Dear Miles Briggs MSP,

I write in response to your consultation, dated 7 March 2024, on a proposed Right to Palliative Care (Scotland) Bill. My name is Ben Colburn; I am Professor of Political Philosophy at the University of Glasgow, and an active researcher in medical ethics.

1. Do you agree that terminally ill adults and children and young people with life shortening conditions residing in Scotland should have a right to palliative care? Please explain the reasons for your response, including what you think a right to palliative care should deliver.

I strongly agree.

My research in recent years has focused on the ethics of end-of-life care, advocating for practices which support an individual's autonomy – that is, their capacity to be the author of their own lives – in the face of the complex predicaments faced at end of life. I believe that everyone has a right to individual autonomy, right up to the end of their life. I don't think that palliative care is necessarily the right option for everyone, so I think it's important to frame this as an option, rather than as a one-size-fits-all solution for everyone facing terminal illness. But my research has shown that both the option of palliative care, and effective palliative care itself, are powerful tools for upholding people's autonomy at the ends of their lives. So, people have a right to palliative care options, alongside other measures.

To uphold autonomy, palliative care must deliver meaningful choice. That means a meaningful choice about whether to pursue palliative care rather than some other end of life option, and also meaningful choices within palliative care. That is important for sustaining autonomy in itself: it seeks to make sure the individual remains the author of their treatment, and of the end of their life in general, and mitigates against the danger that people feel like they have lost control of their lives. Meaningful choices within palliative care are also important for making sure that the specific form of palliative care is one that speaks to their individual circumstances and priorities. I expand on that point below.

The research basis for these conclusions can be found in the following peer reviewed outputs:

Colburn, B. (2020) Autonomy, voluntariness, and assisted dying. Journal of Medical Ethics, 46(5), pp. 316-319. (doi: 10.1136/medethics-2019-105720)

Colburn, B. (2013) Autonomy and end of life decisions: a paradox. In: Räikkä, J. and Varelius, J. (eds.) Adaptation and Autonomy: Adaptive Preferences in Enhancing and Ending Life. Series: Studies in applied philosophy, epistemology and rational ethics (10). Springer: Berlin, Germany, pp. 69-80.

I have expanded further on the ways that palliative care can uphold autonomy in popular publications too, including:

Colburn B. (2016) Autonomy and creativity at the end of life, End of Life Studies Group Blog, University of Glasgow (http://endoflifestudies.academicblogs.co.uk/autonomy-and-

creativity-at-the-end-of-life/ [accessed 9 March 2024]. This is an expanded version of an article originally published in The Scotsman on 15 September 2016).

2. What is your view on the World Health Organisation definition of palliative care, that is the basis of statutory guidance in England on palliative care provision, being the basis for a legal right to palliative care? Please explain the reasons for your response, and whether you think a different definition of palliative care should be considered for health and social care legislation, human rights legislation, and other forthcoming legislation that is relevant to how people may experience end of life.

I am concerned that the WHO definition may be a bad basis for a right to palliative care in Scotland, in the sense that its use might inadvertently thwart your policy intentions. In this part of my response I will explain why, and also offer some ideas about how it might be contexualized within legislation so as to do the work needed for effective law and policy in Scotland.

There are two specific features of the WHO definition that give me pause.

The first is that it implies that something is an instance of palliative care only if it is successful (if it 'improves quality of life', or if it actually 'prevents and relieves suffering'.) My concern is that, if we define a right to palliative care in those terms, there will be a number of unintended negative consequences. First, it will engender unrealistic expectations. Palliative care can help, and is the right option for many people, but it isn't guaranteed to be successful, and it's not the right option for everyone at all stages in their end of life journey. It will be important at all stages, including in any legislation on this topic, to manage expectations and support people in having a realistic view of what palliative care can achieve for them.

Second, I am also concerned that this feature of the WHO definition might lead to undue pressure on practitioners. If the right is framed using the WHO definition, then strictly speaking someone whose quality of life isn't improved, or whose suffering isn't prevented and relieved, hasn't had their right to palliative care respected, even if the practitioner has done their utmost to achieve those things. I am concerned that practitioners in that – unfortunately very common – position shouldn't be liable for a failure to respect their patients' rights, or more generally labelled as failing.

This isn't a reason to abandon the WHO definition entirely, as a way of defining what palliative care is. I can see much value in converging on a definition which has legitimacy and authority, including from its inclusion in English legislation. But I would urge that the right (to palliative care so understood) is articulated in a way that makes clear what is a reasonable expectation: not (sadly) a guarantee of success, but a minimum standard of care which aims at the outcomes mentioned in the WHO report insofar as they are realistically achievable in a given case. Putting things that way - ie in terms of aims and expectations, not outcomes and delivery - would do better to manage expectations and protect practitioners.

