House of Representatives

Supplementary Order Paper

Tuesday, 20 August 2019

End of Life Choice Bill

Proposed amendment to SOP 259

Chris Penk MP, in Committee, to move the following amendments:

New clauses 18C – 18H

After clause 18B (page 17), insert:

18C Independent panel of practitioners to determine whether pressure present

(1) The Minister of Justice must establish the Independent Panel of Practitioners ("the Panel"), which is to be administered by the Ministry of Justice.

(2) The Panel is an independent specialist body of an inquisitorial nature, established for the purpose of ensuring that requests for assisted dying are not made as a result of coercion or other forms of pressure.

(3) The Panel shall comprise no less than 12 members, being —
- (a) a chair, namely a District Court Judge;
- (b) expert medical practitioners (including experts in geriatric care, psychology and adolescent mental health);
- (c) expert legal practitioners;
- (d) expert social workers;
- (e) elder abuse experts;
- (f) other experts whom the Minister considers appropriate.

(4) For the purposes of subsection (3), an expert shall be a person who has gained at least 15 years of experience practising in their field.

(5) The chair of the Panel is to be appointed by the Governor-General on the advice of the Attorney-General, given after consultation with the Minister of Justice, the Minister of Health and the Minister for Seniors.

(6) The members of the Panel are to be appointed by the Governor-General on the recommendation of the Minister of Justice made in consultation with the Minister of Health and the Minister for Seniors, and may hold office for such period not exceeding 5 years as is fixed in each member's warrant of appointment.

(7) The chair or any member of the Panel may be reappointed.

(8) None of the following persons may be appointed as a member of the Panel:
- (a) any member of the SCENZ Group;
- (b) any member of the Review Committee.

18D Functions of Independent Panel of Practitioners

(1) The functions of the Panel are to:
- (a) consider, in committees comprising no less than four members, requests to receive assisted dying that have been made by persons under this Act; and
- (b) determine whether a request to receive assisted dying has or may have been partly or wholly influenced by pressure from any person or circumstance; and
- (c) complete a written Report ("the Report") recording its determination; and
- (d) send the Report to —
  - (i) the attending medical practitioner; and
  - (ii) the independent medical practitioner; and
  - (iii) the Registrar; and
- (e) report annually to the Minister of Justice, the Minister of Health and the Minister of Seniors, as set out below.

(2) The Panel may make findings of fact and a final determination in furtherance of its functions under sub-section (1)(a) – (c).

18E Procedure of panel and role of chair

(1) The Panel may regulate its procedures as it sees fit, subject to the following provisions of this Act and to any regulations made under this Act.

(2) Each committee of the Panel must consist of —
- (a) at least 1 expert medical practitioner and 1 expert legal practitioner;
- (b) in cases involving a determination in respect of a person aged over 60 years, at least 1 expert medical practitioner, 1 expert legal practitioner and 1 elder abuse expert;
- (c) in cases involving a determination in respect of a person aged under 20 years, at least 1 expert legal practitioner and 1 expert medical practitioner with a speciality in adolescent mental health.

(3) In addition to determining requests under section 18D (1), the chair of the Panel is responsible for—

(a) making such arrangements as are practicable to ensure that the members of the Panel discharge their functions in an orderly and expeditious manner; and
(b) directing the education, training, and professional development of members of the Panel; and
(c) dealing with any complaints made about members of the Panel.
(d) issuing practice notes (not inconsistent with this Act or any regulations made under it) for the purposes of regulating the practice and procedure of the Panel;
(a) developing a code of conduct for members of the Panel;
(b) requiring particular members of the Panel to determine particular requests, subject to sub-section (2) above.

18F Procedure for determining pressure

(1) The Registrar (Assisted Dying) must send a copy of any completed request form (section 9(5)(c)) and any completed first opinion form (section 10(3)(b)) to the chair of the Panel immediately following his/her receipt of those forms from an attending medical practitioner.

