Scottish Partnership for Palliative Care (SPPC) Response to Proposals for an Assisted Dying for Terminally Ill Adults (Scotland) Bill

About Scottish Partnership for Palliative Care (SPPC)

SPPC brings together health and social care professionals from hospitals, social care services, primary care, hospices and other charities, to find ways of improving people's experiences of declining health, death, dying and bereavement. SPPC provides a voice for organisations and individuals working in this area, a means of staying informed and connected, and a vehicle for collaboration. SPPC also engages with the public and communities through our Good Life, Good Death, Good Grief alliance.

SPPC was founded over 30 years ago and has grown to be a collaboration of more than 100 organisations involved in providing care towards the end of life. SPPC's membership includes all the territorial NHS Boards, IJBs, local authorities, hospices, other Third Sector organisations and a range of professional associations.

SPPC works closely with Scottish Government to facilitate engagement with the sector and to inform and support implementation of policy.

SPPC's Approach to the Legalisation of "Assisted Dying"

Assisted dying raises issues of a moral, personal and ethical nature upon which many of SPPC's member organisations (for example our member NHS Boards and some charities) are institutionally unable to hold a position. SPPC therefore does not adopt a position in principle either in support or in opposition to a change in the law.

Instead, SPPC's approach is:-

- To take a factual and evidential approach rather than a moral or religious one
- To educate and inform about palliative and end of life care
- To challenge misinformation about palliative and end of life care

- To acknowledge and give an account of complexities which tend to get lost in polarised debates
- To be honest about the limits of palliative care to relieve all suffering
- To be honest about the current deficiencies in care towards the end of life experienced by some people
- To critically review and present a view on the specific provisions of the proposed Bill (once published in detail), such that if the Bill is passed potential harms (to vulnerable people and the practice and provision of palliative care) are minimised.

This response comments on the evidence and argument in the Proposal Consultation Document (“the Proposal”) as well as the specific measures. As is to be expected the Proposal, produced by proponents of change, presents a positive and relatively simple picture of assisted dying. It is important that law making is informed by a broad perspective and relevant facts, and that issues needing consideration by MSPs are identified. This response from SPPC is written with that intent. This response provides relevant contextual information as well as directly responding to areas of focus set out in the consultation questionnaire.

Public Opinion Polls, Public Understanding and Careful Use of Language

Opinion Polls and Public Understanding

The Proposal draws extensively on public opinion polls reporting support for assisted dying. Whilst these polls shouldn’t be dismissed, neither should they be consumed uncritically[1].

It is known that public views about legalisation of assisted dying are significantly influenced by the public’s knowledge and awareness of the complexities relating to end of life issues. Opinion surveys that do not capture this complexity may not reliably reflect public attitudes. Polls which have explored public understanding of what assisted dying actually is (alongside support for it) have revealed that the public is not well informed. A 2017 New Zealand survey found that 66% of those polled thought assisted dying includes turning off life support, 51% thought it includes stopping medical treatment, and 59% thought it includes do not attempt cardiopulmonary resuscitation (DNACPR) requests: these are all options which already form part of current palliative and end of life care practice. A recent UK poll[2] found

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[1] *Assisted Dying: we must prioritise research* Sleeman et al 2021 British Medical Journal https://blogs.bmj.com/bmj/2021/09/08/assisted-dying-we-must-prioritise-research/

[2] Survation for the All Party Group on Dying Well (2021) https://www.dyingwell.co.uk/survation-appg-for-dying-well-survey-july-2021/

that 10% of respondents believed assisted dying included providing hospice-type care to people who are dying. In the same survey 42% believed that assisted dying included giving people who are dying the right to stop life-prolonging treatment (a right people already have of course).

Careful Use of Language

This public confusion is not surprising and it is harmful when people are unclear about their options towards the end of life. The public has low awareness and understanding of end of life issues generally including options for end of life care and their current legal rights in relation to refusing treatment, withdrawal of treatment, Do Not Attempt Cardiopulmonary Resuscitation etc.

The term "assisted dying" is non-specific, confusing and doesn't reflect defining characteristics of the practise which differentiates it from palliative and end of life care (i.e. the choice to purposely shorten life and to control the timing of death). As evidenced in the previous discussion of polls many members of the public understand "assisted dying" to encompass existing elements of mainstream palliative care.

