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SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

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**Submission to ACT Legislative Assembly Select Committee on End-of-Life
Choices in the ACT**

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Executive Summary

While palliative care has developed substantially in our institutions and community over the past two decades, considerable staffing deficits still exist in our capacity to respond to suffering, especially when this is due to unrecognised and undertreated depression, existential angst, family distress, communication breakdown and other psychosocial challenges. Major staffing deficits still exist in psycho-oncology services across cancer services, medical services and palliative care. Without dedicated funding and educational programs to redress this, remediable suffering at the end of life will persist and be poorly addressed within the ACT.

The introduction of medically assisted dying is a disproportionate response that will cause more social harm than good through failure to protect the vulnerable, the mentally ill, those who are socially disadvantaged and disabled, and who may feel an inordinate pressure to sacrifice their lives perceived to be a burden to others. Legislators will find it impossible to develop adequate safeguards that can truly protect these vulnerable citizens. Legislators need to recognise that it is not simply a task of devising laws to permit a small number of citizens to exercise an autonomous right to receive euthanasia or medically assisted dying but, in reality, to subordinate such individual autonomy to protect the rights of the broader society. Legislators must ultimately choose between two systems, one that privileges autonomous choice for a small number who want to seek medically assisted dying, and one that subordinates such autonomy for a few to provide greater protection for the wider community who will be placed at risk by the introduction of medically assisted dying.

Such legislative choice recognises two systems, one set up to relieve suffering by empowering physician assisted suicide, and the second prioritising psycho-oncology and palliative care to ameliorate such suffering. Legislators would be naïve to think that all human suffering can be prevented, for although physical pain can be relieved, emotional and existential suffering are greater challenges within society. The development of the young disciplines of psycho-oncology and palliative care within our communities is essential to assist in the relief of such suffering. Legislators need to honestly face their inability to accomplish all of this, and to choose whether they serve the needs of the few

or the greater needs of the broader community with legislation that protects the vulnerable and enhances palliative care.

A. Introduction: Suffering - the nature of the clinical challenge in providing end-of-life care

Advanced cancer and progressive irreversible illnesses cause substantial suffering for patients. This is the major impetus to improve the care of these patients. Many studies have sought to better understand the nature of and causes of this suffering.

1. Suffering can be understood to result from any threat to the wellbeing and vital integrity of a person. This results in highly distressing emotions, often with a sense of loss and helplessness that endures.¹
2. So severe and overwhelming can this suffering be that its source may seem uncertain, its meaning dire, and it can appear to be beyond control.² This predicament may cause a person to feel desperate and seek to urgently re-establish a sense of control.
3. Researchers have identified six common predicaments towards the end of life that constitute the typical factors or pathways that are most likely to lead to suffering. These include: ³
 - 1) Inadequate symptom control;
 - 2) Undiagnosed depression & anxiety;
 - 3) Unaddressed existential distress;
 - 4) Unrecognized family distress;
 - 5) Fatigue, burnout, and demoralization; and
 - 6) Communication breakdown.

¹ Chapman & Garvin, 1993

² Cassell, 1982, New England J of Medicine

³ Cherny, Coyle & Foley, 1994

What is most striking from this categorization of clinical problems that patients face is the contribution that arises from psychological, psychosocial and existential factors. Indeed physical pain can invariably be well controlled, even if occasionally that region of the body needs to be anaesthetized. The wide variety of analgesics and the expert application of anaesthetic blocks like epidurals makes pain not a reason for people to consider euthanasia. Rather the existential, psychological or spiritual distress that causes suffering is much more challenging to specialist palliative care services, who are consulted in the most difficult of circumstances.

4. It is the contention of this submission that the most deficient part of our Australian, and indeed ACT, palliative care services is the provision of competent psychosocial care. This care is located within the expertise of psycho-oncology and consultation-liaison psychiatry services. While Australian palliative care services were substantially developed during the last two decades, this growth focused on providing palliative care physician and nursing services, but the provision of psycho-oncology and consultation-liaison psychiatry services have never been appropriately funded. A major developmental and educational need exists within the ACT to establish psycho-oncology and consultation-liaison psychiatry services in our networks of oncology and palliative care services.

B. What is the evidence for psychosocial services with palliative care and oncology?

5. To convince the ACT's Department of Health and Human Services that an unmet need exists which will necessitate the growth of new clinical programs to meet the basic requirements of patients with progressive disease and at the end-of-life, epidemiological evidence is needed to provide proof of this unmet need, this human suffering.

6. While specific studies have not yet been conducted in Australia, there are overseas studies that do provide evidence about the psychosocial distress and suffering found in this population of patients. Let us review these studies first of all.

