

## Written evidence submitted by The Association of Palliative Care Social Workers (ADY0335)

### About the APCSW

The Association of Palliative Care Social Workers (APCSW) was established in 1987. It has over 300 members working in specialist palliative care services across the UK.

Aims:

- raise the profile of palliative care social work
- support and advise all palliative care social workers wherever they work
- inspire excellence by sharing best practice
- promote high quality research and evaluation in order to continually improve end-of-life and bereavement care.

For more information please visit [www.apcsw.org.uk](http://www.apcsw.org.uk)

### Important note

The APCSW has not to date taken a position on the issue of legalising medically assisted dying, and nothing in this submission should be viewed as either endorsing or disagreeing with the principle of assisted dying.

Instead, our responses reflect our recommendations about what provisions should be put in place *in the event* that parliament passes legislation.

***To what extent do people in England and Wales have access to good palliative care? a) How can palliative care be improved, and would such improvements negate some of the arguments for assisted dying/assisted suicide?***

Where people can access specialist palliative care services, especially the inpatient and community services provided by hospice multi-professional teams, they and their families receive high quality palliative care that is personalised and holistic.

Sadly, access to palliative care is unequal in terms of geography, socio-economic status and health condition. The Hospice UK report “Equalities in End of Life Care: Challenges and Change” (2021) identifies several groups of people that palliative care services do not reliably serve well. They highlight that people living in areas with higher levels of economic and social deprivation have less access to palliative care than those in more affluent ones. This partly reflects the fact that a high proportion of specialist palliative care services (both in-patient and in the community) are provided by hospices that are charity funded, rather than by the NHS and local authority social care services.

As with other forms of healthcare, people from some ethnic minority groups are less well served. People dying of cancer are more readily able to access palliative care than those with other terminal illnesses such as chronic obstructive pulmonary disease, heart or kidney failure, neurological conditions such as MND, Parkinson’s, and dementia. People who are socially excluded, or who have experiences of discrimination are also less likely to be reached by palliative care services. These include people with learning disabilities, people who are LGBTQ+, those who live in a rural area, are prisoners, are homeless, and those who have Nil Recourse to Public Funds.

We would like to highlight the particularly savage impact on people living in poverty. In our work we encounter adults who have had to battle to access palliative care; as well as whose housing and economic circumstances are woefully inadequate. Good palliative care extends beyond the provision of medical and allied health care – we would advocate for an overhaul of housing policy and process for people with terminal illnesses. This needs to include training and awareness about terminal

illness for housing workers, as well as improved working relationships between housing and palliative care services.

As social workers we have countless experiences of people dying in inadequate housing – a dingy bedsit above a pub where the person couldn't bathe as there was only a shower and felt unable to let his young children visit; a high rise tower block where the person was effectively held prisoner due to poor mobility; temporary housing where the rent is astronomical; as well as hundreds of cases of cramped, damp and unhealthy housing (please see APPG 2021 report, *No Place Like Home*, to which the APCSW contributed).

The dearth of social care means many people with terminal illness are unable to be discharged home from hospital/hospice because there is insufficient care available. Others remain at home but are unable to get the help they need to meet basic care needs.

The Ambitions for Palliative and End of Life Care: a national framework for local action 2021-2026 sets out a framework for people who have PEOLC needs, as follows: Each person is seen as an individual. Each person gets fair access to care. Maximising comfort and wellbeing. Care is coordinated. All staff are prepared to care. This would result in better cohesion of services, which can improve wellbeing, physically, emotionally and spiritually and help some people to make a positive choice to continue living, rather than seeking an assisted death.

All of this inevitably exacerbates the pain and suffering of terminal illnesses. This could mean that people in this situation opt for – or would be vulnerable to being coerced into – assisted dying, because their palliative care needs are not being adequately met.

We would argue that if assisted dying legislation is enacted, it should be accompanied by statutory guidance and sufficient funding to provide equitable access to high quality palliative care for *everyone*. We advocate a population-wide needs assessment for commissioning palliative care services from a mix of public and voluntary sector providers, with clear and well-signposted referral routes to specialist services. In our opinion, these safeguards are necessary to prevent coercion and abuse of any assisted dying process.

We strongly recommend that all health and social care staff are trained and kept up to date on working with people who have life-limiting conditions and their families, and in supporting bereaved people. Palliative care should be a required element on all qualifying courses for doctors, nurses, allied health professionals and social workers. There is a need for continuing high quality research into palliative care improvements, including making it more accessible to those whose needs are currently not well met.

