

Marie Curie in Wales response: Equality and Social Justice Committee, Inquiry into fuel poverty

Marie Curie welcomes the opportunity to respond to the Equality and Social Justice Committee Inquiry into fuel poverty, with a particular focus on the Warm Homes Programme. We are glad to see that priority is being given to address the grave impact that fuel poverty has on communities across Wales and we welcome the progress that has been made to reduce the number of people who are suffering to date. However, more can be done to eliminate fuel poverty in Wales, particularly among people who are at the end of life. This will improve quality of life not only for those who are dying, but their carers and loved ones, as well as health and social care services more widely.

This response will remain high-level and aims to highlight the impact of fuel poverty on those who are dying, their carers and loved ones, and the healthcare professionals that support them. We will not recommend specifics but instead convey how vital it is that health and wellbeing consequences of fuel poverty are considered in future warm home programme iterations, and that there must be a special focus on supporting those who are dying, and their carers.

Fuel poverty and terminal illness

Fuel poverty is an issue that any household can experience, but we know that certain groups are more vulnerable to the health, social and wellbeing consequences of living in a cold house; including older people, those with long-term or chronic health conditions and people with low or declining incomes. People who are diagnosed with a terminal illness often fall into many, if not all, of these categories and are particularly vulnerable¹.

The symptoms of a terminal illness, or side effects from the treatment received for that illness, can often make the person more likely to feel the cold and lead to an increase in heating bills due to a need to keep the home warm. For people with cancer for example, treatments like chemotherapy or radiotherapy and the wider impact of the disease mean many patients experience weight and hair loss, poor circulation, reduced energy levels and side effects like neuropathy - all of which may make them feel colder. People with dementia can experience reduced body heat generation and conservation due to restricted physical activity². With those diagnosed with a terminal illness likely to spend more time at home as a result of declining health, the importance of being able to heat their home is paramount if they are to avoid further risks to their health and wellbeing.

Furthermore, the mental health and wellbeing impacts of living in a cold home should not be forgotten; cold housing is linked to anxiety, depression, and increased stress³. The increased physical symptoms of cold homes leading to a loss of independence

¹ Marie Curie, 2020. *The vicious cycle of fuel poverty and terminal illness*.

² Marmot Review Team, 2011. *The health impacts of cold homes and fuel poverty*.

³ Ibid.

may also affect people's wellbeing⁴. Experiencing fuel poverty is also linked to increased rates of social isolation, as people are less likely to be able to go out and socialise and invite people to their home⁵.

Dying people often experience poorer financial circumstances for a variety of reasons. Many patients have to ensure accessibility and mobility within their home by installing specialised equipment, spend more on travelling to and from medical appointments, and eventually reduce hours and even stop working. In the UK financial struggle is reported by around two-thirds of households affected by terminal illness⁶. Being able to heat a home is so important for a dying person and their loved ones, for reasons of comfort and for the benefit of their health as outlined above, but in the face of financial insecurity this is more challenging.

After receiving a terminal diagnosis, someone should be able to focus on enjoying remaining time with family and friends and not have to worry about whether they can heat their home. Nonetheless, too many people are facing deteriorating health and wellbeing and even premature death as a result of living in a cold environment. Recent Marie Curie research set out to understand the impact of fuel poverty on terminal illness. We found that cold, damp housing can lead to new and serious infections for terminally ill people; exacerbate distressing symptoms like pain; make falls, stroke and other circulatory problems more likely; and heighten the risk of depression, stress, anxiety and loneliness.

The recent Covid-19 pandemic has exacerbated existing health consequences of spending prolonged amounts of time in cold and damp conditions. Lockdown regulations and periods of self-isolation mean people have been spending longer than usual at home. Around 130,000 people who are considered clinically vulnerable were asked to shield from March to August in Wales, with this being the minimum, as many still felt unsafe leaving their homes even beyond the loosening of restrictions.