In one major and recent epidemiological study of over 4000 patients with cancer in Germany, rates of formal psychiatric disorders were obtained by structured psychiatric interviews to demonstrate the nature of this problem.⁴

Mood disorders including depression

Current real time rate:	8.5% of cancer patients
Any one-year rate:	15.6% of cancer patients

Anxiety disorders

Current real time rate:	13.5% of cancer patients
Any one-year rate:	18.5%

Somatoform disorders (e.g. pain syndromes, hypervigilant focus on the body causing impairments)

Current real time rate:	5.6% of cancer patients
Any one-year rate:	10.3%

Substance use disorders (e.g. alcohol abuse)

Current real time rate:	5.5% of cancer patients
Any one-year rate:	9.0%

Post-Traumatic Stress Disorder

⁴ Mehnert et al, *J Clin Oncol*, 2014

Current real time rate: 2.5% of cancer patients

Any one-year rate: 3.2%

Organic psychiatric disorder (e.g. delirium – acute confusional states)

Current real time rate: 2.9% of cancer patients

Any one-year rate: 4.5%

These rates are substantially higher than community-based rates of mental disorders. Overall, some 32% of cancer patients declared unmet psychosocial needs in this recent study in Germany.

Other studies have confirmed the general ballpark figures of this Mehnert et al. study in Germany in 2014. For instance, meta-analytic studies have examined rates of psychiatric disorder across large numbers of observational studies and generated similar overall rates. Thus Vehling and colleagues (2012) reported that among all cancer patients the average prevalence rate of depressive disorders was **11%** (95 percent Confidence Intervals 8.1–15.1) and anxiety disorders **10%** (95%CI 6.9–14.8).⁵

Focusing specifically on palliative care patients, Mitchell and colleagues from around 100 studies reported rates of depression as **16.5%** (95% CI 13.1–20.3), Adjustment Disorders (problems coping adaptively) **15%** (95% CI 10.1–21.6) and Anxiety Disorders **10%** (95% CI 6.8–13.2).⁶ Studies find higher rates of psychiatric disorder in palliative care and at the end-of-life because of the threat of death and the many cumulative losses that have taxed the coping and adaptation of these patients.

These rates are typically three times higher than the rates of mental illness in the general community and across the lifespan. Our clinical experience points to very similar rates occurring within the ACT community. Very few of these patients receive comprehensive psychosocial care for these disorders.

⁵ Vehling, Mehnert et al., PPM (2012),

⁶ Mitchell AJ et al., *Lancet Oncol* 2011; 12: 160–74; Walker J, Holm Hansen C, Martin P, et al. Prevalence of depression in adults with cancer: a systematic review. *Ann Oncol* 2013; 24: 895–900.

7. Given the substantial rates of poor mental health among these patients towards the end of their lives, we might well ask why clinical services are not equipped to respond to this unmet need. Palliative medicine is indeed a young and recently developed specialty, becoming formally taught in our Australian medical faculties following the establishment of academic units for palliative medicine by Governments in 1996. As mentioned, early funding was directed appropriately towards the provision of physician and nursing services, with relative neglect to date of comprehensive psychosocial services.

C. What is meant by Psycho-oncology and related psychosocial care services?

8. Psycho-oncology is a specialty discipline within cancer care that takes responsibility for two primary psychosocial dimensions of care provision:
 - a. The psychosocial response of patients, families and staff to cancer and its treatment at all stages of illness; and
 - b. The psychological, social and behavioral factors that influence the development, tumour progression and survival of patients with cancer.

Thus psycho-oncology contributes to cancer prevention, behaviours related to screening and early diagnosis, through to coping with the diagnosis and its treatment, survivorship (when cured) with all of the morbidity of long-term and late side-effects of treatment, recurrence and management of advanced cancer, palliative care, dying and bereavement for the relatives left behind.

Psycho-oncology is responsible for care delivered by a number of disciplines engaged with cancer care, principally social work, psychology and psychiatry, but also including contributions from specialty nursing, allied health disciplines like physiotherapy, occupational therapy, nutrition, music & art therapy, and pastoral care, and from general practice and community-based palliative care services. The complexity and co-ordination of care delivered by this diverse multi-

disciplinary group is one of the challenges and barriers to development of the discipline.

Both clinicians and researchers recognise the discipline of psycho-oncology. For instance, it is an integral part of the Clinical Oncology Society of Australia (COSA). The International Psycho-Oncology Society (IPOS), the international parent body of the discipline, recently celebrated the 30th anniversary of its founding. Nevertheless, as a young specialty (like palliative medicine), it has been the Cinderella in the development of oncology and palliative care services, arguably because of the common stigma that is associated with any form of mental illness, and none less so when patients struggle to cope with advanced illnesses that threaten life such as cancer.

