30 July 2019

Anthony Hill
Health and Disability Commissioner
By email: sue.o'connor@hdc.org.nz

Dear Mr Hill,

End of Life Choice Bill – Consultation on Draft SOP

Thank you for your letter dated 25 July 2019 providing feedback on version 6 of the draft Supplementary Order Paper (draft SOP) on the End of Life Choice Bill. I have welcomed consultation with you on the draft SOP as some of it relates to the Health and Disability Commissioner Act 1994 (HDC Act), the Code of Health and Disability Services Consumers' Rights (the Code) and the functions of the Office of the Health and Disability Commissioner.

Over the last few months I have been working with the Parliamentary Counsel Office (PCO) and have been provided advice from both the Ministries of Health and Justice while consulting with a range of organisations and Members of Parliament to allay any remaining concerns about the Bill. Some further changes have been made to the draft Bill you received as a result. I am confident that the finalised SOP will address all valid concerns raised with me.

I am pleased to note from your letter that the draft SOP's amendments to the HDC Act and Code addressed some of your previous concerns about the Bill. In relation to your further recommendations and as explained below:

- some were addressed already in line with departmental and PCO advice (clause 18B; inclusion of nurse practitioner in relation to assessment of pressure);
- some further amendments have been made in response to your letter following consultation with PCO (clause 7(3); to clarify investigation of a breach of the Code, clause 24C; to further clarify limitations of specific rights in the Code)
- the remaining two issues are already addressed by the drafting in the Bill and / or operation of steps in the Bill which may have been missed or misunderstood (requirement for medical practitioner to read files and examine person and ongoing obligations in relation to competency are already addressed within the Bill).

To assist, I attach a table outlining the safeguards in the Bill over the various steps.

I respond below in detail to your recommendations in the order of recommendations set out in the appendix of your letter.

Clause 7

I received advice in line with your recommendation that this provision was unclear, and PCO has subsequently amended clause 7(3) to address these concerns.

Clause 7(3) in version 6 of the draft SOP stated that a person who initiates or makes a suggestion of assisted dying "is to be treated as having acted in breach of [the Code.]" I note that this provision has been deemed to interfere with the HDC's function of investigating whether a breach of the Code has occurred, as it assumes a breach before an investigation is undertaken by the HDC.

Clause 7 now states that a health practitioner who contravenes clause 7 "may under the Health and Disability Commissioner Act 1994 be found by the Health and Disability Commissioner or held by the Human Rights Review Tribunal to have acted in breach of the Code of Health and Disability Services Consumer's Rights by providing services that do not comply with relevant legal standards."

Clause 8

A question is raised in your letter about whether an attending medical practitioner is required to complete a competency assessment to ensure the person "understands their other options" or "knows that they can decide" at clauses 8(2)(c) and (d) in order to obtain informed consent for assisted dying.

I believe there is a misunderstanding about the steps in the process.

Both PCO and external legal counsel advise that informed consent is ensured in the draft SOP by the preliminary requirements in clause 8 to provide information to a person about their options (among other things) and the requirement to assess competency to make an informed decision about assisted dying (clause 4A) at least twice and potentially three times before being found to be an eligible person.

More specifically, clause 8 is a preliminary step, setting out requirements that must be met before a person can make a formal request for assisted dying and before the eligibility criteria is assessed (including the formal competency assessment). The purpose of clause 8 is to enable information to be provided and discussions to be had (including with family and other health practitioners) before a person takes any further steps. The person must be made aware of their prognosis, their other options for end of life care, and that they can change their mind at any time, as well as other information. It is designed to enable the information to be provided, and the discussions to be had over time and at a pace that reflects the progress of the person's illness. It does not mean that a person will go ahead or progress with an assisted dying request.

If a person does not go ahead with the request, there is and was no need to assess their competency. However, if the requirements in clause 8 are met and a person does make a formal request, the formal competency assessment must be undertaken. As set out in the Bill, this requires an assessment of their understanding of information received, the ability

to retain the information and to use and weigh it as part of the process of making the decision. Competency must be assessed again by the independent medical practitioner and, if there is any doubt by either the attending or independent medical practitioner, by a psychiatrist.

Note that, if a medical practitioner considers a person does not understand their options for end of life care or that they can change their mind the clause 8 requirements are not met (so the process ends there). If the person appears to understand but there is some doubt about competency, this would be addressed at the assessment stage including by a referral to a psychiatrist where required. It is not necessary to have an additional formal competency assessment at this preliminary information stage, when, if the clause 8 requirements are met and the person wishes to make a request, a competency assessment is undertaken at the very next stage.

Clause 10

A concern is raised that while the independent medical practitioner and specialist are required to read the person's medical notes and examine the person in clauses 11 and 12, there is no such requirement specified in clause 10 for the attending medical practitioner.

