

Written evidence submitted by Dr Caradoc Morris (ADY0076)

As Palliative Medicine becomes increasingly recognised as essential in healthcare, and in the NHS in the UK, the service is increasing. My experience is that it can be poorly understood by healthcare professionals and patients alike. But once patients do access the service I find that most are grateful for it, appreciative of it, and benefit from it.

However access remains an ongoing difficulty for a multitude of reasons. The poor understanding from many can limit the initial referral process. Patients often associate the service with death or assisted suicide and this may frighten them from attending. The services themselves are usually short staffed and under-resourced. Most importantly, Palliative Medicine is an incredibly broad field, overlapping with almost every other specialty. We provide clinical, social, psychological and family care in varying combinations, rather than a purely clinical or pathway-driven service. By virtue of the patient group (those with incurable, life-limiting disease) Palliative Medicine is usually considered when patients still require and deserve care but the parent team 'have no treatments left', and yet there is the expectation that Palliative Medicine will 'do something'. The result is that whilst Palliative Care professionals have the skills and expertise to support patients they are often limited by time and resource, meaning that some patients are short-changed.

An expansion of the service I think would negate some (but not all) arguments for assisted suicide. Many professionals will have examples of patients who simply required more care, better care, or specialist knowledge to improve their quality of life when those patients thought it was not possible. Such service expansion would need to include social care out of necessity; many patients under the Palliative Care service receive psychological support but only require simple nursing care rather than a specialist input. This could change through the course of their disease, but often a patient's difficulties and distress (leading to a consideration of assisted suicide) stem from nursing needs rather than clinical / disease-related needs. In summary, Palliative Care could best be improved by an expansion of resources, an improvement in education within and about the specialty, and an overlapping improvement in social care resources.

But this will not be true for all patients; many will find the nature of having a life-limiting disease or the symptoms and poor health that come with it intolerable despite the best palliative care. My understanding is that data collection in countries where assisted suicide is legal is substandard. And it is impossible to know what the patient feels after the event. But some angles to explore from these countries would include:

- Drivers for patients seeking assisted suicide and whether these drivers are ever overcome.
- Care options that have been explored prior to their request and their success.
- When assisted suicide is performed within the disease trajectory and a comparative analysis with similar patients who do not seek assisted suicide.
- The impact on healthcare professionals (positive and negative).
- The impact on families and carers before, during and after the implementation of assisted suicide (positive and negative).
- The longer term health impacts, including perceptions of healthcare, utilisation of Palliative Care and any economic impacts.
- Mistakes that have been made and how they were addressed; case reports, complaints, professional concerns, family concerns, safeguarding or social concerns.

The professional and ethical considerations are hard to balance, between any individual's (staff or patient's) right to autonomy and self-determination with the ethical concerns of prematurely ending life. From the patient's perspective, as the person experiencing the physical or psychological trauma of their condition they are arguably best placed to make the decision regarding ending their own life. Conversely, without medical training and potentially without knowledge or access of all available care options they may be making an ill-informed decision. Concerns about the possible coercion or safeguarding risks are reasonable and impactful.

Many colleagues I have spoken to worry that the fundamental nature of the clinician in preserving life would be damaged by the option of assisted suicide, much less their own moral or religious reservations. Some worry that the option of assisted suicide will detract from exploring other clinical options and that assisted suicide will become a first port of call. My personal opinion is that Palliative Care and assisted suicide are not mutually exclusive if managed correctly. Many professionals remain concerned about the negative impact on patients and the wider healthcare service of this option, and cite patients who would refuse the service for fear of being 'killed off'. This is of course a likely possibility but a difficult perspective to move forwards with, not only because of the hypothetical nature of the argument but that it would be easy to argue the reverse, that patients may access the service expecting assisted suicide and instead get good Palliative Care. Professional considerations would be where assisted suicide sits within the wider service, as well as a clear outline of what it is trying to achieve. Is the objective termination of life or resolution of symptoms? Are these the same thing? Are there other drivers? Many clinicians will have concerns about these points, as well as who would be involved in performing the act itself.

