

The Utility Regulator's Social Action Plan Consultation - Macmillan Cancer Support response

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Key points

- Many people with cancer in Northern Ireland are struggling with fuel poverty. Cancer patients have increased energy costs at a time when their income has often fallen
- In Northern Ireland, 85% of the people who received financial help from Macmillan in 2008 asked for assistance with fuel costs. This is significantly higher than other parts of the UK (the figure is 42% for the UK as a whole)
- Macmillan Cancer Support is concerned that there is little awareness that people with cancer meet the vulnerable customer definition
- Self-disconnection may occur when a customer is too ill to top-up and may also prevent customers from switching payment types
- People with cancer are not aware of the help available and more should be done by the energy suppliers to promote help available. People with cancer should also be given financial information routinely as they move through their cancer journey
- Macmillan would welcome the introduction of a harmonized approach to debt management - such an approach should include training or awareness raising for suppliers and their employees on dealing with customers who are struggling because of a cancer diagnosis
- Macmillan would support the introduction of a social tariff offering a discounted rate for those vulnerable customers in fuel poverty.

Background

Macmillan Cancer Support welcomes the opportunity to respond to this consultation. We improve the lives of people affected by cancer, providing practical, medical, emotional and financial support. We work to raise awareness of cancer issues and have been campaigning for a better financial deal for cancer patients, who as a result of their condition face a number of increased costs at a time when their income has often decreased.

Consultation questions

Question 1: Respondents are asked to comment on the impact of this paper with regard to equality of opportunity and good relations.

No comment

Question 2: Respondents are asked for their views as to whether we have considered all the characteristics that may contribute to or intensify vulnerability.

Macmillan believes that the regulator has considered all the characteristics that may contribute to or intensify vulnerability. However, we would highlight that while cancer is classified as a disability under the Disability Discrimination Act (DDA) and is also viewed increasingly in the medical world as a chronic illness; many are unaware of this and we therefore fear that people with cancer may be missing out on help directed at vulnerable customers. For example research by Cancerbackup found that only 20% of employers were aware that cancer was covered by the DDA¹.

Every year around 9,300 people in Northern Ireland are diagnosed with cancer and more than 3,700 die of the disease². However, survival rates are improving and there are currently 55,000 people living with or beyond cancer in Northern Ireland³.

As a result of their condition, cancer patients face a number of increased costs at a time when their income has often decreased. Macmillan research found that among working age cancer patients (under 55s) seven out of ten suffer a reduced household income, losing on average 50%⁴. It is estimated that around 4 in 10 cancer patients of working age do not return to work after treatment⁵. Higher utility bills are one of the major additional costs which cancer patients face⁶.

There may be several reasons why a cancer patient faces increased energy costs. Many cancer patients spend longer periods of time at home in order to recuperate during treatment; are unable to engage in hypothermia prevention measures such as keeping active⁷ and there is evidence to suggest that they feel the cold more⁸. The majority of cancer patients are also elderly (three out of four people diagnosed with cancer are aged over 60) and so are more likely to be suffering the effects of fuel poverty. In a Macmillan online survey of people with cancer, three quarters of those who said they were using more fuel since their diagnosis said this was because they felt the cold more⁹. This means that cancer patients have increased energy needs throughout the year tied into their illness and treatment cycles. In a recent online survey of people living with cancer, Macmillan found that, of those who were struggling financially, two thirds were struggling to cope with energy bills since their cancer diagnosis¹⁰.

¹ Cancerbackup, CIPD, *Working with Cancer: Survey Report 2006*, 2006

² Northern Ireland Cancer Registry

³ King's College London, Macmillan Cancer Support and National Cancer Intelligence Network, *Cancer Prevalence in the UK, 2008*, 2008

⁴ Macmillan Cancer Support, *Cancer Costs*, June 2006

⁵ Spelten E, Sprangers M, Verbeek J, *Factors reported to influence the return to work of cancer survivors: a literature review*, *Psycho-Oncology* 11: 124-131 (2002)

⁶ Macmillan Cancer Support, *Cancer Costs*, June 2006

⁷ Rising fuel bills could mean more die of cancer, *The Press and Journal*, 14 October 2008

⁸ *Shivering in acutely ill vulnerable populations*, Holtzclaw, *AACN Clinical Issues*, Volume 15, No. 2, pp267-279

⁹ http://www.npower.com/health_through_warmth/about_htw/Health_impacts/index.htm

⁹ Macmillan Cancer Support online survey of people with cancer, October 2008

¹⁰ Macmillan Cancer Support online survey of people with cancer, October 2008

People living with cancer in Northern Ireland already face additional hardship compared to those living in other parts of the UK. A vast number of the population live in rural locations which means travelling to and from treatment creates a financial burden as well as an often physical one. The average weekly income is lower in Northern Ireland than the rest of the UK and yet the colder climate, poor housing stock and monopoly providers mean average fuel costs are higher. The majority of households are not connected to the gas network so use oil or solid fuel to heat their homes which can be more expensive. Rising fuel costs and the turndown in the economy are intensifying the problem.

