness and Isolation

The Response of Macmillan Cancer Support to the Health, Social Care and Sport Committee's Consultation

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### 1. Introduction

- 1.1 Macmillan Cancer Support welcomes this opportunity to contribute to the inquiry into Loneliness and Isolation
- 1.2 In Wales, 19,000 (WCISU Feb 2015) people are diagnosed with cancer every year and more than 130,000 people are currently living with or beyond cancer, almost 4.5 percent of the population. By 2030 it is expected that 250,000, almost eight percent of the Welsh population, will have been affected by a cancer diagnosis and one in two of us will be affected by cancer at some point in our lives.
- 1.3 The good news is that survival rates are steadily improving and many people recover. On average 70 percent<sup>1</sup> of Welsh residents diagnosed with cancer can expect to survive at least one year. However, despite this positive news we find that loneliness and isolation are unwelcome experiences of too many people living with cancer.
- 1.4 From our own research into the subject, a first for people with cancer. A significant proportion of people diagnosed with the disease in the UK, one in four<sup>2</sup>, will lack the basic support of family and friends during their treatment and recovery. They face loneliness and isolation during the toughest fight of their lives.
- 1.5 A more recent Macmillan/YouGov survey found that 12% of people with cancer in Wales – an estimated 15,000 people have no close friends to talk to about their cancer<sup>3</sup>.
- 1.6 At Macmillan Cancer Support we believe no-one should face cancer alone. We understand that people choose to deal with cancer in different ways, but for those who can manage by

<sup>1</sup> Welsh Cancer Intelligence and Surveillance Unit Official Statistics 2012 data. [Published 10 April 2014](#)

<sup>2</sup> Macmillan Cancer Support. (2013) "Facing the Fight Alone: Isolation among cancer patients." p6 [http://www.macmillan.org.uk/documents/aboutus/mac13970\\_isolated\\_cancer\\_patients\\_media\\_reportfinal.pdf](http://www.macmillan.org.uk/documents/aboutus/mac13970_isolated_cancer_patients_media_reportfinal.pdf)

<sup>3</sup> Macmillan Cancer Support. (2017) [Press release: Hundreds of thousands of people with cancer have no close friends to talk to](#)

themselves there will be many more people with cancer who simply have no-one to turn to. Being diagnosed with cancer is bad enough; facing it in isolation is worse.

## 2. Isolation, Loneliness and People Living with Cancer

- 2.1 Macmillan's UK-wide research on isolation<sup>4</sup>, published in 2013, sought to capture and appraise the scale of isolation among cancer patients. Doing so allowed us to better understand issues around isolation and shape as suite of recommendations to support those in need.
- 2.2 For Macmillan isolation has two main dimensions; first there's emotional isolation, the feeling of loneliness and being alone. Secondly there's physical isolation, being cut off from services and people, or not being able to do things that a person used to do pre-diagnosis.
- 2.3 We were able to draw a range of findings from the first-ever research into the number and profile of people with cancer in the UK. 1,700 people and 150 healthcare professionals were surveyed about the amount of support patients receive during their treatment and recovery, and what effect this has on their physical and emotional well-being.
- 2.4 **While we knew that isolation and loneliness was faced by cancer patients the scale of the problem is striking.** One in four people we surveyed reported a lack of support from family and friends during their treatment and recovery. One in fourteen people (representing 7% of people with cancer) received no help whatsoever, facing cancer completely alone. There is slight regional variation – offering contrasts, perhaps, between urban and rural regions. 12% of Londoners with cancer reported complete isolation, while the figure drops to 5% in Wales<sup>5</sup>.
- 2.5 We also found that we could categorise isolation in a range of ways. We identified five categories of isolation, and identified further issues within each category, and the groups of people with cancer most commonly affected. The five categories of isolation<sup>6</sup> are:

Category of isolation	Isolation issues	Which groups may be particularly affected?
<b>Emotional isolation</b>	Low self-esteem caused by <b>change of appearance</b> as a result of cancer Low sex drive or <b>lack of intimacy</b> creating a barrier between partners <b>Lack of family and friends</b> to support <b>Depression and anxiety</b> caused by cancer, its treatment and other long-term effects Depression and loneliness caused by <b>bereavement</b> due to the death of someone with cancer	People with some head and neck cancers People who have had a mastectomy People with lymphoedema People who have had treatment to the pelvic area People in treatment phase and directly post treatment The bereaved/widowed
<b>Financial isolation</b>	<b>Can't afford to do social activities</b> or holidays <b>Can't afford to pay for transport</b> to and from activities/treatment or <b>can't afford to buy mobility aids</b> to get out and about	People of working age People with dependents (children and elderly parents) People with complex financial situations (mortgages, pensions, insurance)

<sup>4</sup> Macmillan Cancer Support. (2013) "Facing the Fight Alone: Isolation among cancer patients."

<sup>5</sup> Ibid p9-10

<sup>6</sup> Macmillan Cancer Support (2013) "Isolation amongst people affected by cancer – a dossier of evidence on issues and solutions" Powerpoint presentation. Macmillan Cancer Support: London. slides 9 and 10.

	<b>Carer can't afford cover</b> to allow them to go out (respite care)	People on low fixed incomes
<b>Physical/practical isolation</b>	<b>Limited or no means of transport or lack of mobility aids or rural isolation</b> <b>Carer needed for practical support</b> (carer is isolated) <b>Feeling ill</b> as a result of chemo/radiotherapy <b>Cancer-related fatigue</b> <b>Long-term side effects</b> stopping patient from doing 'normal' things (e.g. colostomy bag) <b>Dying alone</b>	Those in rural locations The vulnerable elderly Those in lower socioeconomic groups Those actively going through treatment Those with debilitating long-term side effects (e.g. from bowel cancer) Those in care homes
<b>Information-related isolation</b>	<b>Peers/carers/families don't understand so don't know what the patient is going through</b> <b>Lack of information for making the patient feel like no one else is going through the same thing ("going through it alone")</b> <b>Lack of out of hours services</b>	<b>Children with cancer</b> <b>People with rarer cancers</b> <b>People with learning disabilities</b> <b>People at transition points of care</b>
<b>Cultural &amp; spiritual isolation</b>	Isolation caused by <b>language barriers</b> <b>Stigma and taboo</b> discussing cancer for certain religions/ethnic groups	Minority ethnic groups where English/Welsh is not first language People with sensory disabilities – eg deaf and hard of hearing, blind and partially sighted, etc

- 2.6 Three in five people (58%) said that the reason they lacked family and friend support was that they were too busy to help or lived too far away. Two in five people (41%) of people said that they preferred to deal with their cancer on their own (the cancer may have been relatively mild) and did not want any support in the first place. However, a similar number said they did not know where to turn, thought there was no-one who could help them or felt too tired of ill to do anything to support themselves<sup>7</sup>.
- 2.7 A third of healthcare professionals did not always ask if a patient has support from family or friends, this increased to almost a half of GPs<sup>8</sup>.
- 2.8 We found that overall women were more likely to be isolated than men<sup>9</sup> and cancer patients aged between 35 and 55 were least likely to have support at all times. Fewer than half of these patients said they were fully supported during treatment and recovery, compared to two-thirds of those aged 55 or over<sup>10</sup>.
- 2.8 The negative effects of isolation on cancer patients are very concerning. People skip meals and fail to eat properly at home; some are unable to wash themselves properly, and do

<sup>7</sup> Ibid p6

<sup>8</sup> Ibid p7

<sup>9</sup> Ibid p7

<sup>10</sup> Ibid p9

household jobs such as cleaning. Isolation also contributes to people living with cancer not being physically active and contributes to mental illness<sup>11</sup>.

2.9 Almost half of healthcare professionals made a link between isolated cancer patients and a real struggle to get to and from hospital, worryingly affecting the outcomes of treatment. More than half of healthcare professionals say that isolated cancer patients make poorer treatment decisions, even choosing to skip treatment altogether<sup>12</sup>.

2.10 Our research also identified clinical studies that link isolation with negative clinical outcomes in specific forms of cancer - notably breast<sup>13</sup>; colorectal<sup>14</sup>; and ovarian<sup>15</sup>.