(2) Before making a determination under section 18D(1)(b) the Panel must, in respect of a request by any person to receive assisted dying under this Act, do all of the following —

(a) review the person's completed request form and the attending medical practitioner's first opinion form;
(b) review such records from the person's medical history which the Panel reasonably requests the person to authorise the disclosure of;
(c) review the person's current home or place of residence;
(d) review the person's living will (if in existence);
(e) review the person's financial and property affairs;
(f) refer the person to an independent psychiatrist for a written evaluation of their current mental state, and consider that evaluation;
(g) meet and interview the person;
(h) meet and interview those members of the person's family and any friends or relatives of the person whom it reasonably considers necessary to assist it for the purpose of making a determination;
(i) interview other medical practitioners who are treating or who have treated the person, including the attending medical practitioner;
(j) interview (if applicable) the person's usual lawyer and usual accountant;
(k) make and retain a recording of all interviews.

(3) In making a determination under section 18D(1)(b), the Panel must consider whether any person or organisation may stand to gain financially or otherwise by the person receiving assisted dying, and whether the person is or may be exercising their wish as a result of any one or any combination of factors including, but not limited to –

(a) familial coercion or other familial pressure;
(b) medical or institutional coercion or other pressure;
(c) familial neglect;
(d) medical or institutional neglect;

(e) societal neglect;
(f) any failure or failures of care or treatment by the New Zealand health system in respect of the person;
(g) any adverse mental health condition; and
(h) any other form of pressure.

(4) The Panel must complete and send its Report to the recipients listed in section 18D(1)(d) with all reasonable diligence and speed.

18G Procedure to be followed once Report compiled

(1) The independent medical practitioner must not reach an opinion as to the eligibility of a person for assisted dying under section 11(3) until that practitioner has received a Report from the Panel in respect of the person.

(2) If the Report from the Panel determines that a person requesting assisted dying has or may have been partly or wholly influenced by pressure from any person or circumstance, the attending medical practitioner or independent medical practitioner must —
(a) take no further action under this Act to assist the person in exercising the option of receiving assisted dying; and
(b) tell the person that they are taking no further action under this Act to assist the person in exercising the option of receiving assisted dying; and
(c) provide a copy of the Report to the person; and
(d) complete an approved form recording—
(i) that they have received the Report and provided a copy of the Report to the person;
(ii) that they are taking no further action under this Act to assist the person in exercising the option of receiving assisted dying; and
(iii) the actions they have taken to comply with paragraph (b); and
(e) send the form completed under paragraph (d) to the Registrar.

(3) Nothing in this section limits or overrides the obligation on an attending medical practitioner or nurse practitioner to take no further action in the circumstances set out in section 18B of this Act.

18H Annual report on performance of Panel's functions

(1) The chair of the Panel must, in each year, provide a report to the Minister of Justice, the Minister of Health and the Minister for Seniors on the performance of the Panel's functions under this Act in respect of the preceding year.
(2) The report must include the following details:
(a) the number of determinations made by the Panel in the period to which the report relates; and
(b) the nature of the determinations made by the Panel in the same period, in particular –
(i) how many requests for assisted dying it determined had been or may have been partly or wholly influenced by pressure from by any person or circumstance; and —

(ii) if any such determinations were made, which types of pressure listed in section 18F(3)(a) – (h) the Panel detected; and

(c) any features or characteristics of the requests which it has determined during the same period that give the Panel any cause for concern; and

(d) any recommendations the Panel may see fit to make to the Ministers.

(3) The Minister of Justice must present a copy of the annual report to the House of Representatives as soon as practicable after it is provided to that Minister.

Explanatory Note

This amendment to the sponsor's SOP 259 seeks to strike a better balance between choice and coercion in the Bill, ensuring that those who are truly exercising a voluntary choice to requested assisted dying are not impeded in that endeavour, while vulnerable New Zealanders, whose choice may have been impacted by pressure, are given the protection they need. However, even with this amendment, absolute certainty of the absence of coercion in a case of assisted dying is not possible. Still, this amendment offers a far greater degree of protection to vulnerable New Zealanders than the coercion test in new clause 18B of SOP 259.

