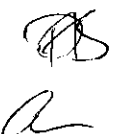


I, Alastair Donald (Sandy) Macleod, of Fendalton, Christchurch, Consultant Psychiatrist and Palliative Medicine Specialist, solemnly and sincerely affirm:

1. I am a consultant psychiatrist and palliative medicine specialist at Christchurch and Burwood Hospitals in Christchurch. I have worked as a consultation-liaison psychiatrist at Christchurch and Burwood Hospitals since 1984. During this period, while my role included attending the seriously ill medical and surgical cases in hospitals, I also pursued my professional interests in palliative care, acquiring specialist status in this emerging specialty. I assumed medical responsibility of Burwood Hospice until the provision of palliative care in Christchurch was assigned to Nurse Maude Association and then for nearly 15 years between 1998 and 2012 I worked as the Medical Director at the Nurse Maude Hospice.
2. More recently I have moved into the area of care of dementia, another common terminal disorder. However, throughout my career I have attended those dying of neurodegenerative disorders such as Huntington Disease.
3. I attained my medical degree from Otago University in 1974. In 1982 I became a Member of the Royal Australian and New Zealand College of Psychiatrists and in 1987 I became a Fellow of the Royal Australian and New Zealand College of Psychiatrists. In 2000 I became a Fellow of the Australasian Chapter of Palliative Medicine (Royal Australasian College of Physicians).
4. Over this period I have published and presented at local, Australasian and international meetings predominantly on the interface between psychiatry and palliative medicine, there are only a handful of such dual trained physicians worldwide. My book on the subject *The Psychiatry of Palliative Medicine: the dying mind* is published in both English and German and has been well received.
5. I attach a copy of my curriculum vitae as exhibit "SDM-1".
6. In this affidavit I address:
 - 6.1 The role of psychiatry and psychology in palliative care;



- 6.2 The concepts of Dignity, Intolerable Suffering and Autonomy in end of life care; and
 - 6.3 Suicidal thoughts and tendencies of patients suffering terminal illnesses;
 - 6.4 The difficulties in assessing capacity and competence of patients who might seek physician assisted death.
7. I confirm I have read and understood the Code of Conduct for Expert Witnesses and I agree to comply with it. Further, I confirm any opinions I express in this affidavit are within my areas of expertise and experience.

The role of psychiatry and psychology in palliative care

8. The relief of bodily, psychological and spiritual pain and discomfort is the primary clinical goal of palliative care. Management needs to be holistic and multidisciplinary involving nursing, medical, psychological, pastoral, social work, and physiotherapy professionals. In the practice of palliative medicine the medical staff need to have knowledge of, and experience in, psychology and psychiatry. Coping with illness and grief, and communication skills are all issues requiring expert psychological management of both the patient and their family.
9. Attending to psychiatric disorders which complicate terminal illnesses is also a crucial component of palliative care. These can include for example addressing disease involvement of the central nervous system, depressive and anxiety disorders, sleep disruption and delirium. Much of the pharmacology required in palliative care – including antiemetic medications, major tranquillisers, benzodiazepines and adjunctive analgesics – are medications predominantly used in the practice of psychiatry. Thus a considerable proportion of the clinical tasks that can be required in palliative care are psychiatric. However, this is, as yet, an under-developed component of many palliative care services.

How palliative care addresses patients concerns about loss of “dignity”, “intolerable suffering” and “autonomy”

10. Palliative care attempts to preserve dignity, prevent “intolerable suffering” and enhance “autonomy”. Preserving dignity in the presence of the physical and psychological ravages of terminal illness is challenging. “Dignity therapy”

championed by Dr Chochinov is a specific therapy designed to encourage fostering dignity by reflecting upon and emphasising the achievements of one's life rather than the difficulties of the current life circumstances. This is more possible in the earlier stages of illness; physical and psychological weakness limits this later in the course of illness. However, there are important strategies that nursing staff in particular can invent to facilitate independence and self-sufficiency within the limitations of the disease during these final phases of the illness. Assisting with, but not performing, teeth cleaning, lighting a cigarette or eating a meal may be such examples. It is difficult for many previously fit and healthy individuals to lose control over their destiny, and accept dependency and reliance upon others as their health fades. This is an area in which expert palliative nurses demonstrate their remarkable skills.

11. "Intolerable suffering" has never been defined. Within a population there is a huge variation of "illness behaviours" – of how one copes with an illness, be it influenza or cancer. Until the disease is experienced it is difficult, if not impossible, to predict what behaviours a patient will display. There are also cultural and religious influences upon suffering.
12. Whether suffering is determined to be 'unbearable' rests upon the impression of the assessing doctor for there is no formal definition of this term.¹ In jurisdictions where physician assisted suicide and/or euthanasia is available, whether or not a patient qualifies for these methods of hastened death ultimately rests on the doctor's consideration of that patient's suffering. It is merely a judgement of the attending doctor in Dutch and Belgium under legislation. "Unbearable suffering" is a subjective concept with very wide and individualistic clinical interpretations.
13. "Autonomy" is a modern attitude exemplified in North American culture. While many claim that physician assisted death and euthanasia facilitates a patient's autonomy at the end of their life, the reality is that in current jurisdictions where assisted dying is available it is still the doctor, or doctors, who make the final decision about whether or not to allow assisted suicide or euthanasia.

¹ Dees M, Vernooij-Dassen M, Dekkers W "Unbearable suffering of patients with a request for euthanasia or physician assisted suicide: an integrative review" (2010) 19 Psycho-Oncology 339-52.

14. In palliative care autonomy is fostered by involving or co-opting the patient in decision-making about their medical and nursing care. This is usually very helpful, though it is dependent upon a good level of communication and understanding between the patient and palliative care staff.