Macmillan operates a hardship grant providing financial assistance to those patients in need. In Northern Ireland, 85% of the people who received financial help from Macmillan in 2008 asked for assistance with fuel costs. In 2008 we helped 1,247 people in Northern Ireland with fuel bills and gave £345,116. This is significantly higher than other parts of the UK (the figure is 42% for the UK as a whole). The amount of money Macmillan gave to help with fuel costs in Northern Ireland increased by 15% from 2007.

Questions 3: Respondents are asked to what extent they believe critical care provision could be improved. In particular respondents are asked to what extent similar emergency provisions in the event of a disruption to supply are required for gas. In responding, it would be useful if specific improvements could be detailed and in particular details of medical conditions or life saving medical equipment that require a constant supply of gas could be given.

The main problems that would potentially occur if a person with cancer found their electricity supply cut off are related to the electrical equipment that is sometimes used to support ill people at home. For example Oxygen equipment, suction machines, nebulizer equipment, electric pressure relieving mattresses/adjustable beds, stair lifts/rails and food blenders for people who may have difficulty swallowing. Keeping a seriously ill person warm and therefore comfortable is also essential and depending on the household's heating setup requires a continuous supply of gas, electricity, oil or solid fuel.

Question 4: Respondents are asked to comment on whether they believe all customers have sufficient access to different payment methods offered by the utility suppliers. Respondents should list the barriers they perceive as preventing some vulnerable customers from accessing all payment methods.

As the regulator highlights there is lack of awareness about the energy industry among consumers. This is acting as a barrier to customers accessing other payment types – customers may not be aware that they can pay by another method or the advantages of doing so. The industry can also appear complicated - some people with cancer have told us that they are confused by the language used by energy suppliers. For example they are not familiar with phrases such as 'crediting an account' or 'placing a hold on an account'. Energy companies should practice plain-speaking in all forms of communication including letters, call centre

staff and salespeople. Macmillan believes that energy suppliers should simplify their information and provide it in a range of languages.

In addition changing payment type or tariff can be confusing and time-consuming. This can be particularly unappealing or unachievable for someone who is unwell.

There are also a considerable number of people living in Northern Ireland who do not have access to a bank account. These customers are penalised as they are unable to benefit from the discounts available to those who pay by direct debit. As it is often the more vulnerable customers who do not have a bank account, perhaps because of bad credit, this is effectively penalising those most at need.

Question 5: Respondents are asked to consider what measures, if any, need to be taken to ensure that pre-payment customers benefit equally from the introduction of retail competition in Northern Ireland.

Customers should not be forced onto pre-payment meters when they find themselves in debt. While pre-payment meters may help some customers to budget, for others it may not be suitable. For example a cancer patient who is unwell may find it inconvenient or even impossible to regularly top-up. Those in hardship may self-disconnect. Macmillan believes that a range of debt management options should be explored with customers and the most appropriate applied.

Macmillan would be disappointed if the introduction of retail competition in Northern Ireland led to a premium added on pre-payment or standard credit tariffs.

The utility companies often use pre-payment meters to reclaim debt. Sometimes the rate of repayment is excessively high (for example a customer may buy £10 of credit but £7 of this will be used to pay back the debt accumulated). For vulnerable customers, particularly those who may rely on heating and electricity for their well-being, this is an unmanageable burden. Macmillan recommends that the regulator introduces a limit on the ratio of debt to credit the supplier can impose, in particular for vulnerable customers such as those with cancer.

Question 6 Respondents are asked to comment on the merits of a harmonized approach in relation to helping vulnerable customers to avoid debt and to manage their way out of debt.

Macmillan would welcome the introduction of a harmonized approach to debt management. We believe this would help to simplify the system for suppliers and the regulator as well as those supporting or advising vulnerable customers such as benefits advisers. We suggest that such an approach should include training or awareness raising for suppliers and their employees on dealing with customers who are struggling because of a cancer diagnosis and its implications specifically around disconnection.

Question 7 The Utility Regulator acknowledges the concerns of stakeholders around self-disconnections. Respondents are asked to

comment on what should be done to prevent vulnerable customers self-disconnecting for reasons of financial hardship.