The Scottish Parliament's Presiding Officer's guidance on the style and content of Bills states:

> *"A Bill should be drafted so that, when read with any relevant existing statutory provision, its intended legal effect is clear".*[3]

SPPC suggests that the proposed Assisted Dying Bill should use alternative wording which is less likely to perpetuate and amplify public confusion and fear, and which accurately and clearly reflects the scope and intent of the legislation. This should include but not be limited to re-titling of the Bill. SPPC acknowledges stigma around suicide terminology but believes that other non-stigmatising plain English terminology accurately reflecting the intent of the proposed legislation could and should be devised. For example something descriptive along the lines of "Enabling and supporting decisions by terminally ill adults to end their life through the self-administration of lethal medication."

Unfortunately public confusion and fear can be further exacerbated when campaigners and advocates for assisted dying present the issue as a binary choice between assisted dying or an agonising death. The Proposal is generally measured in its tone yet still contains rhetorical flourishes which do not reflect the experiences of the majority, are alarmist, unhelpful to public understanding and which do a disservice to families (and professionals)

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[3] Presiding Officer determination (Public, Private and Hybrid Bills): proper form of Bills https://archive2021.parliament.scot/parliamentarybusiness/Bills/25696.aspx

currently providing high quality compassionate care which enables people to have a good death, for example:

> *"….an end to the current blanket ban on the right to a compassionate death is long overdue..."*

What is Palliative Care?

Given this terminological confusion it is worth exploring what "palliative care" is, since the term is used frequently in the proposal.

Though more specific formal definitions can be helpful a good way of thinking about 'palliative care' is to talk in terms of providing 'good care' to people whose health is in irreversible decline or whose lives are coming to an inevitable close.

Perhaps what differentiates 'palliative care' from 'just good care' is the awareness that a person's mortality has started to influence clinical and/or personal decision-making.

However, palliative care is not synonymous with death – it is about life, about the care of someone who is alive, someone who still has hours, days, months, or years remaining in their life, and about optimising wellbeing in those circumstances.

Palliative care interventions are holistic and aim to modify *the impact* of illness/disease by addressing symptoms and should be delivered alongside treatments aimed at controlling or modifying the underlying condition(s). Palliative care can and should be provided alongside treatment aiming to *cure or remove* the underlying illness/disease where such treatments exist.

Generalist palliative care by all health and social care professionals

In Scotland most of the care that people receive when their health is deteriorating could be termed **generalist palliative care**, being provided by health and social care professionals to people living in the community, in care homes and or who are in hospitals.

It is palliative care regardless of whether someone has cancer, organ failure (including neurological conditions) or 'old age', or whether they are living at home, in a hospice, in a care home, in prison or in a medical ward, in ICU or a homeless shelter, or in a neonatal ward.

Specialist palliative care by multi-professional specialist teams

Specialist palliative care can help people with more complex palliative care needs and is provided by specially trained multi-professional specialist palliative care teams who are generally based in a hospice, an NHS specialist palliative care unit or an acute hospital, but whose expertise should be accessible from any care setting and at any time. Services labelled 'palliative' are usually specialist palliative care. Key contributions of specialist palliative care include:

- assessment and management of complex physical, psychological and spiritual symptoms
- supporting complex clinical decision-making, seeking to apply relevant ethical and legal frameworks alongside clinical assessment and respect for personal autonomy and values
- direct provision and management of symptom management interventions
- providing care and support to those important to the person receiving care, including facilitating bereavement care
- providing specialist advice and support to the wider care team which is providing direct care to the person
- liaison with and between different settings
- providing formal and informal education and training for the wider health and social care system
- attending and providing input to multidisciplinary team meetings, including key decision-making contributions
- providing strategic expertise and leadership to support the health and care system to recognise and meet the needs of people approaching the end of their lives.

End of life care

Palliative care includes, but is *not exclusively about,* end of life care.

End of life care is a core part of palliative care which should follow from the diagnosis of someone entering the process of dying, whether or not they are already in receipt of palliative care. This phase could vary between months, weeks, days or hours in the context of different disease trajectories[4]. There can be uncertainty involved in identifying when someone might be expected to die – illness can be unpredictable, and changes can occur suddenly and unexpectedly.

Provision of palliative care

Palliative care is provided by the NHS, the Third Sector, the Independent Sector and local authorities. There is considerable geographic variation in the models and level of provision.

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[4] 'end of life care' is often used to refer to care in the last year of life. However, this is hard to identify prospectively, so this document uses the term differently - to refer to imminent and identifiable dying.

Organisations involved in delivering palliative care include primary care; care homes; care at home services; hospices; NHS 24; Scottish Ambulance Service; NHS specialist palliative care units; acute hospitals; community hospitals.

Legal responsibility for the strategic commissioning of adult palliative care lies with Integration Authorities (IAs).

Opioid Medicines at the End of Life

Doses of opioids may be increased when someone is dying if needed to control symptoms of pain and/or breathlessness. Sometimes this is misunderstood as the increased dose having ended the person's life (and sometimes even misinterpreted as the doctor having used opioids to end the person's life).