2.11 We continue to monitor and survey the cancer patient experience to identify isolation and loneliness; it continues to inform Macmillan's "Not Alone" campaign<sup>16</sup>. Isolation remains an unfortunate feature. Our 2016 Macmillan/YouGov survey found that 12% of people with cancer in Wales – an estimated 15,000 people have no close friends to talk to about their cancer.<sup>17</sup>.

### 3. Reducing Isolation Amongst People Living with Cancer

3.1 On the back of its 2013 research Macmillan made a number of recommendations to improve the outcomes of isolated cancer patients. These were directed at the key agents for change, notably the cancer patient; friends and family; and healthcare professionals.

3.2 First, our recommendations acknowledge that patients have a role in helping themselves become less isolated. Recognising that isolation can have a real and negative impact on personal health and well-being is an initial step to speaking to healthcare professionals and need being recorded. Patients may end up being signposted or supported to overcome isolation, whether via services provided Macmillan; social services or other registered charities<sup>18</sup>.

3.3 Second, we recommend that friends and family of those living with cancer continue to talk to cancer patients about their condition or treatment since it's unlikely to increase their distress. We also suggest that friends and family make themselves acquainted with the materials - available online and elsewhere - that can help with and inform conversations. Finally, if people find conversation too hard we also recommend friends and family find other ways to remain close, through other forms of practical help

3.4 We finally recommended that the third group, healthcare professionals, are made aware of the impact of isolation on the general health and well-being of cancer patients, and that allowances are made for people who happen to lack support. Greater awareness of alternative forms of support would also mean that patients can be signposted, and make full use of, other suitable services should the need be identified<sup>19</sup>.

3.5 The Recovery Package, which was led by Macmillan, is a series of key interventions which, when delivered together can greatly improve outcomes for people living with and beyond cancer.

<sup>11</sup> Ibid p11

<sup>12</sup> Ibid p11

<sup>13</sup> 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>

<sup>14</sup> ji 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>

<sup>15</sup> 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>

<sup>16</sup> Macmillan Cancer Support. (2017) <http://www.macmillan.org.uk/about-us/what-we-do/our-ambition/not-alone-campaign.html>

<sup>17</sup> Macmillan Cancer Support. (2017) [Press release: Hundreds of thousands of people with cancer have no close friends to talk to](#)

<sup>18</sup> Macmillan Cancer Support. (2013) "Facing the Fight Alone: Isolation among cancer patients." p12

<sup>19</sup> Ibid p13

- 3.6 The recovery package is made up of the following elements
- A Holistic Needs Assessment (HNS) which results in a written plan at key points of the care pathway
  - A treatment summary completed at the end of each acute treatment phase and sent to the GP
  - A cancer care review to discuss the patients' needs
  - Access to an education and support event focussed on health and wellbeing to prepare a person for the transition to supported self-management.
- 3.6 These key interventions provide opportunities for the healthcare professional/key worker to identify isolation and loneliness and co-produce appropriate support that meets the needs of the cancer patient. We welcome the reference to the Macmillan Recovery Package within the Cancer Delivery Plan<sup>20</sup> and look forward to working with the Wales Cancer Network to deliver consistent application across Wales.
- 3.7 As the source of cancer policy direction in Wales the recently refreshed Cancer Delivery Plan can be commended for continuing to place the delivery of more patient-centred care at its core<sup>21</sup>. While isolation is not explicitly referred to in the plan, isolation will be tackled through the consistent delivery of key actions, including; access to welfare benefits advice; a common Macmillan recovery package; providing services as locally as feasible<sup>22</sup>; allocation of a named key worker; and supporting people at the end of their treatment, when they leave the acute phase – thereby avoiding people feeling unsupported and isolated<sup>23</sup>. Macmillan supports these key actions and is committed to supporting their implementation across Wales.

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For any further information regarding this response, please contact Greg Pycroft, Policy Officer, Wales – [REDACTED] or [REDACTED].

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<sup>20</sup> Welsh Government (2016) "Cancer Delivery Plan for Wales 2016-2020: The highest standard of care for everyone with cancer". p14 <http://gov.wales/docs/dhss/publications/161114cancerplanen.pdf>

<sup>21</sup> Ibid p3

<sup>22</sup> Ibid p14

<sup>23</sup> Ibid p13