Again, it is important to consider clause 10 in the context of the other steps. This requirement is not specified in clause 10 because the extensive requirements in clause 8 and 9 mean that the attending medical practitioner (unlike the independent medical practitioner and psychiatrist) will have already examined the patient and be familiar with the patients' medical file. As the patient's doctor, the attending medical practitioner will have access to the patients file. The extensive requirements in clause 8 also mean that the attending medical practitioner must read the files and examine the person, for example the requirement to give the person the prognosis for the person's terminal illness, the requirement to confer with other health practitioners in contact with the person, the requirement to provide information on other end-of-life options and the requirement to have discussions with the person on multiple occasions. Therefore, I consider this matter already met without the need for an amendment.

Clause 14, Clause 15, and Clause 16

Throughout your letter you have noted a concern that a person may be assessed as competent at the eligibility assessment stage but could subsequently become incompetent and still receive assisted dying. You recommend that additional competency assessment be required in clauses 14, 15, and 16. This view appears to be based on a (mistaken) interpretation of the Bill: that there are not further requirements on the medical practitioners in relation to competency after the eligibility assessment stage.

To clarify, the Bill has been drafted by PCO to specifically ensure that assessment of competency is required on an ongoing basis and, accordingly, is already specified in the Bill. In particular, this requirement is provided through the definition of "eligible person" as explained below:

- Following the opinion reached that a person is an eligible person for assisted dying, the draft SOP text refers to an "eligible person" in clauses 14A, 15, and 16. An "eligible person" is defined in clause 3 as "has the meaning given to it in section 4." The meaning in section 4 is a person competent to make an informed decision about assisted dying, the meaning of which is defined in clause 4A.
- This drafting technique is deliberately designed to ensure an ongoing obligation in relation to competency. It requires that a medical practitioner is satisfied that a person is competent to make an informed decision about assisted dying on an ongoing basis, including during the processes in clauses 14A, 15 and 16. If a person loses competency, they cease to be an "eligible person" and are unable to progress. A medical practitioner would be in breach of clauses 14A, 15 and 16 and face criminal charges if they proceed where a person is not.
- This drafting was considered most effective in ensuring an ongoing obligation. Requirements at specific stages are problematic from a drafting perspective, do not fit well with the definitions and design of the Bill and do not provide any further protection given the ongoing obligations that exist.

A question is also raised as to whether clauses 14(e)(ii), 15(3)(d) and 16(2)(b) provide for a de facto advanced directive. I can assure you that these clauses do not provide for a de facto advanced directive. An advanced directive is a legal document which specifies what actions should be taken for a person's health if they lose competency and are no longer able to make decisions for themselves.

While the process set out in the Bill allows for a person to delay the administration of medication for up to a period of six months, the person must be competent to make an informed decision about assisted dying under the requirements of clause 4A up to the moment of administration. The person must be competent at all times.

It is noted that the attending medical practitioner or nurse practitioner at the chosen time of administration must ask the eligible person if they "wish" to either receive the medication, to receive it at a different time not more than six months from the date initially chosen, or not to receive the medication and rescind the request, and it is queried why the original word "choose" has been replaced with "wish."

This drafting change was made by PCO to simply align the text with the word "wish" in clauses 8(1), 9(2), and 14A. Whether the word "wish" or "choose" implies a different level of mental competency is debateable, however, I have accepted your preference for the word "choose" to be used at clause 16(2) and PCO have amended the draft SOP accordingly.

Clause 18

It is noted that the draft SOP moves clause 22A from Part 3 of the Bill to Part 2 to be renamed clause 18B. This clause ensures that if a medical practitioner suspects on reasonable grounds that a person is not expressing their wish free from pressure that they should take no further action.

While you rightly recommend amending this clause to include nurse practitioners, this clause has been amended to include references to nurse practitioners following advice from the Ministry of Health.

Clause 24 C

You note that clauses 4(1)(f), 4A, 10(2)(c), 11(3)(c), and 12(3)(c) of the draft SOP require that a person seeking assisted dying is medically assessed to be competent to make an informed decision about assisted dying and able to provide informed consent as only persons who are competent to make informed decisions about assisted dying should be able to access assisted dying services.

Clause 7 of the draft SOP states that a health practitioner who provides any health service to a person must not, in the course of providing that service to the person initiate any discussion or make any suggestion to the person that in substance is about assisted dying or a suggestion that the person exercise the option of assisted dying.

As both of these policies run contrary to specific Rights within the Code because they intend that practitioners do not proactively raise the option of assisted dying and do not rely upon advanced directives, it is necessary for the avoidance of doubt to ensure the situation is clear and the law accessible.

For this reason, the draft SOP states in clause 24C that the provisions of this Act override rights 6 and 7 of the Code of Health and Disability Services Consumers' Rights.

Your request to limit the application of these rights in a specific way is consistent with other advice I've received. PCO have amended the draft SOP in a way that accommodates your concerns and at the same time ensures the provisions are clear to the reader. For operational clarity it is preferable that only one section sets out how the Code operates with the End of Life Choice Act and due to specificity is able to be easily amended if the Rights in the Code are renumbered without an amendment to the Act.

For this reasons PCO have deleted section 24C and inserted in the Schedule, Part 2, the specific rights overridden by sections of the End of Life Choice Act.

I thank you for your comments on the draft SOP.

Kind Regards,

David Seymour
Leader of the ACT Party and MP for Epsom