However, appropriate doses of opioid medicines (e.g. morphine) titrated to the person's pain or other symptoms do not shorten life.[5] [6] The Scottish Palliative Care Guidelines[7] are available to all health and care staff to support best practice in this area.

Shifting Views and Wishes Towards the End of Life

The views, feelings and wishes of people approaching the end of their lives change over time and may alter frequently during the course of an illness. People who have a desire for an early death or who express a wish to get assistance to shorten their life because of distressing physical or psychological symptoms often change their minds when these symptoms are addressed through appropriate palliative care[8] [9]. It is experience of such situations which give rise to some of the concerns about assisted dying expressed by many palliative care practitioners.

Addressing symptoms may involve medicines but it may also involve psychological and spiritual support since the causes of pain and distress are

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[5] *The Myth That Shames Us All* The Lancet (2018) https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)31876-2/fulltext

[6] George R, Regnard C (2007) Lethal Opioids or Dangerous Prescribers. Palliative Medicine 21:77-80)

[7] *Scottish Palliative Care Guidelines*. NHS Scotland, Healthcare Improvement Scotland, Specialist Palliative Care Pharmacists Association, Scottish Partnership for Palliative Care

[8] Prevalence, course and associations of desire for hastened death in a UK palliative population: a cross-sectional study Price A, Lee W, Goodwin L, et BMJ Supportive & Palliative Care 2011;1:140-148. https://spcare.bmj.com/content/1/2/140

[9] Chochinov HM (2006) Dying, Dignity & New Horizons in Palliative End of Life Care. CA: A Cancer Journal for Clinicians 56(2) 84-103.

often complex and multifactorial. Cicely Saunders, founder of the modern hospice movement developed the concept of total pain as a framework for exploring, understanding and addressing people's distress[10].

Total Pain

Some people will have an enduring wish to hasten their death and such individuals have a need and a right to be respected, affirmed and valued, regardless of the legality or otherwise of assisted dying.

Impacts of Legalisation of Assisted Dying on Doctor – Patient Interactions Towards the End of Life

Discussing people's wishes towards the end of life can often involve sensitive and complex conversations, which very many healthcare professionals find

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[10] http://endoflifestudies.academicblogs.co.uk/total-pain-the-work-of-cicely-saunders-and-the-maturing-of-a-concept/

difficult. More investment in building skills and confidence of health and social care staff is needed in this area.

The option of an assisted death may be an easier, quicker and simpler conversational route (for both healthcare professionals and some terminally ill people) than a long and complex conversation which seeks to surface, explore, understand and plan to address the causes of suffering. However, this latter sort of conversation will often lead to people experiencing an improved and positive experience of whatever time they have left until their natural death.

A study of the experiences of palliative care practitioners involved in assisted dying in Canada reported additional challenges which the topic brought into conversations about end of life[11]. Practitioners had to navigate a difficult balance between being perceived as suggesting or obstructing assisted dying.

A major problem in Scotland for people who need and would benefit from specialist palliative care is that they are often referred very late to such services or not referred at all (such services are erroneously perceived by many other professionals and the public as relevant only at the very end of life). An association between assisted dying and palliative care may strengthen this perception and introduce the idea that palliative care is about accelerating death. This may exacerbate the problem of late referral or refusal of referral, with more people missing out on life enhancing care.

The Technical Limits of Palliative Care vs Deficiencies in Provision of Palliative Care

The Technical Limits of Palliative Care

The Proposal states that "some people experience severe emotional and physical suffering at the end of life despite receiving excellent palliative care"[12]. Most symptoms towards the end of life can be effectively managed most of the time. Palliative sedation is an approach which can be considered and used to address intractable suffering where more common strategies have failed. The European Association for Palliative Care defines palliative sedation as *"the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering in a manner that is ethically*

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[11] *Impact of Medical Assistance in Dying on palliative care: A qualitative study* (2021) Mathews JJ, Hausner D, Avery J, Hannon B, Zimmermann C, al-Awamer A Palliative Medicine https://journals.sagepub.com/doi/abs/10.1177/0269216320968517

[12] There isn't good data to quantify this assertion for Scotland. The estimates presented in the Proposal of the number of people in this situation is based on extrapolation from and assumptions about limited English data.

acceptable to the patient, family and health-care providers" [13]. More recently the term "proportional palliative sedation" has come into use reflecting the reality of palliative sedation as a continuum from light to deep sedation and from intermittent to continuous sedation, where patient comfort is the aim, not deep sedation as such. The existence of such approaches is at odds with estimates in the Proposal about the numbers of people in Scotland who "will experience no relief from their pain as they die" despite access to high quality specialist palliative care.