The Explanatory Note to the Bill states that the proposed law is targeted to only a small group of New Zealanders who are "not vulnerable" and who wish to die without unbearable suffering and pain, and asserts that the Bill contains "a comprehensive set of provisions to ensure this is a free choice, made without coercion". However, the coercion safeguards which the Bill provides in its current form, as well as in the amended form proposed by SOP 259, are entirely inadequate in affording that protection and are deficient in multiple respects. Both documents place the entire burden of detecting coercion on a single doctor, who may not even know the patient or have ever met them before, who is merely required to "do their best" to assess whether the patient is being pressured, and who is significantly impeded in that endeavour by the fact that they can only speak to members of the patient's family whom the person approves. Even those legal standards protecting New Zealanders from the loss of their chattels or property through coercion set the bar higher than this test.

In its Report to the Justice Select Committee the New Zealand Royal College of New Zealand General Practitioners labelled the Bill's coercion safeguard as problematic, stating that "coercion of patients will be impossible to discern in every request for assisted death", and that vulnerable people would die wrongful deaths if this was to be the Bill's only test for coercion. Similarly, in her submission to the Select Committee the New Zealand Disability Rights Commissioner described the Bill as "woefully inadequate" and unsafe, stating that it undermines the position of vulnerable New Zealanders and poses significant risks to them, as individuals and as a group, and that the proposed safeguards in the Bill "are deficient, both procedurally and substantively, for both terminal and non-terminal conditions…". Courts in the United Kingdom have also recently found that not even a lengthy court-based inquiry, relying on legal precedent and extensive powers of enquiry, evidence and cross examination, can accurately detect coercion or provide a complete safeguard against it.i In its present form, the Bill will require one doctor to achieve in a relatively short space of time what an entire judicial system may not be able to accomplish across weeks or months.

Coercion and pressure amongst New Zealand's vulnerable communities is a serious and growing problem, and can manifest itself in numerous forms:

1. Elder abuse is endemic in New Zealand. A major study in 2015 found that 10 per cent of elderly New Zealanders (nearly 70,000) have suffered some form of abuse, either physically, sexually, psychologically, financially or through neglect.[ii] Another study has found that 79% of elder abusers are the family / whānau members of the victim, that their children are the most common category of abuser (48%), that elder abuse victims are often very old people in poor health, especially women, and that financial and psychological abuse are the most common forms of elder abuse and neglect.[iii] In addition, of those elder abuse cases involving older people living in residential care, 67% of abusers were family / whānau members while 20% of abusers were staff of the facility. In another recent report the Office for Senior Citizens has found that older Māori, women, and New Zealanders who are separated, divorced or widowed face higher rates of elder abuse, and has projected that the number of older New Zealanders experiencing elder abuse and neglect will increase significantly in the next 20 years.[iv] A recent University of Otago study found that one in five elderly New Zealanders identify as being chronically lonely,[v] while Age Concern reports that loneliness and isolation are common denominators in many cases of elder abuse.[vi]

2. New Zealand's health system is under considerable pressure and this in turn is impacting vulnerable New Zealanders who are accessing healthcare. Across the board, New Zealand's health care system is already at near breaking point as a result of underfunding and population growth.[vii] Elderly New Zealanders currently consume 42% ($983 million) of the health services budget of the Ministry of Health, the same government department that would bear responsibility for overseeing and administering assisted dying under the End of Life Choice Act.[viii] As New Zealand's population is aging rapidly, the Ministry of Health reports that "[p]opulation ageing without health improvement will cause this [42%] share to increase".[ix] Māori constitute a significant proportion of New Zealand's burgeoning older population who are poor and sick, and the absolute number of this older Māori population has been projected to almost treble between 2001–2021.[x] Māori are disproportionately represented in New Zealand's terminal illness rates and there are significant disparities between Māori and non-Māori across a number of serious health conditions including cardiovascular disease and heart failure, rheumatic heart disease, and cervical, lung and liver cancer.[xi] In December 2018 the overall state of Māori health prompted the Waitangi Tribunal to commence an investigation into more than 200 claims that the Crown is operating a "sick, racist system that fails Māori", leading to Māori dying earlier and suffering the worst health outcomes.[xii] According to the Waitangi Tribunal, "Many of these illnesses and problems are practically at epidemic levels".