While social workers assist with the many social and family problems that challenge patients, Clinical Psychology and Consultation-Liaison Psychiatry are two disciplines that form the bedrock of delivery of active psychological therapies within Psycho-oncology. Consultation-Liaison Psychiatry is the subspecialty within Psychiatry that cares for the medically ill across our general hospitals, and a subgroup of these clinicians specialize in oncology and palliative care.

It is the thesis of this submission that the time has arrived for the ACT to build Psycho-oncology programs comprehensively to enrich and optimise end of life care.

D. Is there worldwide support for the importance of these developments?

9. The Union for International Cancer Control (UICC) is one body that illustrates recognition of this need. The World Cancer Declaration (2013) was sponsored by the UICC, and it specifically recommended that **effective pain control and distress management services should be universally available by 2025**. Whereas palliative care programs address pain control, psycho-oncology

and psychosocial services are needed to address the suffering captured under the rubric of distress.

Historically the notion of vital signs in medicine includes the most basic of observations, such as recording a patient's temperature, pulse, blood pressure and respiratory rate. To improve pain control, the palliative care community advocated through the World Health Organization (WHO) to have pain recognised as the 5th vital sign. The psycho-oncology community has followed with advocacy that distress ought to be documented whenever present as the 6th vital sign. Echoing this, the formal policy statement of the UICC read,

Recognition of distress as the 6th vital sign will improve the treatment of cancer patients, improve outcomes for cancer patients, and improve the effectiveness of cancer care systems around the world.

The ACT has substantial work to do to reach this objective across the next decade.

A clinical model has developed which involves the **formal screening for distress**, lest it pass unrecognised because of the busyness and other challenges of clinical care provision. Indeed, many studies across recent decades had identified that psychiatric disorders such as clinical depression, anxiety and related syndromes of existential distress are missed in routine cancer care, despite the best efforts of cancer surgeons and physicians. Thus in 2014, a major Scottish study of 21,000 cancer patients revealed that 73% of depressed patients were not in receipt of treatment.⁷ They pass unrecognised and untreated because of the lack of a formal screening program.

Distress has also been seen as less stigmatized and more easily acknowledged than other states of mental illness such as depression. Hence a program known as "Screening for Distress" has emerged as a pragmatic pathway to first recognise and then alleviate this

⁷ Walker J, Holm Hansen C, Martin P, et al. Prevalence, associations and adequacy of treatment of major depression in 21,151 cancer outpatients: a cross-sectional analysis of routinely collected clinical data. *Lancet Psychiatry* 2014; published online Aug 28

suffering and improve the quality of our care. The ACT has made recent progress in introducing distress screening, but much service delivery must follow.

E. Screening for distress programs

10. In the ACT, screening for distress has been gradually introduced across recent years. The distress thermometer records a score out of 10 for distress. Scores higher than 7 have shown very good sensitivity and specificity for depressive disorders. Scores >4 point significantly to specific unmet needs that allied health services can be invited to respond to. Oncology nurses have generally taken up responsibility for screening for distress.
11. What has emerged since in the ACT is a substantial lack of services to refer these distressed patients to. While most services have access to social work, negligible psychology and psychiatry services can be found. There are significant inequities across metropolitan and regional zones, with major deficits in outlying sectors.

F. Why does the ACT have a paucity of psycho-oncology services in its cancer treatment programs?

12. There are a number of complex reasons to both explain the lack of current services and to recognise the potential barriers to their future development:

These include:

- a. Underdevelopment of clinical psychology in Australia, including Medicare funding restrictions upon episodes of care able to be provided.
- b. Focus of psychiatric services on inpatient and community mental health programs, to the serious neglect of the medically ill.

- c. The relative neglect of psychosocial needs of the medically ill since de-institutionalization of the mentally ill happened in the 1990s.
- d. Department of Health structures that separate responsibility for mental health and acute health, with resultant neglect of psychosocial needs within acute health.
- e. The ever increasing complexity of patient and family need within the development of medicine and its treatments.
- f. Separation of service provision across several disciplines, wherein no single discipline has the skill base within its membership to adequately address the diverse needs that patients and families want addressed. Thus social work runs a crisis-response service with no capacity for continuity of care; psychology is located within community mental health or general practice, but not oncology programs, and psychologists cannot prescribe psychotropic medication; psychiatry has the capacity to prescribe medication alongside deliver psychological therapies, but psychiatrists with expertise in caring for the medically ill are in very short supply.
- g. Historical gate-keeping mechanisms within general practice in our society, without the discipline of general practice being necessarily able to keep pace with the enormous specialty developments that have occurred in cancer care. This contributes to under-recognition and under-treatment of psychosocial concerns among the complex medically ill.
- h. Within oncology services, the complexity of anti-cancer treatments today demand so much focus by these specialists on radiation, immunotherapy or chemotherapy and related treatments that time does not permit comprehensive and person-centred care to adequately address psychosocial needs.
- i. Patient response is so often to turn to unproven therapies and alternative practitioners across the community, lacking awareness of the strong evidence-based help that is available from the discipline of psycho-oncology. Substantial community capital is expended on unproven therapies out of human desperation for help, without knowledge of the range of specialist psycho-oncology help that could be available if properly resourced.