Deficiencies in the Provision of Palliative Care

In reality, *deficiencies* in the provision of palliative care across different settings in the health and care system (quantity, quality, reliability and consistency of provision) are a much more important risk of avoidable suffering than the theoretical technical *limitations* of specialist palliative care discussed in the previous paragraph.

The Proposal claims that palliative care in Scotland is amongst the best in Europe but there is no robust evidence upon which to base this assertion. The main conclusion of the Parliamentary report refenced by the Proposal in this respect is that:

> *"A serious information deficit needs to be filled on data relating to the provision of palliative care in Scotland – starting with inputs and resources, but also including needs analysis, access, quality and outcome".* [14]

There is undoubtedly much good care provided, but there are no systematic mechanisms in place to measure and understand the experiences and outcomes of people dying in Scotland (for example the experiences of people approaching the end of life and bereaved relatives are excluded from the regular Scottish Government Health and Care Experience Survey). In our recent report *Every Story's Ending*[15] SPPC engaged with a wide range of stakeholders to take stock of recent developments and current challenges in the care of people approaching the end of life in Scotland, in order to inform

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[13] European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care https://journals.sagepub.com/doi/pdf/10.1177/0269216309107024

[14] *A report for the Scottish Parliament by Professor David Clark: International comparisons in palliative care provision: what can the indicators tell us?* Health and Sport Committee (2015) https://external.parliament.scot/S4_HealthandSportCommittee/Reports/HSS042015R09.pdf

[15] Every Story's Ending, proposals to improve peoples experiences of living with serious illness, dying and bereavement in Scotland SPPC September 2021 https://www.palliativecarescotland.org.uk/content/everystorysending/

future development. The report identifies areas where palliative care in Scotland should be improved:-

- Inadequate access to responsive support in the community (including social care), particularly in the evening, overnight and at weekends
- Absence of digital systems to allow anticipatory care plans to be recorded, updated and shared between relevant health and social care settings
- Lack of adequate skills, knowledge and confidence on the part of many health and social care staff
- Failures to identify people with palliative care needs systematically
- Failures to have timely, open, honest and supportive conversations in the context of uncertainty and deteriorating health
- Patients and families left unaware of their health situation and available options for care
- Burdensome investigations and interventions of low benefit
- People undergoing treatments which do not reflect their life goals and priorities
- Missed opportunities for rapid discharge home
- Lack of anticipatory care planning and care co-ordination leading to avoidable re-admissions and poorer outcomes in the community
- Inadequate symptom management
- Other unidentified and unmet holistic care needs (e.g. psychological, spiritual and practical concerns)
- Lack of dignity/privacy for people and families in the time around death due to the physical environment in some settings
- Inequities of support for people with particular characteristics and/or life circumstances.

Whilst there is a need for more research to improve palliative care a bigger issue is to consistently implement systems and practice which improve people’s experiences towards the end of life.

The question of how good palliative care is in Scotland is an important one because it has very significant implications for proposals to legalise assisted dying, in relation to safeguards and in relation to resources. These are explored below.

Consistent, Reliable and High Quality Palliative Care – a vital safeguard

Imagine you are a health or social care worker, supporting someone approaching the end of life, providing palliative care. You want to maximise their wellbeing, to listen to their fears and concerns and to try to meet their needs. They feel they have a poor quality of life and voice an interest in assisted dying – at this point it isn't a settled intent but rather it is a call for help. You know they would benefit from a package of care at home support, but you also know that due to tightened eligibility or workforce shortages or lengthy assessment processes you can't realistically offer them that when it is needed, or possibly at all. You believe they would benefit from specialist psychological support, but that service too is not available locally or has a huge waiting list. You know that they are concerned about how tired and stressed their carer is, especially at nights and weekends, but there is no 24/7 support line for them and the local district nurses just don't have the capacity to drop in regularly. Imagine how that person seeking help may feel, and what decision they may eventually reach.

The ready availability of good palliative care towards the end of life is a fundamental safeguard. A significant percentage of those seeking assisted dying in other jurisdictions are not in receipt of palliative care. Of those in receipt of palliative care and seeking assisted dying a larger percentage receive it only briefly.

In any socially just and compassionate society being concerned that good palliative care won't be available towards the end of life should never form part of anyone's decision to shorten their life. Experiencing deficient care or the non-availability of care towards the end of life should also never form part of anyone's decision to shorten their life.