Macmillan stresses that self-disconnection may also be due to the customer being physically too ill to top up. Cancer patients can be confined to bed for long periods of time and those undergoing chemotherapy can suffer nausea, fatigue and debilitation. For those living alone it simply may not be possible to top up and they may have nobody who can do this on their behalf. A carer tending a terminally ill or elderly relative can find all their time is dedicated to this and again topping up may not be a priority. In addition a pre-payment meter takes a certain amount of management and planning which can be stressful for somebody who is unwell. Those who are especially ill may not have the awareness to manage a pre-payment meter.

Macmillan would recommend improving the information given to customers about help with financial worry as a key contribution to preventing self-disconnection. Specific action to raise awareness such as the Payment Awareness Campaign, managed by NEA and the NI Energy Advice Centre, could also help people to help themselves or access the support they need (see question 8).

Additionally, Macmillan would support the introduction of a social tariff offering a discounted rate for those vulnerable customers in fuel poverty. We welcome the regulator's study into the feasibility of introducing this but would not support a rising block element to any potential social tariff.

Improving the energy efficiency of a home can help to reduce bills and therefore financial hardship and the possibility of self-disconnection. However, Macmillan Cancer Support has concerns with the Warm Homes Scheme. Firstly, the grant does not always cover the full cost of the work needed. Some cancer patients are applying for additional grants from Macmillan in order to pay the shortfall. In some cases Macmillan has arranged for a local contractor to complete the work as this has proved cheaper than making up the deficit. Macmillan is concerned that many other cancer patients cannot afford to proceed with the work. Secondly, Macmillan is concerned that not all cancer patients in need are able to benefit from the Warm Homes Scheme. Those with a disability or long-term illness qualify for the scheme if they receive Disability Living Allowance or an income-related benefit with the disability premium. Many cancer patients struggle to access these benefits because they are not told they are eligible or because the unpredictable nature of their disease makes it difficult for them to meet the qualifying criteria. The third main issue is the time limited nature of the grant. This is creating particular problems for some cancer patients who have been unable to proceed before the expiry date because of the onset of illness. These people have decided they cannot face going through the full application process again and as a consequence have decided not to proceed with the work.

Question 8 Respondents are asked to comment on what measures should be undertaken to raise awareness, and which organisation(s) should take the lead on these measures.

The majority of people with cancer aren't told about the financial assistance to which they are entitled. Raising this awareness is an important step in removing hardship. Providing people with cancer with information should be seen as integral to their care and will need to be available throughout their cancer journey. Macmillan is recommending that access to benefits be included in the Cancer Service Framework due to be published for consultation later this year by the DHSSPS. We also welcome other action to increase this awareness, for example the NIE benefit entitlement checks pilot and hope that this will be rolled out, although we would hope that these advisors are given cancer-specific training.

People with cancer should also be able to access financial support services such as benefits advice. Macmillan has established seven benefit adviser posts in hospitals across Northern Ireland and also has a dedicated benefits helpline providing a UK wide service for people with cancer. In the past two years the locally based benefit advisers have helped people with cancer to claim over £5 millions in statutory benefits.

People with cancer need more information about the help available to vulnerable customers from their supplier. This help needs to be much more widely promoted; for example displayed on website home pages and included with bills. Energy companies will need to make it clear to customers that informing their supplier about special circumstances such as a cancer diagnosis might allow them to access additional help. They will need to provide this information within bills and ask prompting questions when customers contact suppliers directly (for example they could ask if there are any special circumstances in the household which the customer wishes to highlight). Macmillan has already worked with energy suppliers in Great Britain to provide training to call centre staff on cancer and sensitive communication. We would be happy to work with suppliers in Northern Ireland to provide this training and help to improve their literature and promotion.

Specific action to raise awareness such as the Payment Awareness Campaign, managed by NEA and the NI Energy Advice Centre, is needed to help people to help themselves or access the support they need. The energy suppliers have a specific role to play in this type of work.

Question 9 Respondents are asked to comment on whether there are any other key issues that should be considered.

No comment

Question 10 Respondents are asked to comment on this future work plan.

We welcome the Regulator's work plan but highlight that many of the positive steps are for consideration only. For example:

- the consideration of introducing harmonised policies on debt management
- the consideration of the requirement for provision of information in alternative languages

- the consideration of the appointment of a panel of experts to advise on issues affecting utility customers
- the consideration of research into raising awareness

While we appreciate the need for careful planning and consultation, we hope that these considerations will in fact lead to positive action for the benefit of people with cancer living in Northern Ireland. We are disappointed that work on raising awareness and improving information could not begin immediately. We hope that following this consultation, the Regulator will begin to work on raising awareness as quickly as possible. Fuel poverty is a very real priority and issue for the many people with cancer in Northern Ireland. Delays mean that little is happening now to improve the situation for those in fuel poverty.