Experience of suicidal thoughts or tendencies in patients diagnosed with a terminal illness

15. In patients diagnosed with severe medical illnesses, it is thought that between 40-50 percent experience some sort of suicidal thoughts during the course of their illness.² They are more likely to occur in those patients in pain, nauseous, tired or angry with their circumstances and care. However, such thoughts and ideations tend to be fleeting in the vast majority of patients. They are most often not accompanied by any seriously conceived plan or method of dying, they are not associated with depressive disorder or hopelessness and most often are just a mere expression of sadness and frustration. Such thoughts are usually motivated by a wish or a hope of escaping from their current health predicament. It is most common for patients to experience such suicidal thoughts in the months initially after their diagnosis. The suicide risk is highest for terminally ill patients during this period.³
16. Suicide is surprisingly uncommon in those suffering cancer, with it being the cause of death in less than one percent of individuals suffering from cancer. The statistics are similar for dementia. Somewhat paradoxically, if the nervous system becomes involved in disease the will to live – the animalistic drive to life – is often enhanced. Most sufferers of dementia (in my unit and we are conducting a research project on this) are appalled by the thought of dying prematurely.
17. In the early stages of Huntington disease the risk is more significant. This is because Huntington disease is a genetic disorder so all sufferers have previously observed loved ones suffer the ordeals of this appalling neurodegenerative disorder.
18. It is common for sufferers of terminal illness to adjust their outlook on life in accordance with the nature and progression of their disease. This change in

² Block SD "Assessing and managing depression in the terminally ill patient" (2000) 132 Ann Int Med 209-18.

³ Misono S, Weiss NS, Fann JR et al "Incidence of suicide in persons with cancer" (2008) 26 J Clin Onc 4731-4738.

mind-set can help terminally ill patients relieve any suicidal thoughts they may have. Most cancer sufferers focus adjusts, they decide to live for the moment or the next day, hoping for an easier day or a visit from loved ones. The philosophy of palliative care advocates the shrinking of one's horizon, a focus on the here and now, and curtailing long-term plans. This is in line with the natural occurrence of this psychological withdrawal from the living (Sigmund Freud called it the detachment of old age). This existential philosophy is also a component of mindfulness, a currently popular psychological therapy.

19. I can only recall a few patients who committed suicide in the terminal phase of disease. They were men of action who used violently fatal methods.
20. There is a real risk that the liberalisation of physician assisted suicide or euthanasia would have a major impact upon suicide prevention programs. Most suicide victims are suffering from a mental illness and these are often very treatable mental illnesses if they were able to be addressed. It would cause considerable confusion for those in society suffering mental illnesses, who are already vulnerable and often more susceptible to suicidal thoughts, if health practitioners and others in society were seen to be advocating that suicide is acceptable and can be facilitated in some circumstances. There is a risk that sufferers of mental health issues may be dissuaded from seeking treatment for their condition from health professionals that might otherwise be very effective because of these mixed messages.

Assessing the capacity and competence of patients seeking physician assisted death

21. In overseas jurisdictions the reasons patients usually initiate requests for hastened death are not usually related to physical complaints. Instead requests for physician assisted suicide or euthanasia tend to be for psychological and existential reasons. The most common reasons for such requests include concerns about loss of control, wishing to die at home, loss of dignity and independence, fears about future pain, poor quality of life or self-care ability. These reasons are discussed in more detail in the article: Ganzini L, Goy ER and Dobscha SK "Oregonians' reasons for requesting physician aid in dying" (2009) 169 Archives of Internal Medicine 489-92. A copy of this article is attached as exhibit "SDM-2". It is fear of the future, not the present, which encourages such requests. This suggests that improved community education

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and understanding about death and dying, and the services capable of adequate caring for these fears (the multidisciplinary palliative care network), would diminish the numbers of those requesting hastened death.

22. Hastened death requests are rare in palliative care (community and Hospice), but slightly commoner in oncology services. GPs are the recipients of most requests. Patients cared for at home are more inclined to request assistance in dying than those in hospital, who are more likely to request non-treatment or withdrawal of treatment. The closer to death the less frequent the requests. This is a variant of the "disability paradox", when we become disabled or limited by illness our thoughts about disability tend to change. In the Netherlands seven percent of all people whose death is expected request euthanasia preceding their death.⁴ Having initiated the process, 13 percent then withdraw.⁵ About 17 percent of Oregonians are potentially interested in aid in dying, though only 1–2 percent actually request it,⁶ and then 36 percent of the patients provided a lethal prescription die naturally.⁷ In Canadian palliative care patients 63 percent believed euthanasia should be legalised, yet only 6 percent would wish to initiate the request.⁸ The experience of physician assisted suicide in legalised jurisdictions is discussed in the article: Okie S "Physician assisted suicide: Oregon and beyond" (2005) 26 New England Journal of Medicine 1627-30. A copy of this article is attached as exhibit **"SDM-3"** to this affidavit.
23. A critical concern regarding requests for euthanasia is the stability of the request, ie. over time (several days at least) does it remain firm? The fragility of such requests is well recognised.⁹ This can be influenced by symptoms such as physical distress, major depression, delirium, fatigue, an unpleasant environment, neglect or over-involvement of family.

⁴ Onwuteaka-Philipsen BD, Rurup ML, Pasman HRW et al "The last phase of life: Who requests and who receives euthanasia or physician-assisted suicide?" (2010) 48 Medical Care 596-603.

⁵ Jansen-van der Weide MC, Onwuteaka-Philipsen BD and van der Wal G "Granted, undecided, withdrawn and refused requests for euthanasia and physician-assisted suicide" (2005) 165 Archives of Internal Medicine 1698-704.

⁶ Ganzin L, Goy ER and Dobscha SK "Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey" (2008) 337 British Medical Journal 1682.

⁷ Okie S "Physician assisted suicide: Oregon and beyond" (2005) 26 New England Journal of Medicine 1627-30. (Exhibit **"SDM-3"**).

⁸ Wilson KG, Chochinov HM, McPherson CJ et al "Desire for euthanasia or physician assisted suicide in palliative cancer care" (2007) 26 Health Psychology 314-23.