High quality palliative and end of life care must therefore be consistently and reliably available to everyone in Scotland when they need it, and evidence must also be available to provide public reassurance about the quality of that care. Consequently significant investment in improving palliative care (in the broadest sense) should be an integral part of any move to legalise assisted dying. We explore resource issues later in this paper.

Eligibility Criteria for Assisted Dying

The proposed criteria are a reasonable attempt to provide a clear definition of eligibility. The key challenge is operationalising the criteria through a process of assessment. All people approaching the end of life are potentially vulnerable and it is vital that the assessment processes are well considered and as robust as possible.

Age

In young people the age of legal mental capacity to give consent should not be assumed to be the same as the age at which an individual achieves the cognitive and emotional ability to make a particular decision. For example there should be clear guidance as to whether and how a 16 year old with capacity, pre-existing mental health problems and/or impulsive behaviours and/or self-harm behaviours might be deemed eligible or ineligible.

Definition of Terminal Illness

The adoption of the BASRiS approach to identifying people who are "terminally ill" has the merit of consistency between different parts of the welfare state and avoids some of the issues related to predicting accurately when someone will die.

It is important that any Assisted Dying Bill should make full and detailed reference to the Chief Medical Officer's guidance[16] (or other similar new guidance) about how the definition on the face of the Social Security (Scotland) Act 2018 is to be operationalised in practise. The Social Security Act makes this connection and states:

"The regulations must provide that an individual is to be regarded as having a terminal illness for the purpose of determining entitlement to disability assistance if, ***having had regard to the guidance mentioned in sub-paragraph (3),*** *it is the clinical judgement of a registered medical practitioner that the individual has a progressive disease that can reasonably be expected to cause the individual's death".*

This is necessary because the simple definition on the face of the Social Security Act is very broad and imprecise. The Proposal (p21) states:

> "Terminal illness is defined, for the purposes of providing social security, as that suffered by those who are deemed by doctors as 'unable to recover', regardless of the time they have left to live".

This in itself is not accurate and would result in a very broad and imprecise eligibility. The Chief Medical Officer's BASRiS guidance provides a lot of detail and essentially attempts to narrow eligibility to people who already have advanced and very serious illness, not just a diagnosis of a condition which is likely to cause their death at some uncertain future timepoint, possibly some years off.

However, the BASRiS approach is still quite imprecise. This is an advantage when not wishing to exclude people from rapid receipt of financial support (BASRiS). However, as an approach for identifying people for assisted dying it will likely include some people who would otherwise live for a considerable period. If adopted it would be really important that the person seeking

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[16] Chief Medical Officer's guidance for clinicians completing a BASRiS form. Scottish Government (2021) https://www.socialsecurity.gov.scot/guidance-resources/guidance/chief-medical-officers-guidance-for-clinicians-completing-a-basris-form-for-terminal-illness

assisted dying clearly understands the imprecision involved and the implications for any decision to proceed.

The approach to determining eligibility for BASRiS relies on individual clinician judgement and it is likely to result in some inconsistencies of interpretation and outcome.

Future Broadening of Eligibility

It seems likely that the proposed Bill would be followed at a future point by a broadening of eligibility. Having established the right to assisted dying for some parts of the population it becomes difficult to deny that right to other parts of the population. Existing legislation is likely to be challenged on the basis of equalities and human rights. This is the experience for example in Canada where a law enabling assisted dying was passed in 2016. In 2021 the law was revised to broaden eligibility. From 2023 assisted dying will be available to people "whose only medical condition is a mental illness". Over time assisted dying will likely become less controversial and become normal. This shifting social and cultural context will facilitate broadening of eligibility.

As with the rest of this paper this likelihood is raised as something which it is important to consider.

Declaration / Assessment Process

Any legislation should provide clear guidance to healthcare professionals as to the standards of diligence required when assessing eligibility as part of the request process. Consideration should also be given as to whether assessing clinicians require any particular skills, expertise and knowledge beyond those universally required of all medical practitioners.

Assessment of Capacity

Severe mental disorder resulting in lack of capacity may be readily detectable. However, a potentially very common combination of factors affecting a requesting person (mild depression, mild cognitive impairment, multiple morbidities and an internalised perception that they are a burden to relatives or others) may be much more difficult to identify. The criteria should be clear as to whether such a person should or should not be eligible for assisted dying. If such a person should not be eligible for assisted dying then any legislation should contain adequate provisions for the identification and exclusion of such individuals.

The previously referenced study of the experiences of palliative care practitioners involved in assisted dying in Canada reported that the requirement for the person to have capacity can impact on symptom management strategies[17]. People were reluctant to receive sedative medication to control pain or other symptoms in case it impacted on their eligibility for assisted dying. People commonly wanted to delay assisted dying to spend time with family, but were also concerned that by delaying they might lose capacity and become ineligible. In these circumstances people sought guidance from palliative care staff about prognosis, which was difficult to provide with the precision sought.