Events in my clinical practice that make me think about assisted suicide are usually those where suffering is evidently extreme and near impossible to resolve. This can apply to many situations though, including those that do not occur as a result of a life-limiting condition. But if assisted suicide were to be considered then it should be when imminent death is an expected and inevitable outcome of the current situation. It should be considered as a last resort based on professional assessment, as patients will often consider assisted suicide based on their own assessments that may not include specialist medical knowledge. A difficult overlap though is with mental health, as so many life-limiting conditions can lead to mental health disturbances. This becomes increasingly complex when factoring in the care needs discussed earlier as possible contributors, or the consideration that the prospect of a prolonged suffering is itself the cause of poor mental health. As a minimum, unmanaged psychological or psychiatric conditions that are felt to be impeding a rational decision making process should preclude assisted suicide.

To put in place any necessary protections from coercion into assisted suicide it will be essential to understand motivations for people to seek assisted suicide and motivations for people to seek the death of the individual who would be assisted. These may be financial, but also represent difficulties in social and health care that would make people seek an end to their present situation rather than seeking direct gain. Processes of manipulation are varied so any protection would need to involve individuals and services who have the knowledge and experience to recognise such coercion and intervene. This knowledge extends beyond health care into social care and even the legal / judicial system, so a potential safeguard could be a nominated case worker who could bridge the different services, as well as building a relationship with the person and their family to understand their connectivity and actively investigate for any potential foul play. It would also give the opportunity for open dialogue as to why the person is seeking assisted suicide and any other alternative support that could be offered. Psychology and psychiatry professionals will have a unique understanding of

the overlap between physical health, mental health and the 'normal' decision making process, so could be involved in the exploration of motivations.

Coercion would be inherently difficult to prove or disprove though. Taking financial gain as an example, a terminally ill person seeking to end their life may leave money to a child in their will. This would be a normal part of their end of life planning, and so seeking assisted suicide would not necessarily represent someone seeking immediate access to any money. A robust definition of what constitutes 'coercion' in this situation would need identifying with categories of how it could be proved or disproved. But one consideration would be that an element of uncertainty may be inherent to some cases if any legislation were introduced.

My belief is that if assisted dying were an option, that it is presented as one of numerous options and considered a last resort after the failure of all others. People considering this option should be counselled about the impact of the decision beyond the obvious, and their motivations and any repercussions explored. For many the motivation would be to relieve suffering, but others may be seeking this option feeling that 'their time had come' or grieving a lost partner, and so any regulations surrounding assisted dying would need to be explained (as well as being clear for professionals). It would be important for patients to be guided through this option as a decision-making process and not a one-off decision. Thoughts, opinions, motivations and feelings would need to be established over time and as part of a spectrum of that person's experience rather than as a response to a particular event. This would require clear and assessed mental capacity, as for any other healthcare decision. As well as having the capacity to make the decision and understand the consequences, this should be framed (and to a degree corroborated) by a clear understanding of the condition from which they suffer and that, presumably, they are trying to relieve through assisted suicide. An example would be a person suffering in the short term but from a symptom that is expected to or has a high likelihood of improving. Uniquely these decisions should perhaps more actively involve the person's family / next of kin / carers, given the far reaching nature of the decision. This is not to take away from the autonomy of the person, but an act such as assisted suicide has the possibility of causing significant psychosocial distress to those left behind and potential litigation consequences for any professionals involved.

The views expressed here are my own personal ones and do not reflect an organisation. Ultimately all of these points are subjective and made on 'educated guesses', as no one can know for certain what would happen in the future for any individual. The government's role in the debate should supporting be the broadest possible data collection and collation. Appropriate legislation will take time to develop and can only be done on the most robust knowledge base. Knowledge will be required from medical professionals of many specialties, the law profession, patient and family support groups and likely religious leaders as well. This will need to be looked at in the context of successes and failures from other international organisations. Such a large scope requires government-level support and implementation and should be their initial focus.

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