- j. Lack of university-based educational programs for psycho-oncology. Indeed, training and supervision deficits ought not to be surprising given the global absence of psycho-oncology clinical services within the community.
- k. Individual disciplines can be inward looking and self-protective rather than patient-centric in their orientation. Disciplines with a stronger foothold may fear loss of territory and employment opportunity, limiting their advocacy for the building of comprehensive services. Yet only by comprehensive multi-disciplinary care, whereby the disciplines of social work, psychology and psychiatry work harmoniously together can the clinical challenges begin to be addressed. Once they begin to work together, these relationships invariably develop well and partner collaboratively to help patients and their families. The unmet clinical need is so huge that competition does not arise.

G. Are there opportunities that signify that the development of Psycho-oncology and related psychosocial services is possible?

- 13. Several developments offer confidence that the time is right for government and the Department of Health and Human Services to pursue the building of Psycho-oncology services:
 - a. The recent provision of some Medicare funding for clinical psychology opens up a fresh opportunity to harness this discipline to provide psychosocial cancer care. This has the potential to blend federal and territory funding sources.
 - b. World-wide recognition by human rights movements that psycho-oncology is a necessary and basic human right in cancer care.⁸
 - c. The complementary nature of the expertise that each disciplinary group within psycho-oncology can bring to patient and family care, with strengths within psychology to deliver therapies like cognitive-behavioural therapy, within social work to deliver family-centred care, and within psychiatry to

⁸ International Psycho-Oncology Society Human Rights Declarations

provide clinical diagnostic services, pharmacotherapy and other complex therapies, as well as overall leadership and clinical supervision of relevant programs.

- d. The broad use of Medicare-funded outpatient and community clinics moderate the cost burden to such developments at a territory level. While some inpatient consultation is needed, most psycho-oncology care can be delivered as an outpatient or community-based model.

H. How might the ACT proceed wisely to build these programs of care provision with cancer and palliative care services?

14. Workforce planning and development is needed to ensure an equitable and properly-funded range of programs to deliver this clinical care. This could be readily established through the creation of a Government-sponsored or Ministerial Task Force, created to guide the Department of Health and Human Services in this developmental agenda. Such a task force would need to be established as a multi-disciplinary advisory body, with appropriate consumer representation, to define the need and workforce profile that is required to be responsive to this unmet need, recommend guidelines for the equitable deployment of such a workforce, and work with the Department of Health to roll out this plan over a short period of time in an equitable and responsible manner.

15. This process recognises:
- 1) The need for new dollars to be deployed in the service of this unmet health need;
 - 2) The crucial role for the Department of Health to provide leadership and integration across the range of disciplines is also recognised;

3) Ministerial sponsorship of such a developmental process would help to guarantee its success in a relatively short period of time.

I. Are there important ways that the development of Psycho-oncology Services might impact on the quality of end-of-life care?

16. If we return to the issue of suffering, we recognised at the beginning of this submission that a range of clinical factors and predicaments contributed to this suffering. Each of these factors has a number of influences that determine how much suffering occurs that needs to be ameliorated.

- a. We noted that **undiagnosed or inadequately treated depression & anxiety** are significant problems. **They have the capacity to take away hope** and reduce a patient's motivation to adhere to or complete complex medical treatments for cancer and other progressive illness. Depressed patients with cancer have a significantly poorer survival time⁹, with reduced adherence to recommended anti-cancer treatments being 3-times higher among depressed patients.¹⁰ There is a basic human rights issue in ensuring that these patients have access to the proper clinical services able to begin to treat and manage the problem. This is an urgent priority for the ACT.
- b. Our medical community has had little education about what is and how to address what is technically termed "existential distress." How does a patient confront uncertainty, deal with death anxiety, cope with the

⁹ Pinquart M, Duberstein PR, Depression and cancer mortality: a meta-analysis. *Psychol Med.* 2010 Nov; 40(11): 1797–1810.