Coercion and duress

Any legislation should provide clear guidance to healthcare professionals as to how they should seek to identify whether a person requesting assisted dying may be under coercion or duress.

Terminally Ill

Any legislation should be clear about the level of experience/expertise it deems necessary to determine whether the requesting person has a "terminal condition/illness". For example would a neurologist be required to determine this for patients with neurological conditions or would it be adequate for a general practitioner to make this determination? As mentioned previously the Chief Medical Officer's Guidance on BASRiS may be a useful model in respect of assessing whether someone is terminally ill.

Exploring the reasons for the request and "explaining" alternatives

Discussing with a person their reasons for requesting an assisted death, as proposed, requires high level communication skills.

The assessing doctor is also required to "*explain any feasible alternatives, which will normally include pain relief, hospice support and other palliative care packages that are available to the patient*." A stronger safeguard would be that the person should experience palliative care, if they are not already in receipt of such care. People commonly and understandably only appreciate the benefits of palliative care once it is experienced rather than explained in the abstract. There is an argument that informed consent on this decision necessitates a specialist palliative care assessment and input which should be a multidisciplinary assessment including psychosocial care needs – and clear documentation of what was discussed and what the unmet needs were and why.

Legislation should be clear about the level of knowledge and expertise required of the assessing doctor relating to these responsibilities. It would

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[17] *Impact of Medical Assistance in Dying on palliative care: A qualitative study* (2021) Mathews JJ, Hausner D, Avery J, Hannon B, Zimmermann C, al-Awamer A Palliative Medicine https://journals.sagepub.com/doi/abs/10.1177/0269216320968517

strengthen the safeguard to suggest referral to a palliative care specialist if the assessing doctor has any concerns. An even stronger safeguard would be for a request for assisted dying to be viewed as grounds for referral to specialist palliative care.

Timescale

Consideration should be given to a maximum timescale for the completion of the declaration, particularly the required assessments (including any required specialist opinions).

Previous relationship between the person and the assessing doctor

The proposal does not require the assessing practitioner to have any prior knowledge of the requesting person or their social and family circumstance. It could be argued that several aspects of the envisaged assessment are more difficult in these circumstances.

Delivery of Medication – potential complications and other issues

Any legislation should give consideration to dealing with medical complications arising during the assisted death. Experience from other jurisdictions suggests that complications are not unusual. Ingestion of medication is not a reliable route for some people, especially if they are already ill. People may vomit the medication or fail to absorb a lethal or rapidly lethal amount. The person may then not die, or the process of dying may be more protracted and distressing than expected. There is not an established evidence base on the best medications and routes of administration to achieve a pain-free dignified assisted death.

The role of any clinical professionals called to intervene in circumstances where complications arise need to be made clear. What is the duty of care owed in such circumstances? Will they be expected to administer intravenous medication to cause the person’s death if the oral route fails and/or causes distress? This need for clarity goes beyond the attending healthcare worker mentioned in the Proposal. There is a need for clarity for others who may become involved in the event of complications (e.g. ambulance staff, GP, A&E staff etc). All will need guidance and direction so that they are clear what actions are expected – they may have a concern about criticism and sanction for doing either too much or too little.

Aside from clinical complications it is easy to envisage complex scenarios being precipitated by the proximity of death and loss at the scheduled time of the assisted death e.g. sudden uncertainties, conflicts between family members, suggestions of undue influence. The attending healthcare professional would need to be equipped to cope with such circumstances, and be working within a clear framework of guidance.

The particular needs of people with reduced dexterity and/or swallowing difficulties should be considered. These are quite common symptoms (for example amongst people with some progressive neurological conditions). People with such conditions might chose an earlier death if self-injection or nurse injection were not available as options.

Monitoring and Oversight

The role, responsibilities and governance of the proposed “reporting body” needs more detailed definition.

A robust reporting regime should allow for monitoring, scrutiny, audit, regulation and research into a controversial, contested and potentially evolving area of public policy.

The reporting body should report to Scottish Ministers.