There is a reputable body of experienced opinion that has documented the harms which have resulted to vulnerable people, by way of coercion and abuse, in those few overseas jurisdictions that have legalised assisted dying. This includes judgments from the United Kingdom Supreme Court, Court of Appeal and High Court,[xiii] the Irish Supreme Court and High Court,[xiv] and the European Court of Human Rights.[xv] Many of these courts have rejected the conclusion of the trial judge, Justice Lynne Smith, in the 2012 judgment of *Carter v. Canada* to the effect that the evidence from other jurisdictions shows that the risks inherent in assisted dying have not

materialized. Widespread abuses have been documented in the Netherlands and Belgium. Abuses have been documented in Oregon and also in Canada, where euthanasia has only been legal for several years. Recently both the United Nations Special Rapporteur on the Rights of Persons with Disabilities and Canadian media have reported attempts by Canadian medical professionals to pressure sick, disabled or terminally ill patients into requesting assisted dying. Disparities in health care services in Canada are also placing pressure on the terminally ill. In May 2018 the Quebec College of Physicians warned the Health Minister that a shortage of palliative care services in parts of Quebec could be forcing patients to choose euthanasia as a way to end their lives. The College specifically warned the Minister that patients requesting medical aid in dying were getting priority access to available resources, "to the detriment of other patients" at the end of their lives. The letter stated: "Palliative care cannot be limited to access to medical aid in dying".[xvi]

In Oregon, 63.3% - 66.9% of all assisted suicides during the past five years were of people on low incomes who were accessing state health care insurance through the Oregon Health Plan.[xvii] The same Oregon Health Plan has denied coverage to terminally-ill citizens for their chemotherapy or drug treatments, instead offering to pay for the drugs enabling them to commit suicide under the Death with Dignity Act.[xviii] The Oregon Public Health Division's annual reports on assisted suicide also show that psychological concerns far outweigh any concerns related to physical pain amongst those patients who are assisted in their suicides.[xix] According to the most recent report, during 2018 one of the four most frequently reported end-of-life concerns and reasons expressed amongst those who were assisted in their suicides was being a "burden on family, friends or caregivers" (54.2%).

Against this domestic and international background, this amendment recognises that coercion of terminally ill New Zealanders may take a variety of forms, such as:

1. Elder abuse, whether physical, psychological or financial;
2. Overt or subtle pressure exerted by family members or friends;
3. Overt or subtle pressure exerted by medical practitioners or other persons involved in a person's care;
4. Pressures on a person arising from a failure by the New Zealand health system to adequately meet their needs (particularly prevalent amongst Māori and elderly New Zealanders);
5. Internalised pressures experienced by the person themselves such as feelings of abandonment, of being an unwanted burden on family, friends or caregivers, financial pressure, or depression.

A single doctor cannot tolerably be expected to discharge the all-important burden of assessing coercion in any patient. The following substantive amendments are therefore made to the Bill:

- An independent specialist body, the Independent Panel of Practitioners ("the Panel"), is to be established for the sole purpose of ensuring that requests for assisted dying are not made as a result of coercion or other forms of pressure (*new clause 18C(1)*):

- Members of the Panel are to be appointed by the Minister of Justice and the Ministry of Justice is to be responsible for servicing the Panel *(new clause 18C)*:

- The Panel is to be chaired by a District Court Judge and to be comprised of highly experienced practitioners in medicine, law, social work and elder abuse, who are better equipped by their expertise and experience to detect hidden forms of coercion and who can collectively pool that expertise through the creation of committees (*new clause 18C(3)*):

- The sub-panels are to contain at least 1 expert medical practitioner and 1 expert legal practitioner and - for assisted dying cases involving elderly persons or persons under 20 years of age - an elder abuse expert or an adolescent mental health expert (*new clause 18E(2)*):

- The Panel must consider each request for assisted dying, make findings of fact, and issue a final determination regarding coercion in the form of a Report which it must send to the relevant medical practitioners and to the Registrar (Assisted Dying) (*new clause 18D*):

- The assisted dying process is suspended during the first and second opinion processes of the attending medical practitioner and the independent (SCENZ) medical practitioner, so as to allow the Panel to conduct its determination and to complete and send its Report. However, the Panel must proceed with all reasonable diligence and speed (*new clause 18F(4); new clause 18G(1)*):