¹⁰ DiMatteo MR, Hanskard-Zolnieriek KB: Impact of depression on treatment adherence and survival from cancer, in *Depression and Cancer*. Edited by Kissane DW, Maj M, Sartorius N. Oxford, Wiley-Blackwell, 2011, pp 101-124

development of some loss of control from illness and frailty, stay in touch with the essential meaning and purpose in their life, and thus adapt constructively to their illness, even when this is a progressive and life-threatening one? The growth of palliative care over the last 20-30 years has seen considerable research and understanding of these issues mature, particularly within the discipline of psycho-oncology. Alas, this knowledge has not been translated into the general education of medical students, nurses and allied health practitioners. A discipline such as clinical psychology has a long way to go to be equipped to address these needs within our community. **Major educational agendas exist and need special funding such as dedicated educational units in our universities to accelerate this educational agenda.**

- c. We have made greatest progress over the last two decades in the building of the discipline of palliative medicine, with a dedicated training program auspiced by the Chapter of Palliative Medicine within the Royal Australasian College of Physicians. Alas, this does not mean that we don't meet instances of **inadequate symptom control** among some patients in need. Our programs still need to mature, and only by addressing major deficits such as the absence of adequate psychosocial care can we free up our physicians to focus on and further improve physical treatment approaches overall.
- d. **Family distress is a major source of community burden resulting from end-of-life care.** The distress caused by cancer reverberates through the family, who are most commonly the main source of patient caregiving. Loss of workforce capacity and productivity result. This distress can carry over into bereavement and, for up to one fifth of primary caregivers, the morbidity of psychiatric disorders such as depression or prolonged grief disorder continue. Palliative care programs have substantially restricted means to deliver bereavement care, with

most budgets not permitting employment of the most experienced and specialist disciplines to deliver this care.

Preventive models of family support for those families most at risk of poor bereavement outcomes have been researched, but not yet translated into clinical programs per dint of inadequate numbers of service providers.

- e. Communication breakdown is a perennial problem across clinical services, and although both research and training programs have begun to address many of the inherent issues, there is a long way to go to achieve the quality of care that our community wants and deserves. The existential burden of cancer contributes greatly to the challenges that exist here. Psycho-oncology has been the leading discipline to conduct research and provide **communication skills training**, in an effort to begin to redress these issues. The lack of adequate psycho-oncology staffing has been a major limitation in the capacity of these programs to grow appropriately.

- f. The final major problem which research has identified as interfering in the quality of end-of-life care is **burnout, or compassion fatigue**, whereby overstretched services become exhausted, staff defend subconsciously against the personal toll of delivering such care, and our patients and their families suffer as a consequence. Social, family, occupational and health stresses occur in all clinicians at various stages of their lives. Proper training and skill development are crucial to overcome burnout. Fortunately, palliative care services have lower rates of burnout than medical or surgical oncology, intensive care, and other related specialties. Nevertheless, this remains a central challenge for all clinical programs to deliver care of the highest quality. Psycho-oncology services have been important in supporting all members of the multidisciplinary team, running Balint-type groups for physicians and clinicians to debrief about difficult patients and guard against burnout, conducting studies of the

factors contributing to burnout and helping our institutions to reduce its rate of occurrence.

J. Does psycho-oncology have a role in assessing and helping patients with cancer or other progressive and life-threatening illnesses who wish to hasten their death?

17. Many studies of the desire for hastened death, the development of suicidal thinking, despair about the value of life and requests for physician-assisted suicide or euthanasia have highlighted the prominence of depression and related psychiatric disorders in the development of this state of mind. The psycho-oncologist plays a central role in assessing such patients, helping them to recognise any hopelessness or helplessness, any worthlessness, any shame, or any sense of loss of the meaning or purpose of their life. **In the therapeutic stance adopted to begin to help such patients, the psycho-oncologist must be a source of hope, however else the clinical state is treated.** Hope is an indispensable stance, whether the prognosis for length of life is years, months, weeks or only days. As strange as this last statement might seem to a non-clinician, there are always sources of hope, tasks to be discerned and roles to be lived out fully, even in patients who are quite close to their dying.

By being able to deal with existential angst, treat clinical depression, allay discomfort about living with uncertainty, affirm the dignity of a person who has started to doubt their value, reassure patients that they are not a burden, support relatives in sustaining optimal communication and mutual care, maintain the morale of medical care providers, and keep hope present rather than despair in those who are seriously ill, the psycho-oncologist has a substantial, integral and important role to play in care provision.

The development of psycho-oncology services is vital for the ACT to be able to deliver optimal medical care.