24. Assessing capacity is very difficult. The presence of a mental disorder does not necessarily imply incompetence and there are no established criteria for determining whether a patient is competent to choose death. One condition that can affect the capacity of patients is delirium. It is usual when dying of chronic illness to pass through delirium *en route* to coma and death. The rate of delirium in hospice patients is perhaps as high as 80 percent.¹⁰ Severely depressed or demoralised persons likewise can lack capacity.¹¹ It is, however, uncertain as to what capacity to decide to be assisted to die actually *consists* of. When is a will to die rational? The criteria used in patients who may be declining potentially life-saving treatment are: whether they are in clear consciousness, are displaying an appropriate level of sadness for the condition they are in but not to the extent of depression, have an appropriate and hopeless medical prognosis and are not under any undue external influence. I have attended in my career upwards of a dozen such persons who have declined such interventions (and subsequently died of the illness) and many oncology patients who make reasoned decisions not to pursue offers of high risk, futile treatments. But for such patients the option to re-enter treatment remains available to them, thus their decision is never quite (at least in their minds) final, even though the therapeutic opportunity may have been lost. Assessing capacity is not impossible, but it is difficult and would require highly skilled psychiatrist assessments. Psychologists would not be in a position to make such assessments as they do not have the understanding of the associated issues involved, including medication, mental and physical issues.
25. The prevalence of psychological distress and psychiatric illness in those dying of terminal illnesses is significant.¹² Affectations of the brain and mind influence judgement and decision making. Most terminally ill people are at times fearful and anxious. Serious emotional turmoil is commonly associated with incapacity. At least 15 percent of terminally ill cancer patients are

⁹ Chochinov HM, Wilson KG, Enns M et al "Desire for death in the terminally ill" (1995) 152 American Journal of Psychiatry 1185-91.

¹⁰ Lawler PG, Gagnon B, Mancini IL et al "Occurrence, causes and outcome in patients with advanced cancer" (2000) 160 Archives of Internal Medicine 786-94.

¹¹ Kissane DW and Kelly BJ "Demoralisation, depression and desire for death: problems with the Dutch guidelines for euthanasia of the mentally ill" (2000) 34 Australian and New Zealand Journal of Psychiatry 325-33.

¹² Macleod AD (Sandy) *The Psychiatry of Palliative Medicine: The Dying Mind* (2nd ed, Radcliffe, Oxford, New York, 2011), 1-4.

experiencing major depression,¹³ though this prevalence falls as death approaches.¹⁴ A similar number are dysthymic, dysphoric and demoralised.¹⁵ Diagnosing depression in the medically ill is notoriously difficult. Many of the physical symptoms suggestive of major depression may be caused directly by the cancer, thus the diagnosis is reliant upon psychological symptoms alone. Often in such patients therapeutic trials of antidepressant medications and psychological treatments are the only method of (retrospectively) ensuring accurate diagnosis – these trials take 4-6 weeks. Clinical surprises are not uncommon – some respond when one would not have thought they might and vice versa. After over three decades of assessing and managing mood disorders in the physically ill I not infrequently remain diagnostically uncertain when first assessing such patients. Depression can influence the wish to hasten death and treating a depression can result in a change of mind and can improve the desire for life-sustaining therapy, at least in some.¹⁶

26. Regarding coercion, I have had the occasional experience of families (and rarely patients) question as to whether such assertive treatment causing such horrendous adverse effects is necessary or questioning whether their loved one should be allowed to endure the ignominy of such an illness. Presumably they are questioning the value of the patient's ongoing survival. However, rarely in my experience is such questioning persistent or determined; usually such comments were made in a frustrating circumstance. There are, however, concerns that if physician assisted suicide or euthanasia is to become available coercion for patients to choose hastened death may become more prevalent. This could even be for reasons such as where it might allow for the convenience of arranging funeral dates ahead of time or organising work commitments around the death of, for example, a parent. There are obvious practical advantages of such scheduled deaths for the relatives. However, a potential psychological cost may arise from the loss of that period, perhaps several days, whilst a family hovers around the death bed awaiting finality.

¹³ Hotopf M, Chidgey J, Addington-Hall J et al "Depression in advanced disease: a systematic review. Part 1. Prevalence and case finding" (2002) 16 Palliative Medicine 81.

¹⁴ Macleod AD (Sandy) *The Psychiatry of Palliative Medicine: The Dying Mind* (2nd ed, Radcliffe, Oxford, New York, 2011), 99.

¹⁵ Kissane DW and Kelly BJ "Demoralisation, depression and desire for death: problems with the Dutch guidelines for euthanasia of the mentally ill" (2000) 34 Australian and New Zealand Journal of Psychiatry 325-33.

¹⁶ Ganzini L and Lee MA "Psychiatry and assisted suicide in the United States (editorial)" (1997) 336 New England Journal of Medicine 1824-26.

Whilst undoubtedly uncomfortable, and maybe inconvenient, it is a time and an opportunity for families to re-connect, reunite, and perhaps repair their differences. In hospices one commonly observes the value of this vigil for families.

27. The vulnerability of the dying and their risk of being influenced to opt for hastened death is an obvious concern, particularly if capacity is lost or family members are impatient to access inheritance for example. For many, particularly adolescent children (often less so for younger children), observing death for the first time can be distressing and disturbing. Dame Cecily Saunders maintained that a crucial role of palliative care is to look after the dying well so that the next generation would be less fearful of the process when their turn came. Sanitising dying, however, may have risks for future generations who may come to expect and demand physician assisted death or euthanasia. This is perhaps just one area where the slippery slope argument can be raised as a concern.
28. Another area where the slippery slope may be seen to be of particular concern is those suffering from chronic psychiatric illnesses. In the Netherlands a firm line has been drawn in this regard, but not so in Belgium. I have recently reviewed an article submitted to a European journal (not yet accepted for publication) describing the first 100 psychiatric patients allowed physician assisted suicide in Belgium. There are significant concerns about physician assisted death being provided to such patients. In particular a major concern in relation to these patients is whether or not adequate treatment of the underlying condition has occurred prior to facilitating their hastened death and whether the diagnoses established were robust – a significant proportion had personality disorder diagnoses. The “slippage” is most likely to be diagnostic, veering toward allowing requests from those who suffer the “burden of living” rather than those who suffer intractable severe psychiatric illness.
29. An additional area of concern is that of Advance Directives. For example if a person writes up an Advanced Directive stating that they would wish for physician assisted suicide or euthanasia if they were to develop dementia or some other neurological disease, yet during the course of their terminal illness and cognitive decline they change their mind, could that Advanced Directive

still be relied upon? Such cases are apparent in the Benelux countries but the directive is honoured. In a sample of 208 deaths under the euthanasia law, representing 12 per cent of the deaths during 2007 in Flanders, 32 per cent were administered life-ending drugs without their explicit request.¹⁷ The decisions to terminate the lives of these elderly, hospitalised patients in comatosed or demented states, who had previously indicated a wish for life not to be needlessly prolonged, were made by medical staff in agreement with the family, usually following a sudden decline in the patient's health, leaving them unable to communicate. Hastened death requests have the potential to be a colossal issue in chronic neurological and psychiatric illnesses. I discuss these issues in an article I have authored: Macleod AD "Assisted dying in liberalised jurisdictions and the role of psychiatry: a clinician's view" (2012) 46 (10) Australian and New Zealand Journal of Psychiatry 936. A copy of this is attached as exhibit "**SDM-4**" to this affidavit.

