Right to Palliative Care (Scotland) Bill
Citizens Advice Scotland response

1. Do you agree that terminally ill adults and children and young people with life shortening conditions residing in Scotland should have a right to palliative care?

- **Strongly agree**

Please explain the reasons for your response, including what you think a right to palliative care should deliver.

Citizens Advice Scotland is in agreement with the right to palliative care.

Citizens Advice Scotland collates both qualitative and quantitative evidence across a wide range of issues. While we don't gather quantitative evidence on palliative care issues, our qualitative evidence reveals that those with terminal illness need advice on a range of issues, including housing and social security. This data demonstrates the complexity of the circumstances people are experiencing at one of the most difficult times in their lives and the importance of bringing them stability, choice and control over their care and support. We have included the experiences of some of the people the CAB network in Scotland has advised, with names changed.

A right to palliative care should consist of an infrastructure that enables a connected approach to supporting people to die well, in a dignified, safe environment, in the place they choose, with adequate support and receiving the treatment and care they choose. As Donna's story demonstrates, palliative care needs to be able to support people in complex situations and provide financial, health and social care. The individual needs of the person must be at the heart of this, so a person-centred approach is paramount.

Being able to die at home, with family and friends, if that is the person's choice, is an important part of providing dignity, comfort and security.

> Claire came to a CAB as her Personal Independence Payment (PIP) award was coming to an end and she was on enhanced mobility only. She received advice in relation to PIP and terminal illness but as part of the discussion, the adviser noted the difficulties Claire had living in a house she could no longer manage in. Claire hasn't been able to get up her stairs in the last three years and has to get a friend to help her go to her downstairs toilet and also has to help her shower outside in a shower tent with a shower pump.

The foundational importance of a safe, secure and sustainable home cannot be overstated, given its impact on almost every aspect of our lives. There should be a shared understanding, definition and commitment to affordable housing in Scotland for people who are terminally ill. Everyone needs a safe, warm and affordable home as home is foundational to wellbeing.

> Janet is terminally ill and has nurses coming into her home to provide palliative care. She lives in a private rented property and over a week ago the boiler broke down. She is trying to resolve this through the letting agent. The landlord asked for two quotes, but then sent out their own maintenance people to check the boiler at which point boiler was condemned. This

> has left Janet with no heating or hot water. The letting agents have suggested finding her somewhere else to live but Janet does not want to move out of her home. She has been going to other family member's homes to shower as she has nurses coming in and does not want them to think she is unclean.

2. What is your view on the World Health Organisation definition of palliative care, that is the basis of statutory guidance in England on palliative care provision, being the basis for a legal right to palliative care?
Please explain the reasons for your response, and whether you think a different definition of palliative care should be considered for health and social care legislation, human rights legislation, and other forthcoming legislation that is relevant to how people may experience end of life.

The definition is framed in a way that care is about improving quality of life and treatment. Any definition of palliative care must be person centred and ensure that people receiving palliative care have choice and control over the care and treatment they receive. The definition should include the importance of respecting the person's choice and preference over the various aspects of their palliative care ensuring the needs and wishes of people receiving care are valued, respected and at the heart of decision making and care provision.

If the intended outcome of palliative care, that is namely improving the quality of life for patients and their families, is to be achieved, the additional costs of terminal illness must be recognised and adequate financial support provided, especially for households on the lowest incomes. CAS supports the call from Marie Curie in *Dying in the Margins; The Cost of Dying* for equity-informed palliative and end of life support for people experiencing deprivation and financial hardship. Many people who are at the end of life will have additional needs that are likely to come with additional costs. While some of these additional needs may be provided for, such as end of life care in the home, there will be costs that aren't such as the need to heat the home for longer or hotter, or by maintaining a more expensive, healthy, tailored diet or accessing private or complementary treatment. Disability benefits are available at the highest levels of payment for people with terminal illness without having to satisfy the required period condition and with decisions being made within seven days. This does have a positive impact and can alleviate financial stress at a difficult time, but we are aware that even this doesn't work for everyone. There should be a "no wrong door" approach to ensure that can ensure people with terminal illness get all of the financial support they are entitled to.

The CAB network in Scotland sees people unable to heat their home, eat well or charge essential independent living aids due to the cost of energy and low income. This exacerbates their health conditions and provides extra stress and anxiety. The case below explicitly refers to someone in this difficulty who is also terminally ill.

> Hugh has Stage 4 terminal lung cancer which has spread to the lymph nodes and is unable to work due to ill health. He is in receipt of Universal Credit (LCWRA), Council Tax Reduction, Personal Independence Payment (enhanced rate both components) and a private pension. He initially attended the bureau because he only had £1.54 left on his smart prepayment meter and was provided with a fuel voucher. Hugh's LPG tank was getting low and due to his terminal illness he needs to keep the heating on for longer to keep warm but cannot afford it with the rising costs of fuel.

In relation to whether the WHO definition of palliative care should be considered we urge that any definition is as consistent as possible with other definitions to minimise confusion and complexity. The Human Rights Act 1998, United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Act 2024, and the proposed Human Rights (Scotland) Bill all incorporate a right to palliative care and place a legal duty on public bodies to uphold human rights standards relating to palliative care.

3. Any new law can have an impact on different individuals in society, for example as a result of their age, disability, gender re-assignment, marriage and civil partnership status, pregnancy and maternity, race, religion or belief, sex or sexual orientation, caring responsibility, or location (urban or rural and island community settings).
What is your view on the different impacts that a right to palliative care would have and the different considerations there would be in implementing that right for different groups and people in Scotland living with terminal illness(es)?

We would urge that the additional impact of living in a remote or rural area be considered in defining what a right to palliative care means. Less frequent and accessible public transport and higher fuel costs in rural areas will impact on people's ability to attend medical appointments as well as on family members, carers and health care professionals' ability to support people in their homes.

Building on our suggestion to include a financial element into the definition, we can see that people in rural areas experience a compound of barriers: high cost of living and food, limited food choice and accessibility issues.[1]

In addition, the definition of fuel poverty used by Scottish Government includes a definition of fuel poverty for rural and islands communities.[2] The Scottish House Conditions Survey states that the fuel poverty rate for rural (35%) households was higher than the fuel poverty rate for urban (30%) households. Additionally, the rate of fuel poverty for remote rural households (47%) is higher than for all other areas.[3] Our own data shows that in 2023/24, the average amount of energy-related debt that was brought to Scotland's CAB network was around £2300. The figure is significantly higher in remote and rural areas, where the average was £3047.

If adequate housing, income, access to health services, social inclusion and non-discrimination are some of the social determinants of health which are crucial to positive end of life experience, as stated in the consultation, we suggest that mitigation for the various additional costs that can arise when living in a remote or rural setting must be mitigated for.