18. One of the most difficult clinical tasks for all physicians is the development of the clinical experience and medical wisdom to be able to prognosticate reasonably accurately. Research has repeatedly shown that oncologists have a five-fold error rate in accurately assessing the length of a person's life.¹¹ This is a highly complex task, with many biological, psychological and social factors influencing what the final outcome is.¹² **The experience of the psycho-oncologist in understanding the science of prognostication is vital, and becomes one straightforward explanation for why the general psychiatrist, GP, general psychologist or even medical social worker is less able to help the patient with advanced cancer or terminal illness.** Many of these clinicians have not been appropriately trained and equipped to understand and recognise when other clinicians may have erred or the patient and family have misunderstood what the prognosis may ultimately prove to be. Unfortunately, this is a reality of modern and highly specialized cancer care. Considerable experience in understanding prognosis allows the psycho-oncologist to recognise when a patient has misunderstood what their oncologist intended and correct this misunderstanding. Correction of misunderstanding restores hope and helps the patient re-focus on living out their life, instead of becoming overwhelmed by grief and losing direction. Many consultations with properly trained psycho-oncologists have this element to the patient assessment, whether the malignancy involves early stage or advanced disease. The complexity of cancer care is one very important reason for why psycho-oncology has needed to develop as a specialty of its own.

K. Are there challenges for legislators interested in introducing physician-assisted suicide or euthanasia to benefit those wanting autonomous choice

¹¹ Christakis NA. Death Foretold. Univ Chicago Press, 1999

¹² Glare P, Christakis NA. Prognosis in Advanced Cancer. Oxford University Press, 2008

over when and how they die that derive from the insights of psycho-oncology?

19. From what has been covered thus far in this submission, it should have become clear that our motivation in making this submission is about enhancing the quality of care that we deliver as a community in caring for patients and their families with cancer and other progressive, life-threatening diseases, including during end-of-life care. **We have much still to achieve to realize an optimal standard of care provision.**

20. It is conceivable that many who advocate for physician-assisted have witnessed poor quality care to loved ones in their past. Others have limited insight into what psycho-oncology can do, rarely refer if they are clinicians, and out of pity for those perceived to be suffering, and want to be able to hasten death via physician-assisted suicide. In our experience, which is informed by extensive international work, clinicians who prescribe barbiturates to their patients to hasten their dying lack skills in restoring hope and improving quality of life in patients facing the end of their life. They focus solely on the provision of medication to hasten death, should the patient seek this.

21. We don't perceive that that the fundamental clinical stances of 1) supporting quality of life and optimal palliative care, and 2) supporting euthanasia are compatible. As a result, the medical community divides and two different standards of care emerge – one that promotes hope, the dignity of the person and affirms living until natural death intervenes, and the second that is neutral about the value of a person, allows them to suicide if they wish, and sees managed death as the solution to many complex and challenging medical problems. Do legislators who advocate for euthanasia understand this dichotomy? Do they consider the potential for a poorer standard of medical care for many, resultant from the wishes of some? Ethicists recognize this as a principle of justice, and legislators have to choose whose needs in this regard are greater.

22. Are legislators concerned for the disabled, those incapacitated, those who might be pressured by a medical community that embraces physician-assisted suicide? Are they concerned about cases of involuntary euthanasia seen in other societies that legalize this practice? Are legislators confident that they can design suitable medical and psychiatric safeguards to protect the vulnerable who become suicidal and suffer mental illness through the bylaws and gate-keeping mechanisms built into such legislation? These are some of the many very difficult issues that government must determine.

23. Kissane had the opportunity to study the patients that Philip Nitschke cared for in Darwin when euthanasia was legal in Australia. Together, they published the clinical accounts of these patients in the *Lancet* in 1998.¹³ The legislative gate keeping mechanisms established by the Rights of the Terminally Ill (ROTI) legislation failed to protect the vulnerable. Poor medical care was evident, with inadequate use of palliative medications, non-use of radiation therapy, inadequate treatment of depression and suicidal thinking in patients; in short, the abysmal use of palliative care.^{14,15,16} The experience of observing the poor quality of care delivered during this period of the ROTI legislation convinced us of the legislative challenges of protecting the vulnerable while trying to meet the needs of those desiring voluntary euthanasia.

24. We have seen, across the many years of our medical careers, too many mistakes made to hold any confidence that such bylaws can truly protect the vulnerable that governments ought to protect. We also believe that the introduction of legislation for physician-assisted suicide will inadvertently lower the quality of mental health care that we deliver within our society.

¹³ Kissane DW, Street A, Nitschke P. (1998) Seven deaths in Darwin: studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. *Lancet*, 352: 1097-1102.

¹⁴ Street AF, Kissane DW. (1999-2000) Dispensing death, desiring death: an exploration of medical roles and patient motivation during the period of legalized euthanasia in Australia. *Omega*, 40: 231-248.

¹⁵ Kissane DW (2000). Case presentation: a case of euthanasia, the Northern Territory, Australia. *J Pain Symptom Manage* 19(6): 472-3.