30. It is well recognised that for a period (perhaps up to a few days) after enacting suicidal behaviour (or definitively deciding on making an attempt) the person's mental state improves – both mood and anxiety are transiently eased by the self-destructive action. Every psychiatrist has been 'fooled' by this phenomenon at some stage in their career. This may account for the observation that in Oregon 36 per cent died without consuming the lethal drug.¹⁸ As Quill commented "Perhaps the knowledge that they could end their life if they so desired makes them feel less trapped – therefore freer to keep going".¹⁹ To address these psychological aspects of patients at the end of their life there needs to be greater emphasis on the provision of more honest and accurate disease prognoses (doctors tend to over-estimate prognoses), as may firmer emphasis on AND (Allow Natural Death) guidelines, more accurately diagnosing dying, and support and encouragement for those withdrawing from futile treatments. Uncertainty is psychologically stressful, certainty is easier to manage.

¹⁷ Chambaere K, Bilsen J, Choen J et al "Physician assisted deaths under the euthanasia law in Belgium: a population based survey" (2010) 182 Canadian Medical Association Journal 895-901.

¹⁸ Okie S "Physician assisted suicide: Oregon and beyond" (2005) 352 New England Journal of Medicine 1627-30. (Exhibit "**SDM-3**").

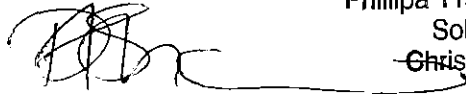
¹⁹ Quill TE "The million dollar question" (2005) 352 NEJM 1632.

AFFIRMED

at Christchurch this 11th day of
 May 2015
 before me:

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Alastair Donald Macleod



Phillipa Frances Shaw
 Solicitor
 Christchurch

A Solicitor of the High Court of New Zealand



"SDM-1"

CURRICULUM VITAE

22/04/2015

This is the exhibit marked "SDM-1" referred to in the affidavit of **Alastair Donald Macleod** affirmed at Christchurch this 11th day of May 2015 before me:

PERSONAL INFORMATION :

Name: Alastair Donald (Sandy) Macleod

Date of Birth: 23/03/51

Sex: Male

Address: 46 Kotare Street,
Fendalton,
Christchurch, 8041
New Zealand.

Phone: 64-3-3430822 (home), 64-3-3754274 (work)

Fax: 64-3-3430823 (home), 64-3-3754267 (work)

Email: ad.macleod@cdhb.health.nz (work), admacl@xtra.co.nz (home)



Phillipa Frances Shaw
Solicitor
Christchurch

A Solicitor of the High Court of New Zealand

QUALIFICATIONS :

M.B.Ch.B. (Otago), 1974

E.C.F.M.G., 1974

M.R.A.N.Z.C.P., 1982

F.R.A.N.Z.C.P., 1987

F.A.Ch.P.M.(R.A.C.P.), 2000

PROFESSIONAL AFFILIATIONS / MEMBERSHIPS :

Royal Australian and New Zealand College of Psychiatrists

Royal Australasian College of Physicians (Chapter of Palliative Medicine)

Australian and New Zealand Society of Palliative Care

Neurologic Association of New Zealand

LANGUAGES :

English

EMPLOYMENT HISTORY :

PRESENT POSITION :

Consultant Psychiatrist, Psychiatric Consultation Service, Christchurch and Burwood Hospitals. 1985 to present.

Consultant Psychiatrist and Physician, Brain Injury Rehabilitation Service, Burwood Hospital, 2014 to present.

Consultant Psychiatrist, Health Care of Elderly, TPMH. 2014 to present.

Clinical Senior Lecturer, Department of Psychological Medicine, Christchurch School of Medicine. 1982 – 1997 and 2001 to present

Adjunct Associate Professor, Health Sciences Centre, University of Canterbury. 2010 to present

EMPLOYMENT HISTORY:

Medical Director, Brain Injury Rehabilitation Service, Burwood Hospital. 1999 - 2014.

Palliative Medicine Specialist, Palliative Care Service, Christchurch Hospital. 2012-13.

Medical Advisor, Hospice NZ. 2012 -2013

Medical Director, Nurse Maude Hospice. 1998 - 2012

Visiting Psychiatrist (and founder with Dr L.Briggs, Social Worker), Refugee and Migrant Service, Family Mental Health Service, Christchurch. 1999 - 2010.

Senior Lecturer, Department of Psychological Medicine, Christchurch School of Medicine. 1997 - 1998

Consultant, Brain Injury Rehabilitation Service, Burwood Hospital. 1995 - 1996

Medical Director, Burwood Hospice. 1993 - 1996

Consultant Psychiatrist, New Zealand Police. 1985 - 1991

Consultant Psychiatrist, Consultation - Liaison Service, The Princess Margaret Hospital, Christchurch. 1986 - 1989

Consultant Psychiatrist, Consultation - Liaison Service, Christchurch and Burwood Hospitals. 1985 - 1986

Private Psychiatric Practice, Calvary Clinic, Christchurch. 1984 - 1986

Consultant Psychiatrist, Sunnyside Hospital, Christchurch. 1983

Medical Officer Special Scale, Sunnyside Hospital, Christchurch. 1982

Psychiatric Registrar, Department of Psychological Medicine, University of Otago, Dunedin. 1978 - 1981

General Practitioner, Christchurch, NZ and Leyton, London, UK 1977

Ship Surgeon, Port Line. 1977

House Surgeon, Wellington Hospital. 1975 - 1976

OTHER RELEVANT EXPERIENCE

EXPERIENCE WORKING in an OVERSEAS COUNTRY (not previously listed):