We would like to highlight the role of social workers in palliative and end-of-life care services. Social workers' professional repertoire includes skills in engaging, communicating and building relationships with people in crisis, and with those who are marginalised and disadvantaged. We are experienced at making 'biopsychosocial' assessments i.e. holistic assessments of their physical, social, psychological and spiritual needs, and in responding to these needs. We work and support wider family members and other informal carers. We are experienced at assessing risk and can intervene to protect people who are subject to coercion, abuse or exploitation. All of these skills are central to meeting the care and support needs of people living with and dying from progressive, terminal conditions.

### ***Would better palliative care negate the arguments for medical assistance in dying?***

Our experience as palliative care social workers is that when people who are terminally ill access holistic care as described above, this can dramatically improve their end of life experience and reduce the likelihood that they will feel that their life is unbearable. Practical advice and support to address hardship such as food and fuel poverty and unsuitable housing, combined with good

medical and nursing care and psychosocial support, can vastly enhance quality of life and enable the majority of people to die peacefully, without pain or undue distress.

However, our experience is that there are some people for whom even the best palliative care available does not achieve this. There are people who find that - despite the most skilful care and tailored medication available to relieve their pain, alleviate symptoms such as nausea and vomiting or breathlessness, or help them to resolve practical issues or relationship problems - the distress or restrictions of their situation and the prospect of continuing deterioration is unbearable. Access to assisted dying could provide autonomy and choice for these individuals to die safely and with dignity.

Some of our members have had the experience of patients they are working with ending their own suffering through suicide. This is immensely distressing for the family, friends and professionals involved, as well as the individual who has felt compelled to take this course of action.

## ***2. What can be learnt from the evidence in countries where assisted dying/assisted suicide is legal?***

We would draw attention to research findings reported by palliative care social work colleagues in north America, where medical assistance in dying (MAID) is legal. Based on a study in Washington State, USA, Gerson (2020) reports the experience of palliative care professionals that for some people, knowing they have the option to access MAID enables them to carry on living with their illness, until they die naturally. Gerson also reports the cautionary experience of palliative care practitioners that some of their patients chose to end their own lives prematurely, sometimes by violent means, because they could not afford to pay for the drugs involved in MAID. Her research also highlights concerns that lack of funding for palliative care may be an important contributory cause of other suicides.

Antifaeff (2019) reports experience from Canada, which leads her to stress the importance of thorough psychosocial assessments. She argues that this needs to comprehensively review the individual's reasons for requesting an assisted death, to ensure that there are no further measures that would alleviate their physical, psychological, social or spiritual problems. This includes actively considering the possible influence of any mental illness or mental incapacity. Additionally, she highlights the importance of establishing, as far as possible, that there is no evidence of coercion that is influencing the dying person that they have become an intolerable burden to others (situational incapacity). Finally, she stresses that it is important that, where MAID is offered, this is done in the context of a thorough discussion of all alternative forms of palliative intervention that could be provided to relieve suffering.

## ***3. What are the professional and ethical considerations involved in allowing physicians to assist someone to end their life?***

We would argue that physicians should not be required to take sole individual responsibility, in law or otherwise, for the decision to assist someone to die through medical intervention. Instead this should be professional multi-professional team decision, following an assessment by a specialist palliative care physician and a psychosocial professional (preferably, a social worker) in a new role with a title such as Approved Palliative Care Practitioner. This is explained in more detail under q5 below.

Reflecting what we have said earlier, we would suggest that the following questions should be addressed, were medically assisted dying to become legal:

- Is there any evidence that mental illness, which could be treated, might be affecting the person's decision?
- Have all other palliative care options been offered and fully explained?

- Has the possibility of any undue pressure or influence been excluded?
- Does the person have capacity to make this specific decision, under the criteria set out in the 2005 Mental Capacity Act?
- In the case of someone lacking such capacity, are there sufficient grounds for concluding that this is in their best interests, again as set out in the mental capacity legislation?  
This should be regarded as exceptional, but could be considered if the individual had provided clear advance notification when they had capacity, that they would want this, under conditions which are now met.

There is also a question about whether professionals should be allowed to opt out of participation in the process of assistance in dying. This would be difficult to accommodate in practice as if a practitioner, such as a GP, were to block a person's access to this route, they would be depriving the person of their legal right. However, for some conscientious objectors, even the act of referring to a colleague could be perceived as facilitating assisted dying. It might be possible to allow a person to opt out of administering or attending a person undergoing MAID, but this would not completely resolve their issue of conscience.