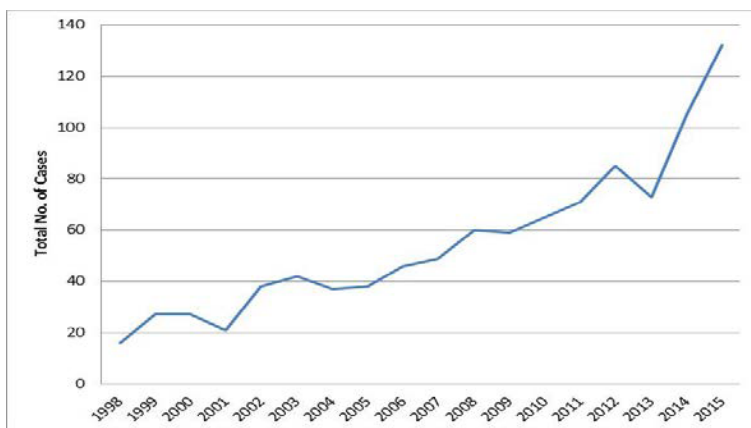
¹⁶ Kissane DW. (2002) Deadly days in Darwin. In: *The Case Against Assisted Suicide*, K. Foley & H. Hendin (eds). Pp. 192-209. Johns Hopkins University Press: Baltimore.

L. Are there models of medically assisted dying in operation in other countries that satisfactorily protect the vulnerable?

25. Oregon is most commonly put forward by euthanasia advocates as an example that administers assisted dying to a small minority of citizens without endangering society. Yet Oregon has been the most secretive of societies in publishing outcome findings to enable study of its system. A very telling study was commissioned by Compassion in Dying to follow people expressing interest in Physician-Assisted Dying, with the goal to showing that depressed patients don't access PAS. Dr Linda Ganzini was commissioned to lead this study, and her published findings (2008) were that one third of those who completed PAS were indeed clinically depressed, but not helped to have this condition treated.¹⁷ When asked why this study was not continued with a larger cohort, Ganzini noted that Compassion in Dying redrew funding as the results were the opposite that they had hoped for. The conclusion is that the Oregon legislation, despite being proposed as very protective, does not in fact succeed in protecting vulnerable people.

26. It has also been suggested that the rate of medically assisted dying is stable in Oregon. Yet when one tracks the rate of utilisation over time, its recent growth has been at 13.2% annually.¹⁸ Such growth has been argued to represent the normalization of medically assisted dying in this society.

Oregon deaths by PAS annually.



¹⁷ Ganzini L Depression in those seeking PAS. General Hospital Psychiatry, 2008

¹⁸ Emmanuel et al, JAMA, 2016

27. Belgium has very liberal legislation that permits euthanasia for children and the mentally ill. Thus medically assisted dying is not restricted to the terminally ill, but can be used by those who decide that their sickness is intolerable. Chambaere and colleagues (2010) studied 6927 deaths across a six month period in Belgium,¹⁹ and reported that 66 deaths occurred without any request coming from the patient, the family providing the consent for euthanasia, and in 8% of these cases, the family cited concern that their decision would have upset or harmed the patient receiving the euthanasia. Family burden was identified in 50% of the 66 cases where no patient consent was obtained.

28. Turning to euthanasia of the mentally ill in Belgium, in their second reporting period (2004-2005), 9 deaths were for reasons of chronic depression, Alzheimers, Huntington's and Jacob-Creutzfeld disorders. In their third reporting period (2006-2007), 13 mentally ill patients were euthanized from depression and dementia; in their fourth reporting period (2008-9), 62 mentally ill were euthanized; and by their fifth reporting period (2010-2011), this number had risen to 105. Patients with anorexia nervosa, schizophrenia, autism, personality disorder and prolonged grief were now included among those accessing euthanasia, alongside depression. This is a process of normalization of assisted suicide within a society. Rachel Aviv²⁰ wrote up one such case in the New Yorker magazine in October 2015, where a woman with depression and estrangement from her children accepted euthanasia without contacting these children. Her son expressed his subsequent desire for reunion, while the psychiatrist's notes on file recorded the patient's wish to die as immature and ambivalent, wishing she could have contact with her grandchildren.

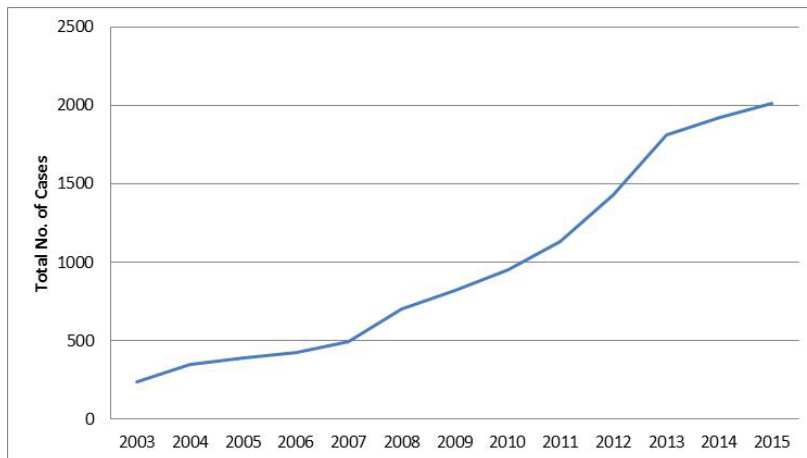
29. The exponential rate of growth of euthanasia in Belgium is 19.6%. The process of normalization of medically assisted dying has been seen in every country, and ultimately changes forever the nature of medical practice.