Honorary Clinical Assistant, Department of Psychiatry (Prof. J. Shurley), University of Oklahoma, USA. March, 1984

Honorary Clinical Assistant, The National Hospital for Nervous Diseases and Neurosurgery (Prof. M. Ron), London, UK. March - June, 1984

Honorary Clinical Assistant, Consultation - Liaison Service, Massachusetts General Hospital (Profs T. Hackett and N.Cassem), Boston, USA. July - August, 1986

Palliative Care Physician, Territory Palliative Care Service, Darwin, Australia. June - July 2003

RESEARCH ACTIVITIES**RESEARCH EXPERTISE**

Special Interests : Psychiatric sequelae of trauma
Psycho-oncology / palliative care
Neuropsychiatry

RESEARCH GRANTS

War Pensions Medical Research Trust Board (1998) \$24,490
Campbell Ballantyne Fellowship (2007) (with Jane Vella-Brincat) \$30,000

DISTINCTIONS

Kathleen Todd Fellowship in Psychiatry 1984
Dawn Short Trust fund Scholarship 1984

TEACHING ACTIVITIES

RMO Orientation Course "Looking after Yourself" - a yearly lecture to new house-surgeons -1997 to present.

PSME 401 Nature, Extent and Assessment of Mental Disorder. 2000-2006

Palliative Care (4th Year Medical Students) - Hospice attachment clinical morning (X6/year) 2000 to 2008

MSMX 708 Chronic Pain and Psychiatry. 2005 to present

Convenor: Christchurch Hospitals Friday Clinical Meeting 2000-2004 (medical student attendance)

Collegial education - my major interest and teaching investments have been educating colleagues through the liaison component of consultation-liaison psychiatry, presentations and discussions at hospital grand rounds, presenting at pharmaceutical sponsored meetings for General Practitioners

PUBLICATIONS

BOOKS:

Macleod RD, Vella-Brincat J, Macleod AD. *The Palliative Care Handbook; incorporating the Nurse Maude Palliative Care Formulary: guidelines for clinical management and symptom control*. Hutcheson, Bowman & Stewart, Wellington. ISBN 0-473-08172-5, 2002 (3000 printed), Second Edition 2004 (5000 printed), Third Edition 2007 (3000 printed), 4th Edition 2009 (4000 printed), 5th Edition 2011 (5000 printed)

Macleod Sandy. *The Psychiatry of Palliative Medicine: the dying mind*. Oxford, Radcliffe. 2007 (2nd Edition, 2011)

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- Sellman JD, Kendal NAS, Macleod AD. The use of opioid medications in patients with chronic non-malignant pain who have drug dependency. *Drug and Alcohol Review* 1995; 14: 109-113
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- Wells JE, Williams TH, Macleod AD, Carroll GJ. Posttraumatic stress disorder: do electrical startle responses and thyroid function usefully supplement self-report? A study of Vietnam War veterans. *Australian and New Zealand Journal of Psychiatry* 2003; 37: 334-339
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Macleod AD. Palliative care series: psychiatric and psychological aspects. *New Ethicals* 1995; August: 19-27

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Macleod AD, Vella-Brincat J. Helping medicine capsules go down. *Prescriber Update* 2003; 24: 6-7

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OTHER SIGNIFICANT CONFERENCE INVOLVEMENT

Convenor: Australian and New Zealand Society of Palliative Care 3rd Biennial Scientific Conference, Christchurch 1996

Co-convenor: 39th Congress of the Royal Australian and New Zealand College of Psychiatrists, Christchurch 2004

Convenor: Annual RANZCP (NZ Branch) Conference, Queenstown, September 27-30, 2011

AUDIOVISUAL RECORDINGS

"Depths of Blue - Living with depression". Documentary - Mental Health Series. Mercury Television 2000. Awarded a THEMS Australasian Award.

OTHER CREATIVE WORKS:

Parr Alison. *Silent Casualties: New Zealand's Unspoken Legacy of the Second World War*. Tandem Press, 1995 (a joint project with Ms. Parr)

PROFESSIONAL ACTIVITIES

ACADEMIC AND PROFESSIONAL ADVICE AND SERVICES

Medicines Assessment Advisory Committee (MAAC) Ministry of Health / Medsafe. 1997 - 2011.

Independent Medical Advisor - Medical Misadventure Unit, Accident Compensation Corporation. 2003 to present.

Panelist: Ministerial Advisory Group on Veterans' Health (Expert Panel) 2009 – 2011.

Panelist : Veterans Health Expert Panel 2014 to present.

Editorial Advisory Board. *BMJ Supportive & Palliative Care*. 2012 to 2015.

SERVICE TO EXTERNAL ACADEMIC AND PROFESSIONAL ACTIVITIES

Invited Expert: Review of the War Pensions Act (Sir Geoffrey Palmer, Law Commission), 23 April, 2008

External Clinical Review: Cranford Hospice, Hastings 26-27 November, 2008

COMMUNITY SERVICE

CONTINUING EDUCATION

i) Media Commentaries

"The evil shadow of war" - David Clarkson, *The Press*, April 24, 1999

"Euthanasia - the doctors' dilemmas" (Opinion) - AD Macleod, *The Press*, April 20, 2002

"Living with the faces of the dead" - Andrew Macdonald, *The Press*, April 25, 2003

ii) Conferences, seminars, workshops

RANZCP (NZ Branch) Annual Conference 1990. "Tattooing - a sign of psychopathology"

NZ Pain Society, Annual Scientific Meeting 1992. "Drug abusers, terminal illness and opioid"

NZ Society on Alcohol & other Drugs, 1st Annual Conference 1992. "Chronic pain in the addicted patient"

Geigy Psychiatric Symposium, Sydney 1993. "Opioids in the management of chronic non-malignant pain"

Palliative Care Update for General Practitioners Workshop (Glaxo Foundation), Auckland 1995. "The confused patient"

Palliative Care for GPs (SKB Pharmaceuticals) 1995. "Symptom Control in Palliative Care"

ANZSPM Biennial Conference 1996. "Psychostimulants in terminal depression"

International Medical Society of Paraplegia, Annual Scientific Meeting 1996. "Opioids and spinal pain"

Trustbank Southland Course 1996 (Invited Keynote), Management of Acute/Chronic Pain, Invercargill 6-7 September 1996. "The psychiatric management of chronic pain"

Society for the Study of Psychiatry and Culture, Annual Meeting (Invited Keynote), Wanaka 16-20 October 1996. "Tattooing in NZ"

Recent Developments in Mental Health: a collaborative workshop between Viet Nam, Australia and New Zealand, Hanoi, 13-15 November 1996. "The management of chronic post-traumatic stress disorder in World War II Veterans".