The second feature of the WHO definition that concerns me is the way it lumps all of the aspects of a person's end of life predicament in together, listing 'suffering', 'pain', and

'physical', 'psychosocial' and 'spiritual' problems. As a basis for legislation, this risk implying that all these factors can be addressed consistently and by the same interventions. As above, I worry that that will engender unrealistic expectations. More to the point here, I think it avoids engaging the most important point about end-of-life care – the reason we might think people have a right to palliative care in the first place! – which is that terminal illness often involves very difficult trade-offs between these things. Very often a patient finds themselves having to choose between relieving pain and maintaining consciousness so they can sustain their psychological functioning and social relationships, for example. The risk in using the WHO definition is that it occludes this, and for that reason risks framing a right to palliative care in a way that doesn't give us resources to deal with difficult trade-offs in the right way.

This is a concern that I have investigated in joint work with Dr Jennifer Corns (Colburn B & Corns J Understanding and Enriching Agency in Palliative and End of Life Care. Macmillan Cancer Support. https://macmillan. fuseuniversal.com/ [Accessed 9 March 2024]). It is also the topic of joint research with Prof. Bridget Johnson, in which we have scrutinized the growing tendency to treat palliative sedation as the default option in late-stage terminal illness, and show that it is an inadequate response to the real diversity of individual circumstances and priorities. (Colburn, B. and Johnston, B. (2023) Palliative sedation: autonomy, suffering, and euthanasia. Current Opinion in Supportive and Palliative Care, 17(3), pp. 214-218. (doi: 10.1097/SPC.0000000000000665).

In brief, my concern is that the WHO definition risks de-emphasizing the importance of helping people understand and resolve difficult trade-offs in their end of life priorities for themselves.

I think we can still make use of the WHO definition of palliative care and take account of these concerns as long as the right to palliative care is framed carefully.

Of the factors present in the WHO definition, I think the central one is the aim of alleviating suffering. Following the research of Dr Jennifer Corns, I think we should understand suffering as significantly disrupted agency (Corns, J. (2022) Suffering as significantly disrupted agency. Philosophy and Phenomenological Research, 105(3), pp. 706-729. (doi: 10.1111/phpr.12841)). With that as a foundation, we can understand the primary aim of palliative care as the alleviation of suffering, in two senses: we want to tackle disruptions to suffering in all its forms (e.g. pain, social isolation, psychological distress, etc) and also to make sure that our approach is one which upholds the individual's agency in respect of their treatment, rather than compounding suffering by undermining it (as a one-size-fits-all solution would do).

The key, therefore, is to frame the right to palliative care in terms of upholding individual autonomy in end of life contexts. What individuals should be able to expect is access to a range of palliative interventions, some clinical and some non-clinical, and to supported decision-making. These things together will allow the individual to identify the right interventions to support them in managing their specific end-of-life trade offs in a way that reflects their own values and priorities.

I take it that in fact this describes existing good practice in many palliative care contexts. Framing the right to palliative care in these terms will allow us to reinforce and build on that good practice, and also alleviate the concerns I have articulated above about the WHO

definition, by encouraging realistic expectations and upholding and respecting individual autonomy at end of life.

I have developed some tools for this approach to palliative care in joint work with Dr Jennifer Corns and with Macmillan Cancer Care, available here: Colburn B & Corns J Understanding and Enriching Agency in Palliative and End of Life Care. Macmillan Cancer Support. https://macmillan. fuseuniversal.com/ [Accessed 9 March 2024].

3. Any new law can have an impact on different individuals in society, for example as a result of their age, disability, gender re-assignment, marriage and civil partnership status, pregnancy and maternity, race, religion or belief, sex or sexual orientation, caring responsibility, or location (urban or rural and island community settings). What is your view on the different impacts that a right to palliative care would have and the different considerations there would be in implementing that right for different groups and people in Scotland living with terminal illness(es)? Please explain the reasons for your answer, including the impact this proposal could have on particular people if it became law, and if there are any ways you think the proposal could avoid negative impacts on particular people.

I think the right to palliative care would benefit all groups within society by offering individuals an important and valuable option for their end-of-life journey. If implemented properly, i.e. by focusing on upholding autonomy and alleviating suffering in its various forms, and by attending to the specific circumstances and priorities of the individual patient, I think it would go a long way towards mitigating existing inequalities people from marginalized groups face in their experiences of death and dying (see e.g. the recent University of Glasgow – Marie Curie exhibition 'The Cost of Dying' for powerful evidence of those inequalities).