¹⁹ Chambaere K et al, CMAJ 2010. DOI:10.1503/cmaj.091876

²⁰ Aviv, Rachel, "The Death Treatment", June 22 2015, *The New Yorker*

Legislators would be naïve to believe that they can introduce a tightly controlled process that won't increase in subsequent years once the door is opened.

Belgium growth in euthanasia is 19.6%²¹



For psychiatrists who have spent their careers attempting to restore hope in the depressed and demoralized so that suicide is prevented, these trends towards physician-assisted suicide are enormously worrying.

M. The intellectual appeal of controlled dying when one is ready.

30. Many people in society fear the process of dying. Others have witnessed the death of a relative or friend. They are often saddened and shocked by such a process as we are a death-denying society, with little familiarity with the dying process until people become elderly. To observe a death with a terminal delirium, where inadequate palliative care is administered, can be frightening for the lay person to observe, and many parliamentarians have told of such stories. These narratives are about inadequately funded and accessed palliative care. They should not become the reason to vote for physician-assisted suicide. Legislative decisions ought not be based upon a single sad case story. The needs of the vulnerable, the elderly, the frail and disabled, those who are sick yet want to live, these are the people on which legislation ought to be framed. Too

²¹ Emmanuel et al, JAMA, 2016

often people develop an intellectual position in favour of euthanasia “when the time is right”, only to discover that their own life is precious, and to cling to life for as long as possible when their natural death is approaching. It can be so unwise to risk forever changing medical practice based on a single personal experience; yet legislators record such decision-making in Hansard reports again and again.

N. Can palliative care and physician-assisted dying comfortably co-exist?

31. Legislators must appreciate the fundamental differences in philosophy and approach that exists between the disciplines of palliative care and voluntary assisted dying practices. In Belgium, efforts have been made to integrate palliative care and euthanasia (Materstvedt, 2013).²² The hospice unit becomes the place to stay until the time is right for euthanasia to then be delivered. The result is that patients fear admission to palliative care, and when there is pressure upon bed occupancy, it becomes economically advantageous to deliver euthanasia so that another patient has a bed to be admitted into.

32. In Australia, palliative care has never been viewed as futile. There are always treatments that can be given to optimise quality of life and sustain the focus on living life out fully, until a natural death intervenes. Suggestions made by the few to integrate palliative care with voluntary assisted dying risk damaging the reputation of palliative care as a discipline and increasing the public’s fear of inpatient hospice units. Palliative care maintains hope for sustained quality of life, and studies have indeed shown that optimal palliative care, in contrast to regular oncological care, increases survival.

²² Materstvedt LJ, Progress in Palliative Care, 2013

O. Conclusion

33. To conclude this submission, we return to the vital need for palliative care and the related discipline of psycho-oncology to grow to improve the care that our society delivers at the end-of-life. Moreover, the standard of care is established well before that terminal phase is reached, and it is folly to artificially split such care up into chronic / advanced disease and end-of-life. Continuity of care is a vital principle for patients and their families, and many of the strategies used in patients with early stage and curable cancers also apply to those with progressive disease. Increasingly we salvage people who experience recurrence of their cancer. We also need to strive to salvage those who, for a time, lose hope about life. There is much that can be done to help those afflicted in this way, and our goal is to advance this standard of care and help our profession to ever improve on the quality of the care we deliver.

34. Psycho-oncology is the specialty that is comprised of multi-disciplinary care delivered by psychiatrists, psychologists and social workers, among others, and is a vital and essential dimension of comprehensive palliative care. Psycho-oncology is lacking from many oncology programs in the ACT. Its development is a crucial and urgent need to improve the quality of care that we deliver to patients with cancer and their families, including but not limited to care at the end of life. In this submission, we advocate for the development of psycho-oncology in the ACT.

P. Recommendations

35. That a Taskforce be established by the Department of Health and Human Services, comprised of appropriate experts, and commissioned to examine the unmet psychosocial needs of patients receiving oncology and palliative care services and to advise on the appropriate psycho-oncology workforce to adequately address these unmet needs.

36. That the Government ensures that appropriate new funding is established to adequately staff psycho-oncology programs equitably across our territory and to establish educational units to urgently teach psycho-oncology and lift its workforce across the coming decade.

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