With the World Health Organisation estimating that 30% of excess winter deaths are directly attributable to living in a cold environment⁷, it is vital that we work to eliminate fuel poverty in Wales. According to this statistic, it is estimated that just over 30,000 excess winter deaths in England and Wales can be attributed to living in cold homes over a five-year period (between 2014-15 and 2018-19)⁸.

Inclusion of people with a terminal illness and those at end of life

Marie Curie strongly feels that those living with terminal conditions and those at end of life should be explicitly considered when considering health consequences of fuel poverty. We welcome the new focus on health consequences in general, for example

⁴ Marie Curie, 2021. *No Place like home? Report of the APPG for Terminal Illness inquiry into housing and fuel poverty at the end of life.*

⁵ Marmot Review Team, 2011. *The health impacts of cold homes and fuel poverty*

⁶ Marie Curie, 2019. *The cost of dying: The financial impact of terminal illness.*

⁷ World Health Organisation, 2011. Environmental burden of disease associated with inadequate housing. A method guide to the quantification of health effects of selected housing risks in the WHO European Region. Summary report.

⁸ Marie Curie, 2021. *No Place like home? Report of the APPG for Terminal Illness inquiry into housing and fuel poverty at the end of life.*

the health criteria pilot of the Nest Scheme, however people in their final months, weeks and days are often excluded if they do not have a certain health condition listed in the eligibility criteria.

As previously explained, living in a cold home can exacerbate the symptoms of many terminal illnesses, such as cancer, dementia, and chronic obstructive pulmonary disease. Living in cold, damp homes may even hasten death for these conditions. We understand that there is some degree of flexibility when people apply for support from Nest, but without explicit mention of ‘terminal illness’, many people will not consider themselves eligible for such support and therefore miss out on a scheme that could drastically improve their quality of life in their final months, weeks and days.

Consideration of healthcare professionals

Marie Curie would also like to draw attention to the direct impact that fuel poverty is having on our health and social care workforce, particularly for those who are caring for people in homes that are fuel poor.

The below quote from a Marie Curie Healthcare Assistant portrays this:

“Caring for patients in the winter months presents its own challenges, particularly when you’re working in houses that are freezing cold with no central heating and you have to find ways to keep the patient warm. I remember one night I spent with a patient and it was freezing... It was a struggle to go through the night, but I made sure the patient was fully covered. They had two electric heaters, so I put them by the patient to make sure they were warmer than me.”

Healthcare professionals have worked tirelessly over the pandemic and poor working conditions for those delivering care in the community is detrimental to morale and work satisfaction.

Awareness of Warm Homes programme

We know that other UK-wide schemes aimed at eliminating fuel poverty are not well known amongst the public, for instance the Warm Home Discount Scheme. This scheme provides discount on energy bills for eligible households in England, Scotland and Wales, but in 2015, 40% of people with a disability in the UK were unaware that this support existed⁹. Anecdotal evidence shows that awareness is low for programmes operating on a Wales level too, and an effort to increase understanding of such schemes could ensure that they are reaching and helping as many people as possible.

Public health campaigns informing people on staying warm and signposting to appropriate energy efficiency programmes could be extremely beneficial, particularly in the run up to winter. Furthermore, targeted efforts should be made to support those

⁹ Scope. *Evidence to the National Assembly for Wales Climate Change, Environment and Rural Affairs Committee inquiry into fuel poverty*. Available at: business.senedd.wales/documents/s95777/FP%2026%20Scope.pdf

deemed most vulnerable in the face of fuel poverty, such as those with chronic illnesses and/or a terminal diagnosis.

Under National Institute for Health and Care Excellence (NICE) guidance NG6¹⁰, health and social care professionals in Wales are required to carry out an annual check on the heating situation of their patients. These annual checks should be used as opportunity to support and sign-post individuals to these energy efficiency programmes available in Wales.

¹⁰ NICE, 2015. *Excess winter deaths and illness and the health risks associated with cold homes* [Online]. Available from: <https://www.nice.org.uk/guidance/ng6/chapter/1-Recommendations#recommendation-4-identify-people-at-risk-of-ill-health-from-living-in-a-cold-home> [Accessed 3 December 2020].