APPG for Terminal Illness Housing and Fuel Poverty at the End of Life Inquiry

Response by Sue Ryder, 31 March 2021

Sue Ryder supports people through the most difficult times of their lives. Whether that’s a terminal illness, the loss of a loved one or a neurological condition – we’re there when it matters. Our doctors, nurses and carers give people the compassion and expert care they need to help them live the best life they possibly can.

This paper sets out our responses to the inquiry into housing and fuel poverty by the APPG on terminal illness. We’d be happy to explore these issues further with the APPG.

1. The challenges of providing end-of-life care at home to people with a terminal illness who are living in older, overcrowded or unsuitable housing

Housing can be unsuitable for people at the end of life for a number of reasons such as rooms with not enough space for necessary equipment (e.g. oxygen tanks) and adaptations (e.g. stair lifts, hoists, walking aids) or shared facilities, bedsits and tower blocks which become impossible to leave for someone at the end of life. Inadequate housing stock combined with people’s lack of funds to pay for alternatives and adaptations can ultimately result in people at the end of life being restricted to one room or even bed unnecessarily. They then do not get the equipment and care they need to help with pain and symptom management which means their choices are limited and they may need to move into a hospital or hospice when they would prefer not to.

In addition, knowing that the person they cared for may have suffered unnecessarily at the end of life can leave a lasting legacy for the people left behind. Coupled with the feeling that they should have been spending precious time with their loved one who was dying when instead they have sometimes been spending time on complex administration trying to access support they need, inadequate housing can place a terrible burden on the families and carers of people who have died.

2. The extent to which fuel poverty and living in a cold home affects the health and wellbeing of people living with a terminal illness

Problems with accessing the Warm Home Discount Scheme such as not knowing if you will receive the payments, and in many cases not receiving them until after winter means that people at the end of life living in fuel poverty are faced with the dilemma of choosing between potential debt in order to live in a warm house, or living (and potentially dying) in a cold house. Often the financial burden of mitigating these circumstances falls on families and can result in debt as well as negatively impacting health and wellbeing.
3. **The difficulties faced by people living with terminal illness in affording the costs of housing, including heating costs, particularly for those living in rented accommodation or who require home adaptations due to disability**

The choice to die at home or the place of your choosing is a basic right that should be respected and facilitated. Yet, similarly to the issue of living in fuel poverty and a cold home, the costs and the timescales of equipping a home to adapt it as someone's condition deteriorates can be too much. This means people can spend their final years and months in an environment which is not only unsuitable, but denies them a choice on how to live their lives.

Whilst grants do exist, often the application processes are very complex and time-consuming to navigate. Long waiting lists, such as for the Disabled Facilities Grant, are an issue in themselves in that they delay needed home adaptations, but also pose an additional source of stress for patients and their families during a very difficult period of time.

4. **The challenges of providing end-of-life care to people who are homeless, living in temporary accommodation or experiencing housing transience**

The challenges outlined above are intensified when someone has no permanent place to call home. Not only does this mean they may not be able to access the services, adaptations and equipment they require, their experiences of engaging with formal services is often very negative, so engaging with end of life care services and support is doubly difficult.

5. **The particular challenges faced by people experiencing housing and fuel poverty in rural areas and urban areas of the UK.**

The provision of appropriate care support can be prohibitive in rural areas because of an unavailability of care providers covering rural areas due to distance, coupled with a need for more affordable transport. This means that people’s preferences and choice regarding their preferred place of care and death are restricted and it also places a much larger burden on informal social support networks. The limits that are placed on people's choices mean they may not be able to be around the people, places and environment that are so important to them.

6. **Potential legislative, policy or practice solutions that would improve the experience of people experiencing housing and fuel poverty who are living with terminal illness, their families and carers**

The potential changes to the DS1500 certificate and the ‘six month rule’ around access to benefits could be extended further so that a person at the palliative stage of their condition is also granted automatic fast-tracked social care support, adaptations, and guaranteed access to funds such as the Warm Home Discount Scheme. There needs to be consistency in the definition of terminal illness and this should not be time-limited.
When someone is palliative, assessments by social care and others should consider the person’s anticipated deterioration in health rather than their current needs. Carrying out ongoing assessments of people with a terminal illness is inappropriate and poses another source of stress and emotional uncertainty when such a trajectory could have been anticipated and planned for.

Consideration should be given for every locality or ICS footprint to have a dedicated office for palliative care housing support. This would be set up to provide quick and flexible access to the support and services required by people at the end of life, with the ability to provide access to home adaptations and equipment so people can remain in their own home comfortably, or where a home is not suitable due to its limitations/circumstances, people with palliative care needs are rehoused somewhere more suitable.

It is important that the systems for winter fuel payments by energy providers are made simpler and streamlined for people with palliative care needs. One option would be for energy providers to have a designated Palliative Care/End of Life team to advise on tariffs and discounts.

Overall, there's an urgent need to streamline all of the systems related to end of life care as patients do not have the time - literally - to navigate protracted systems.