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Responses to Health, Social Care and Sport Committee written follow up questions, following oral evidence session of 13th December 2022

General hopes and fears

Q - What is required from the Scottish Government to support organisations and public bodies to implement the significant changes to current ways of working proposed by the Bill?

What is required from the Scottish Government includes the funding and support necessary to ensure that a responsive, sustainable, trained and valued social care workforce can be put in place to deliver the social care needed by people with rapidly progressing terminal illnesses like MND. This is essential to ensure, amongst other things, that carers are enabled to take the breaks they will be entitled to by law. Caring for someone with an illness like MND can be a 24/7 role and too often carers are having to step in to be a second 'care worker' when care providers are short staffed. If this workforce is not in place, it will be impossible for carers of people with profoundly disabling illnesses like MND to take breaks. A strong workforce will also be necessary to ensure that people with MND who want to spend the precious time they have left at home with their family, can. We must ensure they are not left with no choice other than to go into a care home because sufficient care-at-home support cannot be provided.

Q - Does the Bill as introduced take appropriate account of and appropriately support the changing demographic picture and the considerable and growing need for palliative care?

No – the Bill does not take this into account or support it at all. The Bill as introduced makes no reference to those with terminal or life limiting illness; older people; or palliative care. The Bill must address the needs of people who are terminally ill. People with rapidly degenerative terminal illnesses such as MND have social care needs which, correspondingly, rapidly increase. Meeting this increasing social care need must be planned for as early as possible in a person's illness so that support provided can be responsive, timely and person centred. Without such planning, the National Care Service will fail some of Scotland's most vulnerable people. The Bill must refer to people who are terminally ill to ensure that the mechanisms for effectively supporting them, through social care and other services, are put in place.

Palliative care and long-term conditions

The Scottish Partnership for Palliative Care (SPPC) [highlights](#) that palliative care includes but is *not exclusively about* end of life care. The following questions, however, focus heavily on end of life care. It is essential that any reference in the Bill to palliative care and terminal illness is not unnecessarily limited in its scope. We would like the Bill to acknowledge palliative care in its broadest sense and would prefer it to refer to the needs of those with terminal illness rather than exclusively focussing on end of life. This preference will be reflected in our responses to the following questions.

Q - How should the varying needs of all those at the end of life be considered in an equitable way?

Routine Anticipatory/Advanced Care Planning of all people with terminal illness must be undertaken early to ensure needs are considered in an equitable way. The needs of people with highly disabling terminal illnesses like MND, who require increasingly intensive social care, must be prioritised.

Training in terminal illness (including condition specific) and palliative care, should be mandatory for all those working in the National Care Service.

Q - What should a national care service ideally be seeking to achieve with respect to quality of care outcomes for people in receipt of palliative care, irrespective of where they are receiving that care? How should this be measured?

Others, such as the SPPC, may address palliative care outcomes. We will address *social care* outcomes for people with terminal illness, including those in receipt of palliative care. Regarding the quality of social care, the national care service must be responsive and person centred enough to meet the needs of people with a rapidly degenerative terminal illness like MND. For people with illnesses such as MND, the NCS must be able to smoothly and quickly progress from, for example, one care worker twice a day, to two carer workers four times a day, to night time and 24 hour care when needed. This responsiveness is essential to avoid carer burnout and to enable terminally ill people to stay at home if they choose. A responsive, valued and trained social care workforce will be essential to deliver this. Training will be critical, including, for example, on how to use the equipment necessary to care for people with illnesses like MND. Regularity of care workers is also essential for quality of care. Too often people with MND talk of a 'revolving door' of care workers when what is needed is consistency so that care workers can get to know the person they are caring for, and their family, as well as their care worker colleagues jointly providing care to the person with MND – this is essential for quality of care. In addition, the timings of care provided have a huge impact on quality. When someone with MND receives their first social care visit too late in the morning; their final 'tuck in' visit too early in the evening (sometimes 6 or 7pm); or, care visits which aren't spaced out properly, it can have a huge impact not only on the person receiving care's quality of life but their physical health and wellbeing too.

People with illnesses such as MND, and their (informal/family) carers, must be at the heart of processes for setting quality of care outcomes and their evaluation.

Self-directed support

Q - How does Self-Directed Support (SDS) facilitate end of life 'supported decision-making'? Is it outcomes focused and to what extent is it compatible with the principles and provisions set out in the NCS Bill?

Again, we will respond to this question in relation to people with terminal illness rather than those necessarily at end of life. When done well, people with MND can find SDS helpful - it can be outcome focussed and person centred. In my oral evidence session, I gave examples of two cases of people with MND using SDS. The first family were enabled to employ a family member to provide night-time care for the person with MND allowing the full time carer to be rested enough to care for her husband during the day. Another family were able to secure enhanced payments for a skilled Personal Assistant who was able to provide the level of quality care needed. In both cases, SDS offered flexibility and person centred support allowing people with MND to have their care provided in a way that was personalised and worked for them.