Palliative Care Workshop, Waikato Postgraduate Medicine 1996. "Antidepressants"

NZ Hospital Pharmacists Association Conference 1997. "Methylphenidate"

ANZSPM (NZ Branch) Annual Meeting 1997. "Philoctetes"

National Consultation Liaison Psychiatry Meeting 1998 "Legless"

Roche Psychiatric Weekend, Queenstown 1999. "The psychiatry of World War I (1914-1918)"

NZ Pain Society, Annual Scientific Meeting 2000. "Pethidine - not the preferred opioid for chronic non-malignant pain"

Fifth World Congress of Psycho-Oncology, Melbourne 2000. "Disgusting patients"

Neurologic Association of NZ, Annual Scientific Meeting 2000. "Concussion Clinic"

Palliative Care Study Day, Nelson Marlborough Health Services (Invited Keynote), Blenheim 2000. "Symptom control in palliative care"

Obesity Meeting for GPs (Abbott Labs.) 2000. "Psychological aspects of obesity". Christchurch

RANZCP 36th Congress, Canberra 2001. "Conversion paraplegia"

Amputees Federation Conference (Invited Keynote) 2002. "Phantom pain"

Hospice Palliative Care Seminar, South Canterbury Hospice 2002. "Depression and dying"

Intern/RMO Tutorial, Royal Darwin Hospital 2003. "Delirium"

Sydney Institute of Palliative Medicine, 13th Annual Symposium (Invited Keynote) 2004. 'Management of Delirium'

ANZSPM Biennial Conference, Auckland 2004. Workshop "Delirium"

Queenstown Course in Internal Medicine (Invited Keynote), 9-12 September 2004. 'C - L Psychiatry Update'

Australasian College of Anaesthetists Congress, Auckland 2005 (Invited Speaker). "Pain, Opioids and Personality"

RANZCP 40th Congress, Sydney 2005. "Concussion"

Satellite Meeting (IASP) Clinical-Legal Issues in Pain Special Interest Group (Invited Speaker), Melbourne 2005. "Functional Somatic Syndromes"

World Federation of Neurology Congress, Sydney 2005 (Invited Speaker). "Palliative Care of Dementia - Huntington's and Alzheimer's"

Neurological Association of New Zealand, 50th Annual Meeting, Dunedin 2005. "Cochrane's problem"

Indian Palliative Care Conference (Invited Speaker), Chennai, 2006. "The management of terminal delirium"

ANZSPM Biennial Conference, Newcastle 2006. "Posttraumatic growth or PTSD?"

International Congress of Neuropsychiatry (6th), Sydney 2006 "Huntington's disease and disgust"

Royal Australasian College of Surgeons, Annual Scientific Congress (Invited Speaker), Christchurch. 7-11 May, 2007. "Waddell and the deceiving patient", "Terminal care – pain relief in advanced cancer"

NSW Society of Palliative Medicine (16th Annual Symposium 2007) (Invited Speaker). "The disgusting patient", "Personality, pain and pills"

Royal Australian and New Zealand College of Psychiatrists Conference, The Vintner's Art (Invited Speaker), Napier, 2007 "World War II Veterans"

'Kochipallcon', Indian Palliative Care Association (Invited Speaker), Kochi, Kerala, India. 8-10 February 2008. "CNS Adverse Effects of Opioids".

Australian and New Zealand Society of Occupational Medicine: Annual Scientific Conference, Taupo. 22-24 August, 2008. Invited Speaker. "Managing RTW after TBI".

The Press Christchurch Writers Festival: The Brain that Changes Itself; Norman Doidge in conversation with Dr Sandy Macleod. 4-7 September, 2008

Huntington's Disease Association Annual Conference, Christchurch, 20-21 November, 2008. Invited Speaker. "Difficult Symptoms in HD".

Clinical Controversies: examining the evidence (Invited Speaker). "Palliative Care and Psychiatry". Melbourne, 25-26 October, 2008

ANZSPM Palliative Care Forum. Visiting Lecturer: "Confusion and Consciousness". Peter McCallum, Melbourne; Hobart; RPAH, Sydney; Royal Brisbane Hospital, Brisbane. 4-7 May, 2009

NZ Hospital Pharmacist Association Psych Sig Conference (Invited Speaker) "Psychiatry and Palliative Medicine", Christchurch, August 15, 2009

2nd World Congress of Cultural Psychiatry, Norcia, Italy, September 27-30. "Depression or Demoralization in Refugees".

World Federation of Neurology Congress, Bangkok, October 25-30, 2009 (Invited Speaker). "The management of late-stage Huntington's disease"

ANZSPM Palliative Care Forum. Visiting Lecturer: "Anxiety and Depression at the End of Life". Adelaide, Perth and Darwin. May, 2010

Invited Speaker: ANZSPM Biennial Conference, Adelaide, September 2010. Plenary presentation 'Famous Literary Deaths'. Workshop "Psychoanalytic Theory and Dying"

National Refugee Resettlement Forum: Future Voices – Future Choices, Wellington June 1-2, 2011. 'Refugee coping with the Christchurch earthquakes' M.Osman, A. Hornblow, A D Macleod, P Coope (presented by M. Osman)

World Cultural Psychiatry Congress, London, UK. 8-10 March, 2012. Mood disorder in refugee and migrant populations. Symposium S63-Cross Cultural mental health challenges in New Zealand. WCPRR 2012; 7: Supplement 1:S1-S149

PONS (Canterbury Psychooncology Branch) Confusion: another vital sign. Christchurch 24 September, 2012.

RANZCP Queensland Branch Dinner Meeting 8 November 2012. Fear and Anxiety: the psychological aftermath of the Christchurch earthquakes.