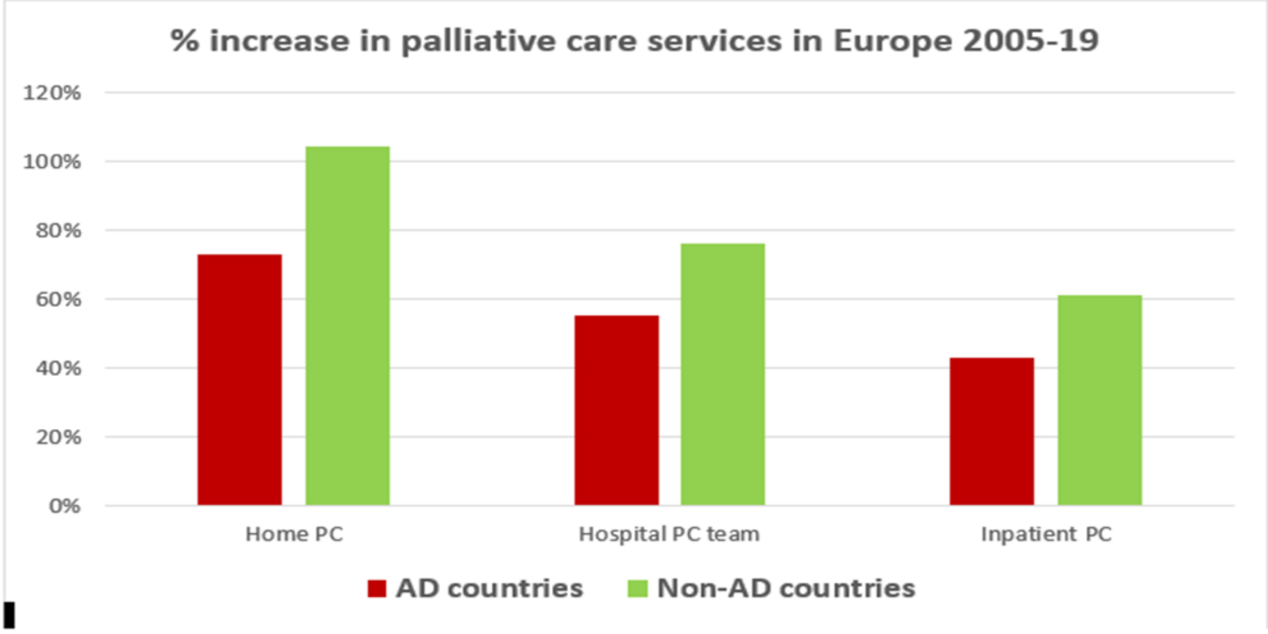
Information governance relating to the data gathered through the declaration, questionnaire and follow up forms should support exploration of important research questions.

Resources for Palliative Care and Assisted Dying

Since the consistent provision of high quality palliative care is an important safeguard to reduce the risks to vulnerable people of legalising assisted dying, investment to improve palliative care should be part of the identified resource implications of introducing assisted dying.

Using international examples the Proposal suggests that introducing assisted dying leads almost inevitably to investment in palliative care. The Proposal notes that when the Australian State of Victoria passed assisted dying legislation the government provided funding of Aus$72 million. This would equate to £33 million in Scotland, allowing for Scotland’s smaller population. The Proposal also notes that after assisted dying was legalised in Canada the government committed to providing $6 billion over ten years to improve palliative care. This would equate to £512m in Scotland again allowing for our smaller population.

However, there is no logical necessity that legalising assisted dying results in substantial additional investment in palliative care. Funding decisions are geographically, politically and institutionally contingent. A recent survey of the development of specialist palliative care in Europe shows that in Belgium and the Netherlands (where assisted dying and euthanasia are well established) there has been no increase in palliative care provision between 2012 and 2019[18]. Interpreting data of this sort and forming international comparisons is always difficult. However, illustrating graphically the data in this article casts further doubt on the suggestion that assisted dying always goes hand in hand with development of palliative care.



Assisted dying counties: Belgium, Netherlands, Switzerland
Non assisted dying countries: Austria, Denmark, Finland, France, Germany, Ireland, Italy, Norway, Portugal, Spain, Sweden, United Kingdom

Proponents and those contemplating voting to legalise assisted dying should seek firm commitments from Scottish Government about significant and specific investment needed to improve palliative care. SPPC would be happy to work with the proponents of the Bill to identify some of the resource requirements for improving palliative care. The Financial Memorandum accompanying the draft Bill should reflect costs relating to the improvement of palliative care in Scotland.

Although assisted dying may lead to some savings (people die earlier and so make less use of health and social care services) it is important to remember that additional costs may be incurred in one service/setting whilst savings accrue elsewhere. There is a concern that this may occur for specialist palliative care services. Whilst the Proposal does not stipulate that specialist palliative care practitioners should be involved in the provision of assisted dying such services can be expected to be working with people who are

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[18] Trends analysis of specialized palliative care services in 51 countries of the WHO European region in the last 14 years. Arias-Casais et al. Palliative Medicine. 2020 https://journals.sagepub.com/doi/10.1177/0269216320931341#_i7

seeking and eventually proceeding with assisted dying. Specialist services in other jurisdictions report increased demands on time and diversion of resources from palliative care in order to support people and families around assisted dying. Assisted dying may be experienced as an unfunded additional demand locally even though there may be net savings across the system. The reality for many services will be additional pressures and difficult choices between undertaking assisted dying assessment and its enactment, and meeting the needs of other people and their families.