There is one potential problem here, in terms of possible impact on people with disabilities, which I think it's important to consider when framing new laws in this area. It's a problem not for a right to palliative care itself, but a problem that arises if that is the only option for a person facing their end-of-life predicament. My research has shown that there is a real concern amongst people with disabilities that their end-of-life treatment can be framed in ways that show disrespect for their ability to understand and make decisions for themselves about what they want to happen. For example, opposition to assisted dying laws is sometimes framed in terms of 'protecting' people with disabilities, a framing which is experienced as discriminatory and disrespectful. Participants in one study 'often expressed concern that disabled people may be especially vulnerable to being denied end-of-life choices because of the way they are devalued in society', and that 'people with disabilities may be denied choice because they are assumed incompetent to make their own decision' (Fadem, P., Minkler, M., Perry, M., Blum, K., Moore Jr, L. F., Rogers, J., & Williams, L. (2003). Attitudes of people with disabilities towards physician-assisted suicide legislation: Broadening the dialogue. Journal of Health Politics, Policy and Law, 28, 977–1001: 987-8). I think we should take that worry very seriously. It shows us that there would be something discriminatory – against people with disabilities, and potentially against other vulnerable

people with protected characteristics – in framing a legal right to palliative care in a way that makes palliative care the only option for a person facing terminal illness, or fails to provide meaningful options within palliative care, even if that right were articulated in terms of 'protection' for the vulnerable. We should, in a nutshell, aim for empowerment, not protection.

The research basis for this recommendation is in Colburn, B. (2022) Disability-based arguments against assisted dying laws. Bioethics, 36(6), pp. 680-686. (doi: 10.1111/bioe.13036). That piece also contains references to further evidence, primarily from assisted dying debates, but it is also relevant to discussions around palliative care for people with disabilities too.

4. What is your view on how a right to palliative care should be implemented? For example, you may wish to consider which bodies would be responsible for delivering palliative care and what their duties may be, and what data would need to be collected to assess how the right is being implemented.

To draw together some threads from my other responses: I think a right to palliative care needs to be implemented in a way that meets four key criteria. It must (a) uphold individual autonomy by (b) alleviating suffering in a way that is (c) responsive to specific individual circumstances and priorities, especially through (d) provision of meaningful choice especially when there are difficult trade-offs to be made. There is useful research on positive ways in which the option of palliative care could be designed so as to meet these criteria (as well as identifying some pitfalls to be avoided), e.g. Colburn, B. & Corns, J. (2023) Understanding and Enriching Agency in Palliative and End of Life Care. Macmillan Cancer Support. https://macmillan. fuseuniversal.com/, and Colburn, B. and Johnston, B. (2023) Palliative sedation: autonomy, suffering, and euthanasia. Current Opinion in Supportive and Palliative Care, 17(3), pp. 214-218. (doi: 10.1097/SPC.0000000000000665). Both of those sources include references to further useful research on this topic.

Concerning which bodies should be responsible for delivering palliative care, I tentatively agree with the proposal that this be Integration Authorities working with existing health and social care infrastructure. I think the key is to find a balance between recognising the wisdom and experience represented by our current mosaic of providers (including some really excellent palliative care hospices), and also recognising the need to make sure this diversity is resilient (especially financially), robust (in terms of high expectations across the board) and accessible (in terms of it being easy for an individual patient to see what their options are and make meaningful choices between diverse options).

The list in the consultation of data to be gathered and published seems right to me.

5. Are there any other comments you wish to make on the proposed Bill, for example, on its financial implications, impact on equalities and sustainability? Please explain the reasons for your response.

I believe strongly that palliative care is the right option for some people facing terminal illness, and also that it is not the right option for other people. I think it is important that any new law is framed in a way that doesn't presume a 'one size fits all' solution or impose

palliative care as the only end of life pathway for everyone in Scotland. I have in mind especially the relationship between palliative care and the option of an assisted death, currently not legal in Scotland but the subject of a separate private member's bill. Commentators on end-of-life care sometimes treat palliative care and assisted dying as rivals, as though supporting one means not supporting the other. The claim is sometimes made that legalized assisted dying results in less support and fewer resources for palliative care, or that a well-funded and universally accessible scheme of palliative care would undercut the justification for assisted dying laws.

My research has refuted these claims (cf. Colburn, B. (2022) Disability-based arguments against assisted dying laws. Bioethics, 36(6), pp. 680-686. (doi: 10.1111/bioe.13036) at 684-5 and Colburn, B. (2020) Autonomy, voluntariness, and assisted dying. Journal of Medical Ethics, 46(5), pp. 316-319. (doi: 10.1136/medethics-2019-105720). In fact, social and financial support for palliative care is high, and tends to rise, in places where assisted dying is legalized. And – this is the more important point – the antagonistic framing of palliative care and assisted dying, as though we have an either-or choice between them as a society, is a serious mistake. In fact, these proposals complement each other because both are important for upholding autonomy and alleviating suffering for people in terminal illness. The key thing is to provide meaningful options for someone in that position so they can make the right decisions for themselves given their individual circumstances and priorities. A right to palliative care will be a vital part of that, even if it cannot by itself provide every individual with all they need at all stages of their end-of-life journeys.

Professor Ben Colburn, University of Glasgow, 9 March 2024

Data protection statement: I confirm that I have read and understood the privacy notice (referred to above) to this consultation which explains how my personal data will be used.