

Written evidence submitted by Dr Sheila Fisher (ADY0064)

1. Access to good Palliative Care and can improvements reduce/negate some of the arguments for assisted dying/suicide?

This, to me, is the chance to really make a difference for good. I commend the initiatives that are growing in many areas to improve access to Palliative Care.

I will focus on two:

i) During the pandemic the staff at our hospice worked hard to build an educational programme to reach out to all 52 Care Homes in our Borough and into Community Services with the aim of ensuring best palliative care, including empowering patients through listening to their wishes, advanced directives and anticipatory prescribing and empowering staff to have confidence around decision making. Evidence suggests an increase in people dying in their preferred place and feedback is excellent. This now has secure central funding and community outreach to professionals and the public is in progress. Networking with other partners is also growing.

In parallel work has been done to create a single point of access pathway (Whisper) so that people can gain rapid palliative care support wherever they are at whatever time – Hospice in your Home (or Care Home) is core to the Hospice work. Do people know about these initiatives? Can they feel assured they will get the support they need? If we could answer yes to these questions I feel it would make a difference.

ii) Increased and greater focus through the Integrated Care Networks – themselves such a positive step, encouraging people to work together. A quote from our GM hub:

The Palliative and End of Life Care Network has helped primary care to identify people at end of life (defined as the last 12 months of life) with a second wave of support, which included the use of an electronic tool and training to offer patients the chance to develop an advance care plan. Clinicians were encouraged to record the personalised care details on the electronic palliative care coordination system (EPaCCS).

There is a need to address misconceptions about Palliative Care: too often equated to end-of-life alone rather than help to live 'as long as possible as well as possible'. Education and positivity would make a difference. Too often, even now, I hear of clinicians saying 'I can't do any more for you now so **I will have to refer you to Palliative Care**'. Is it any wonder that people feel written off and enter a new care system with very negative expectations?

Beyond this we need open debate on accepting that people are in those final months and moving away from ever more intense (and often futile) interventions. Inevitably this may mean some people die before they might if 'everything that could be done was done', but the gain would be quality of life and dignity and autonomy and, as a church minister these days, I would say compassion. The work of leaders such as Atul Gawande and George Fitchett shows that this approach gives three core gains: people have better quality of life, people actually live longer and their final days are in accord with their wishes and, in these financially challenged times, unnecessary and sometimes costly interventions are avoided.

We approach dying in a negative way – 'do not attempt resuscitation [DNAR]' rather than we are coming to the time of 'accepting natural death'. The first suggests withholding care, the second a caring approach to the inevitable. People too often take a very negative view to the former

'writing me off' whereas the latter holds dignity and active respect for the person and their wishes. Can we change the conversation??

Looking at healthcare at the conclusion of a long and active and varied career, I see this as the one real opportunity we have to make a change that is truly a 'win' for all. It is not directly linked to assisted dying but I feel looking at our approach to the final 12 months of life would reduce the pressure and reassure members of the public. It would not take away some of the rarer situations but I would strongly wish that we hold a nuanced approach including these elements of care rather than continuing a binary debate on sanctity of life v the right to die.

2. Lessons from other countries

A much shorter response as the evidence is there and published.

Core is the empowerment given by knowing suffering can be ended; if I am right in my reading, most prescriptions are never used. That suggests that, if the approach outlined above was followed, the actual demand for assisted dying might reduce. I have actively been involved in anticipatory prescribing where a catastrophic bleed might take place. The family coped wonderfully and the time the patient had at home was so much better than the previous approach of keeping someone in a hospital [or hospice] bed and waiting – no chance to have time or peace, just lie thinking about when the blood might start to flow..... They said knowing they had the medication to hand to cope and the training to give it allowed them to live on with as little worry as possible.

3. Professional and ethical considerations

No professional must ever feel coerced into making such choices. There does need to be a back up in accord with recommendations already made. It must be clear that all possible other means have been attempted. I would see few cases remaining but there are times when suffering cannot be controlled, perhaps best illustrated by the case of Dr Nigel Cox.

In my long professional life there was only one time when I would have been willing to take this step but I have been careful to allow sedation to the point where it could be classed as 'terminal sedation' rather than allow someone [or their families] to be in pain or distress. Of course, technically this is not assisted dying but, to me, it is a spectrum and, as doctors, we are not required to prolong dying, sadly I feel that either from fear of being thought to be not doing all possible or lack of confidence, dying is too often prolonged.

4. Physical/mental health criteria

This naturally and properly links back to capacity and respect for capacity. We already withhold life saving treatment when someone with capacity refuses it; to be ending their life is one critical step further. With the safeguards already out lined I would again see this as a further step in a spectrum of care.

What is more difficult is those without capacity and I openly inform people that I have a strongly and carefully worded Advanced Care Statement as I would not wish my physical existence to be extended when all that was 'me' had ceased to function. Actively ending life in these situations would be ethically very difficult but there is a debate about when to give comfort instead of active therapy and allow natural death to take place. Again a place for advance statements and care for and listening to family members.

5. Protections

There is real danger of coercion but also we need to acknowledge that 'to not be a burden' is actually a perfectly reasonable perspective; too often not acknowledged but simply pushed aside with the words 'don't worry about that; of course you aren't'.

If there is one part of this debate I would see as a potential 'slippery slope' this is it.

Protections could include evidence that the person has had an advance directive in place before their decline and that its provisions are consistent [means encouraging such statements and revisiting them at a period which is sensible – my mother found reviews of her DNAR in her Care Home distressing – 'I've said it again and again, why do they upset me by doing it all again and making me sign it again?']

Answers above on the process, checks and balances, help here.

6. Information

I would plead this is in the context of the care network in question 1. We need a nuanced approach and this should be part of that approach once other avenues had failed and at the person's request.

There is a need for a careful conversation [more than one, the end point being all feel full and true understanding has been reached] with suitably trained empathetic healthcare professionals to determine if this really is the course of action the person wishes to take and the case should be supported by evidence of suffering that cannot be relieved by other means.

The information then becomes practical and should be clear and reassuring on what is done, how and by whom, in what setting, with what support?

7. Capabilities

Mainly answered above but am assuming this relates to the sad experience of some people with terminal neurological conditions who have capacity but not the physical ability to self-administer end of life medication. My feeling is that assisting them should be built in as a provision but no-one should feel coerced into doing this.

In post-paid work life as a minister I have had people be willing to declare 'if I had had any way to help him/her end the suffering I would have done it'. It is something people see as part of care for someone they love. If helping them administer medication is a final act of love, why should it be an issue whose hand takes that final step?

8. Government role

My plea is to look to make this whole area more nuanced and less divisive. It is difficult and distressing enough without becoming a binary debate. Quality of death is so much broader and holding assisted dying as a facet in the wider debate could achieve so much more.