Resourcing for appropriate frameworks of guidance and support to maintain the emotional, psychological and spiritual wellbeing of staff would be required.

The Proposal doesn’t reference the costs of the required lethal medication or staff time for assessment and attendance when the assisted death takes place. Perhaps this is because they are assumed to be less than any savings made, but again this presumes an effective mechanism for reallocating savings.

As part of any implementation of an Assisted Dying Act resources should be allocated to support a programme of research into the impacts on public attitudes and behaviours, the impacts on provision on mainstream care received towards the end of life, the experiences of people and their families, of staff involved and other relevant and emergent issues.

Rights and Priorities

The proposed legislation would create an explicit legal right to an assisted death, but as things stand there would be no corresponding explicit right to palliative care in Scotland.

At the end of this paper we suggest specific practical action on human rights and on resources for palliative care.

Other Comments

Conscientious Objection and Professional Regulation

Arrangements to support practitioners who have a conscientious objection to participation in the assisted dying process need to be very clear and robust. Similarly there would be a need for very clear guidance from the General Medical Council, General Pharmaceutical Council, and Nursing and Midwifery Council in regulating practice including investigation of complaints. This would require guidance specific to the Scottish legal position.

Staff Welfare

Some staff involved in the care of patients towards the end of life will experience moral distress as a result of assisted dying. Reports from other jurisdictions suggest that many practitioners struggle with ethical dilemmas and value conflicts (professional and personal). This is true for staff involved with people seeking assisted dying but not directly involved in provision. Appropriate frameworks of guidance and support for emotional, psychological and spiritual wellbeing of staff are a necessary part of any proposal for assisted dying.

Far fewer medical professionals report a willingness to being involved with assisted dying than express support for it in principle. Evidence suggests that support for assisted dying is lower amongst those specialties with extensive involvement with palliative and end of life care.

People with Additional Communication Needs

Arrangements would need to be made for people who have communication difficulties and who are unable to sign the required documentation. It should be made possible for the declaration/consent to be given in ways that fit with an individual’s communication needs – typed, using assisted technology, written, or verbal.

Remote and Rural Areas and Service Access

People in remote and rural areas may find it more difficult to access assisted dying. Difficulty in accessing the proposed assessment processes may also be experienced by people with mobility challenges, whether in rural or urban settings.

Storage of Medicines

It is proposed that the medicines required for assisted dying should be stored at a pharmacy. This may be difficult in remote and rural areas and it would be more likely that they be stored at a dispensing doctor’s practice.

Death Certification

The purpose of death certificates is to record objectively so far as can be determined the cause of death and that is the legal duty of the completing clinician. In the case of assisted dying the cause of death will be self-administration of lethal medication. Death certification also accommodates recording of underlying or contributary conditions. Not recording the actual cause of death, as the Proposal suggests, would undermine the basis of death certification in Scotland (and the public health record and research based on it). This approach seems out of line with the approach adopted in other "sensitive" circumstances of death. Not recording assisted dying on the certificate could create stigma about the person's choice.

Practical action on resources and human rights

There are obvious mechanisms within the Parliament and within the current Programme for Government through which MSPs and government could address the need for an explicit human right to palliative care, and also address the need for investment to improve palliative care raised earlier in this paper:

Human Rights

The Scottish Parliament should ensure that if it passes an Assisted Dying for Terminally Ill Adults (Scotland) Bill that it also places an explicit human right to palliative care on the face of the anticipated Scottish Human Rights Act. This would be in line with a recent resolution of the United Nation Human Rights Council adopted in October 2021[19], which calls upon states to ensure access to palliative care. Scotland could be a world leader in taking such a step.

Resources

Scottish Government's Programme for Government includes the development of a new strategy for palliative and end of life care. This is an obvious framework through which the very significant investment necessary for improvement of palliative care can be identified and applied.

Mark Hazelwood
CEO
Scottish Partnership for Palliative Care

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[19] *Resolution 48/3 Human Rights of Older People* UNHRC 2021 https://media2.giphy.com/media/i39RvwsBdgwUoS4GqZ/giphy.gif?cid=ecf05e472c1mjt77d7mmfwq6ovxcoqxvhdpyyiyjqqyhkou7&rid=giphy.gif&ct=g