This raises the fundamental question as to whether professionals should have the power to override the rights of a patient who feels that their suffering has become intolerable to access the assistance they need to end their life.

It is our opinion that professionals who are involved in the decision making or administering of assisted dying should receive high quality, structured supervision and opportunity for reflective practice.

There should also be consideration given to how relatives and loved ones may be affected by assisted dying. Access to bereavement support needs to be considered – as well as whether the nature of this support might be different in an assisted dying situation.

***4. What, if any, are the physical and mental health criteria which would make an individual eligible to access assisted dying/assisted suicide services?***

We do not have an agreed position on this.

***5. What protections could be put in place to protect people from coercion and how effective would these be?***

As set out in Q3, we would argue that the decision to proceed with medical assistance in dying should not be the responsibility of a medical professional alone. Death is as much a social event as a medical one. The APCSW suggests decisions about assisted dying could be resolved through an interdisciplinary process, rather than being the sole responsibility of doctors, or left to the bureaucracy of the judicial process. This approach could incorporate medicine and social work; or better still, be addressed through a multidisciplinary team consultation. Responsibility would then be shared among professionals who know the person concerned, in partnership with that person, and those who are important in their lives. This would rely on effective inter-agency working and communication, which as numerous reports and incidents attest to, can be challenging. Robust guidance on information sharing, confidentiality and information governance protocols in relation to assisted dying would be required.

A role such as 'Approved Palliative Care Practitioner' could be constructed on similar lines to the Approved Mental Health Practitioner, Best Interests Assessor or the new role of Approved Mental Capacity Professional. The decision to request assisted dying is as much a social as a medical one. As explained earlier, social workers, especially those specialising in end of life care, are able to bring a holistic perspective that encompasses the physical, social, psychological and spiritual aspects of the person concerned.

We are skilled in developing constructive trusting relationships with people who have a life-limiting illness and those who are important in their lives, including children and young people. Specialist palliative care social workers have the skills to enable people who are considering assisted dying to think through the implications of the choices available. We are trained to work with issues that are ethically complex and sensitive, where there are competing and conflicting views and demands. We can work with adults and their families to resolve conflicts and to prepare for whatever lies ahead.

As professionals working within palliative care, we have a deep respect and appreciation of all that this specialism has to offer. We support ongoing research and development in the field. Our view is that were assisted dying to become legal, it needs to be an additional option in a comprehensive offer of well-funded, high quality and personalised palliative care.

In addition, we would also recommend that all cases of MAID should be reported to the coroner, who would then be able to detect if there were clusters that needed to be investigated.

## **6. What information, advice and guidance would people need in order to be able to make an informed decision about whether to access assisted dying/suicide services?**

People would need honest and open conversations about the likely trajectory of their illness and prognosis. This would potentially require a shift in the way that medical professionals communicate with patients. It is still not uncommon in our experience for some doctors to be reluctant to openly explain to patients that their illness is terminal – or that they are approaching the end of treatment options. Patients need to have this information and understand the options for palliating their symptoms, such as pain, nausea, digestive issues and fatigue.

The health and social care and welfare benefits system is confusing to navigate – indeed it often requires professionals such as welfare advisors, social workers and support workers to unpick what is available and how it can be accessed. People with life-limiting illnesses need clear information about the services – including financial support – available, as their illness progresses. For example, a lot of people don't realise that most hospices support the majority of people in their own homes, and that you do not have to be admitted to receive care. Nor are they aware of the range of services like physiotherapy, counselling, and help with finances, housing, legal and funeral planning that is available at most hospices.

However – with reference to the previous point regarding inadequate funding and provision of palliative care – patients need to know the likelihood of being eligible/able to access particular services and resources. Hospice care is not available to everyone, likewise certain benefits and social care provision is stringently means-tested.

Decision-making around MAID should be a process, not a one-off event. The individual concerned should have multiple opportunities to explore the issues with professionals, allowing time for reflection and ability to change their mind.

Lastly, of course, clear information about the actual process involved in assisted dying - and what the person is likely to experience at each stage - will also be vital.

Again, we would argue that social workers are well placed to support people to effectively access, understand and process relevant information, as well as to advocate for them where needed.

## **7. What should the Government's role be in relation to the debate?**

Government should include social workers in all discussions about Medical Assistance in Dying.

## References

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