- The Panel must consider whether persons requesting assisted dying may be exercising their wish as a result of any one or any combination of coercive factors. It is equipped for this purpose with a range of information-gathering mechanisms and methods of interview (*new clause 18F(2) – (3)*):

- If the Panel determines that coercion is or may be present in a person's request, the attending medical practitioner or independent medical practitioner must take no further action to assist that person in exercising the option of receiving assisted dying (*new clause 18G(2) – (3)*):

- The Panel must provide annual reports on its progress to the Minister of Justice, the Minister of Health and the Minister for Seniors, who must then present the Report to the House of Representatives. Each report must document the number of instances of coercion which the Panel has detected in requests for assisted dying during over the preceding year, and any particular concerns it may have or recommendations it wishes to make (*new clause 18H*).

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[i] *R (Conway) v Secretary of State for Justice* [2017] EWHC 2447, [2018] 2 All ER 250 at [100]–[104], in a decision that was upheld by the UK Court of Appeal (27 June 2018) and the UK Supreme Court (27 November 2018).

[ii] Charles Waldegrave *Measuring Elder Abuse in New Zealand: Findings from the New Zealand Longitudinal Study of Ageing (NZLSA)* (Family Centre Social Policy Research Unit, 2015) at 12.

[iii] Judith A Davey and Jayne McKendry *Financial abuse of older people in New Zealand* (Institute of Policy Studies, Working Paper 11/10, November 2011) at 2.

[iv] Office for Senior Citizens *Towards gaining a greater understanding of Elder Abuse and Neglect in New Zealand* (June 2015) at 5.

[v] Hamish A Jamieson and others "Profile of ethnicity, living arrangements and loneliness amongst older adults in Aotearoa New Zealand" A national cross-sectional study" (2017) 37 Australasian Journal on Ageing 68 at 71.

[vi] Cherie Sivignon "Elder abuse often linked to loneliness and isolation: Age Concern Nelson Tasman" Stuff (online ed, New Zealand, 13 June 2018).

[vii] Audrey Young "Huge demand for services in Auckland stretches health system to the limit say bosses" *The New Zealand Herald* (online ed, New Zealand, 22 February 2018); and 1 News "'The system is so overstretched' – Andrew Little says health system underfunded by $2.3 billion" 1 News Now (online ed, New Zealand, 7 June 2017).

[viii] Ministry of Health "DHB spending on services for older people" (13 July 2016) <www.health.govt.nz>.

[ix] Ibid.

[x] Statistics New Zealand *Demographic Aspects of New Zealand's Ageing Population* (March 2006) at 21.

[xi] Ibid.

[xii] Carmen Parahi "Waitangi Tribunal investigates sick, racist health system that 'fails Māori'" *Stuff* (online ed, New Zealand, 15 October 2018).

[xiii] *R (Nicklinson) v Minister of Justice,* per Lord Neuberger at 121*;* Lord Mance at 183 and Lord Sumption at 224, 225, 229. See also *R (Conway) v Secretary of State for Justice* [2017] EWHC 2447, [2018] 2 All ER 250 at [100]–[104], a decision that was recently upheld by both the UK Court of Appeal (27 June 2018) and the UK Supreme Court (27 November 2018).

[xiv] *Fleming v Ireland & Ors* [2013] IESC 19 (019/2013).

[xv] AFFAIRE HAAS c. SUISSE (*Haas v Switzerland*, Application No. 31322/07, 20 January 2011), at 58.

[xvi] CBC News, "Lack of palliative care pushing Quebecers toward medically assisted death, College of Physicians says", 31 May 2018.

[xvii] Oregon Public Health Division, Oregon Death With Dignity Act: Data Summary 2018, 6: "The proportions of patients who had private insurance (32.4%) and Medicare or Medicaid insurance (66.9%) in 2018 were similar to those reported during the past five years (35.8% and 63.3%, respectively)". Medicaid Insurance is a federal program managed by the State of Oregon through the Oregon Health Plan which provides health insurance for low-income individuals.

[xviii] Bradford Richardson "Insurance companies denied treatment to patients, offered to pay for assisted suicide, doctor claims" *The Washington Times* (online ed, United States, 31 May 2017).

[xix] Oregon Public Health Division *Oregon Death with Dignity Act: 2018 Data Summary*, at 12.