

## Committee on Social Protection, Community and Rural Development and the Islands

Opening Statement from Averil Power, CEO Irish Cancer Society

*28 February 2024*

On behalf of my colleague, Irish Cancer Society Night Nurse Anna Drynan-Gale, and Dr Suzanne Denieffe from South-East Technological University, I want to thank Committee Members for inviting us here today.

The Irish Cancer Society's vision is that one day, no one in Ireland will die of cancer. But this vision is not yet a reality. While more people are surviving all the time, cancer is still the single largest cause of death in Ireland, with over 9,000 people dying each year from the disease.

The majority of people would prefer to die at home. The Irish Cancer Society made this possible for over 1,900 people with cancer last year by providing a free in-home Night Nursing service. People who have used the service frequently tell us that it meant the world – both to the person who was dying and their loved ones – that they could pass away in the comfort of their own homes.

However, we have also heard from our nurses about very poor living conditions in some of the homes they visit, including inadequate heating. This is particularly concerning because cancer patients, including those in palliative care, are often more vulnerable to the cold as a result of their condition and their treatment.

We wanted to better understand both the extent of this problem and what can be done to address it. Therefore, we funded Dr. Denieffe and her team to carry out research, with input from patients, carers, nurses and energy providers.

**The findings were stark:**

- Only **13%** of nurses reported that the homes where they provided support were ‘always’ adequately warm.
- **One third** of nurses had experienced a case where they felt the person they were caring for had to go without heating.
- **Almost a third** (31%) of nurses reported that a person they had cared for, or their family, had initiated a conversation about energy hardship.
- **Half of the nurses** (49%) believed someone they had cared for was struggling to make ends meet financially.

The nurses spoke of people living with mould, draughts, condensation, and dampness. Some stayed in bed all day to avoid having to heat more than one room. Others went without heating altogether.

One carer spoke of a need to keep the house warm as visitors arrived to spend time with their dying relative at the end of their life. The same person explained that their household costs decreased once their loved one went into hospice care. This left the carer feeling distressed. On the one hand some financial pressure was

relieved. On the other, the carer questioned if they should have kept the dying person at home for longer.

Another carer spoke of hiding energy bills so their loved one wouldn't have to worry about them.

In general, there was low awareness of, or uptake of various existing energy hardship interventions, or of the possibility of registering as a vulnerable customer on medical grounds. The winter energy credit scheme was widely welcomed. There was a desire for State supports to consider health-based needs alongside any means-testing applied.

Several of the participants mentioned the energy efficiency of their housing, and said they were living in old, poorly insulated houses. The cost of upgrades was mentioned as a barrier to changing this.

Overall, this Energy Hardship report illustrates harsh realities thrust upon people with a life-limiting cancer diagnosis and their loved ones, throughout their end-of-life journey. This problem cannot remain hidden behind closed doors. It is a public issue. How we treat and support people at their most vulnerable says *everything* about who we are as a society. It is therefore incumbent upon policy-makers to design a fair system to protect people at the end-of-life and their families.

The stark findings in this research underline the need for better State support for those who are terminally ill.

In particular, we are calling on Government to:

- Provide an automatic entitlement to the Household Benefits Package, Fuel Allowance payment and Additional Needs Payment to a person with a life-limiting cancer without means-testing;
- Provide electricity credits for the remainder of that person's life to support with electricity costs and
- Prioritise households with people receiving palliative care for SEAI grants to reduce waiting times.

To conclude, to think of anyone in their final days not having adequate heating is simply heartbreaking. To consider that this is a reality in Ireland in 2024 is shocking.

Often, conversations around death and dying are necessarily complex and nuanced. But not this one. Our message is simple and irrefutable: everyone should live well at the end of life.

No-one should spend their final days

- shivering;
- wrapped around a hot water bottle because they can't afford heating; or
- worrying about how their families will pay the bills after they are gone.

I thank the Committee for giving us the opportunity to lay bare the sad reality of the position too many families are finding themselves in today. And I urge you to work with us to change it.

ENDS