Queensland Consultation Liaison Symposium, PAH, Brisbane 9 November 2012. Depression in the Dying.

ANZAAG Conference, Brisbane, March 16. Plenary Presentation: "Anaphylaxis, Awareness and PTSD"

Human Genetics Society of Australasia. Queenstown, August 5, 2013. Invited plenary response – End of Life Issues: the Dutch Experience (A. Tibben, Maryan Street, C. Gavaghan). "Huntington Disease for the Genetic Counsellor"- Concurrent session.

iii) Public lectures

iv) Provision of continuing education

Hospice Education Trust. Yearly seminar on psychiatry and palliative care.

St John of God Health and Disability Services. Staff education 2002, 2004, 2005. "Huntington's disease"

ORIGINAL INVESTIGATION

Oregonians' Reasons for Requesting Physician Aid in Dying

Linda Ganzini, MD, MPH; Elizabeth R. Goy, PhD; Steven K. Dobscha, MD

Background: Oregon is the only US jurisdiction with a legal process, the Oregon Death with Dignity Act, that allows terminally ill patients to obtain physician aid in dying (PAD).

Methods: Fifty-six Oregonians who either requested PAD or contacted a PAD advocacy organization completed a survey indicating the importance of 29 reasons for their interest in PAD on a scale where 1 was not important and 5 was very important; 28% of people referred from the PAD advocacy organization enrolled in the study.

Results: Forty-one patients died by the end of the study; 18 received a prescription for medication under the Oregon Death with Dignity Act, and 9 died by lethal dose of medication. The most important reasons for requesting PAD, all with median scores of 5, were wanting to control the circumstances of death and die at home; loss

of independence; and concerns about future pain, poor quality of life, and inability to care for one's self. All physical symptoms (eg, pain, dyspnea, and fatigue) at the time of the interview were rated as unimportant (median score, 1), but concerns about physical symptoms in the future were rated at a median score of 3 or higher. Lack of social support and depressed mood were rated as unimportant reasons for requesting PAD.

Conclusions: At the time they express initial interest in PAD, Oregonians are motivated by worries about future physical discomfort and losses of autonomy and function. When confronted with a request for PAD, health care providers should first work to bolster the patient's sense of control and to educate and reassure the patient regarding management of future symptoms.

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ONE IN 10 DYING PATIENTS will, at some point, wish to hasten death.¹⁻⁵ In Oregon, such patients may request physician aid in dying (PAD) as outlined in the Oregon Death with Dignity Act (ODDA), which allows a competent, terminally ill patient to receive a lethal dose of a medication, usually a barbiturate, under some conditions.⁶ Since enactment of the ODDA in 1997, between 1 and 2 persons out of every 1000 who have died in Oregon have chosen PAD.⁶ To date, our understanding of the reasons Oregonians pursue PAD is almost entirely derived from proxies, via interviews with and surveys of patients' family members and health care providers. These proxies ranked depression, poor social support, or uncontrolled physical symptoms as less important reasons for patients' seeking information about PAD than desire for control over the circumstances of death.⁷⁻¹¹ The goal of the present study was to directly survey Oregon patients actively interested in the ODDA regarding their reasons for pursuing PAD.

METHODS

Patients were recruited for our study from 2 sources. The first group included patients who contacted Compassion and Choices of Oregon (CCO; an organization that informs individuals about end-of-life choices and offers services to those who choose aid in dying) for information about PAD, which resulted in CCO opening a client file. During the past decade, CCO staff have given information to or attended the deaths of three-quarters of Oregonians who chose legal PAD.¹² This organization sent letters of invitation to every person who contacted them and who had made an explicit request for a lethal dose of medication under the Oregon Death with Dignity Act to a physician, hospice employee, nurse, or caregiver; was considered mentally capable; and in whom at least 1 physician predicted death within 6 months. The second group included patients who made an explicit request for PAD as outlined in the ODDA. These patients were referred by ethics consultants and palliative medicine and oncology specialists at 4 large medical centers in northwest Oregon.

In all cases, the referring agency or health care provider notified requesting patients about the opportunity to take part in the study, and interested patients then contacted the re-

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This is the exhibit marked "SDM-2" referred to in the affidavit of Alastair Donald Macleod affirmed at Christchurch this 11th day of May 2015 before me:

Phillipa Frances Shaw
Solicitor
Christchurch



A Solicitor of the High Court of New Zealand

Table 1. Characteristics of 56 Study Participants^a

Characteristic	Study Participants
Age, mean (SD), y	65.8 (11.8)
Educational level, mean (SD), y	16.1 (3.2)
Sex	
Male	27 (48)
Female	29 (52)
Race/ethnicity	
White	55 (98)
Nonwhite	1 (2)
Marital status	
Single/divorced/widowed	34 (61)
Married or with partner	22 (39)
Living situation	
Independent	53 (95)
Dependent	3 (5)
Terminal diagnosis	
Cancer	43 (77)
Amyotrophic lateral sclerosis	6 (11)
Cardiopulmonary disease	5 (9)
AIDS	1 (2)
Hepatitis C	1 (2)
Hospice enrolled	20 (36)
ECOG Score	
0	10 (18)
1	24 (43)
2	7 (12)
3-4	14 (25)
Missing data	1 (2)

Abbreviations: AIDS, acquired immunodeficiency syndrome; ECOG, Eastern Cooperative Oncology Group.

^aData are given as number (percentage) of participants unless otherwise indicated.

^bA score of 0 indicates fully active, no functional restrictions; 1, restricted in strenuous activity but able to carry out light work; 2, ambulatory and intact self care, unable to work, and up and about more than 50% of waking hours; 3-4, limited self-care or completely disabled.

search team directly. Potential participants were included in the study if they were adult Oregon residents, cognitively intact as measured by a mental status instrument (scores >23 on the Folstein Mini-Mental State Examination or >7 on the Short Portable Mental Status Questionnaire¹³⁻¹⁵), and competent to consent to participate in the research (determined by the MacArthur Competence Assessment Tool).¹⁶ Most surveys were administered by one of us (E.R.G.) in the participant's home. The study was approved by the institutional review boards of the Portland Veterans' Affairs Medical Center and the participating medical centers. All participants gave written informed consent, including permission to contact their physician or CCO regarding their outcome.

In addition to providing demographic information, participants completed several measures about their attitudes and overall position on legalization of PAD, confirmed that they had explored PAD through CCO and/or explicitly requested a lethal dose of medication, and indicated whether they had discussed their views on PAD with family members. They rated their overall position on the legalization of PAD on a 5-point scale ranging from "strongly oppose" to "strongly support," and their desire for death in the previous 2 weeks, with 0 being "I desire to live as long as possible" and 10 being "I have a strong desire to die soon."

Survey items regarding reasons for requesting PAD were drawn from qualitative studies of terminally ill patients, previous surveys of health care professionals and family members in Oregon who cared for patients who obtained a lethal pre-

scription, and the investigators' experience in evaluating and caring for such patients.^{7-11,17,18} Participants ranked the importance of 29 possible reasons on a scale of 1 to 5, where 1 was "reason not at all important in decision to request a lethal prescription" and 5 was "reason very important in decision to request a lethal prescription."

Data are presented as frequencies and proportions for categorical data, means and standard deviations for normally distributed data, and medians with interquartile ranges for highly skewed data. The Mann-Whitney test was used to compare continuous but skewed data. An α level was set at .01 to adjust for the large number of analyses, and all tests were 2-sided.

RESULTS

Compassion and Choices of Oregon invited 178 clients to take part in this study. Of these, 12 (7%) were ineligible because they had died, were moribund, lived outside of Oregon, or were not terminally ill, and 47 (28%) contacted the research team expressing interest in participating. The remaining 11 participants were referred from 1 of 4 other medical centers (referring health care providers did not keep track of the number of persons notified about the study). A total of 58 agreed to participate; however, 2 did not complete the section of the study measuring reasons for the request. Study participants were equally divided by sex and were predominantly white, well educated, and lived independently (mean age, 66 years) (Table 1). The most common terminal diagnoses were cancer and amyotrophic lateral sclerosis. Only 1 in 3 participants were enrolled in hospice at the time of the survey, and fewer than half were married. Forty-one participants (73%) died a median of 2 to 3 months after they participated in the study. At death, 18 (44%) had received a prescription for medication under the ODDA, and 9 (22%) died by lethal ingestion.

Study participants confirmed their strong interest in PAD: 55 (98%) strongly supported legalization of PAD, 47 (84%) sought information on obtaining PAD from CCO, and 46 (82%) indicated they explicitly requested PAD. Fifty-four participants (96%) discussed their attitudes about PAD with family and friends, and 47 (86%) indicated that the people closest to them would probably support their choice to pursue PAD. The desire to die in the 2 weeks before the interview was low (mean [SD], 2.1 [3.3]).

The chief reasons participants pursued PAD, all with median scores of 5, were loss of independence, wanting to control the time and manner of death and die at home, and the prospect of worsening pain or quality of life and the inability to care for themselves (Table 2). Other key reasons, with median scores of at least 3.5, were having witnessed intolerable deaths, perception of self as a burden, loss of dignity, and fear of mental confusion in the future. Physical symptoms experienced at the time of initial interest in PAD were much less important: pain, shortness of breath, fatigue, confusion, and loss of bowel and bladder control were all rated a median of 1. In contrast, all physical symptoms that the patient anticipated in the future were rated a median of 3 or higher. Most respondents did not endorse existential reasons, such as feeling ready to die, that life tasks were complete, or that life

was pointless. Social issues were rated overall as not of concern; lack of social support and perception of self as a financial drain were both rated with a median score of 1. Participants did not acknowledge depression as an important reason for pursuing PAD. There were no statistically significant differences in reasons for the request in comparing those who received a lethal prescription and those who did not (data not shown).

Of 56 subjects, 41 (73%) rated a single most important reason for asking for PAD. Eleven requested PAD primarily to feel in control, 5 to avoid dependence on others, 5 because of worries about pain in the future, 4 because of worries about poor quality of life in the future, and 3 because of worries of loss of sense of self. All other most important reasons were chosen 2 times or less.

COMMENT

Oregon is one of the few jurisdictions internationally and the only US territory that has a legal process allowing patients to obtain PAD. The ODDA allows a physician to prescribe a lethal dose of medication to be self-administered by a requesting patient whose life expectancy is less than 6 months. A second physician must confirm the limited life expectancy and that the patient is capable of making the request. Between 1997 and 2007, 341 Oregonians died by legal PAD. One requirement of the law is that all prescriptions must be reported to the Oregon Health Division and aggregate data published annually. From this source, we know that, compared with other Oregonians who die, those who choose PAD are somewhat younger, predominantly white, better educated, less likely to be married, and more likely to die of cancer and amyotrophic lateral sclerosis; 86% are enrolled in a Medicare-certified hospice at the time of death.⁶

Our data suggest that when patients first request PAD, they do so not because of physical symptoms or quality of life at the time of the request but in anticipation of future suffering that they perceive as intolerable. Their desire to die is not strong, and they do not believe that their life is poor in quality, meaningless, or worthless. Rather, they appear to be protecting against the risk of future experiences they do not believe they can endure. Although future physical symptoms are important considerations for these individuals, they are more strongly motivated by the prospect of loss of autonomy—loss of control, quality of life, and ability to remain at home, with looming restrictions and dependence on others.

We are aware of only one other study that gathered data directly from persons actively considering or pursuing PAD. Pearlman et al¹⁷ completed longitudinal, qualitative interviews of 12 patients and family members of 23 additional patients from the Pacific Northwest who were actively pursuing PAD (including 17 who ultimately self-administered the medications). They also found that loss of sense of self, fears about the future, negative experiences with dying, and desire for control were prominent reasons for pursuing PAD. Unlike our study, they found that experiences of weakness, discomfort, pain, and functional losses were more prominent reasons. In addition to differences in study design, this may

Table 2. Reasons for Wanting Physician Aid in Dying^a

Reason	Median Score (IQR)
Wanting to control circumstances of death	5 (4-5)
Future poor quality of life	5 (4-5)
Future pain	5 (4-5)
Future inability to care for self	5 (3-5)
Loss of independence	5 (3-5)
Wanting to die at home	5 (1-25-5)
Perception of self as burden	4 (2-5)
Loss of dignity	4 (1-5)
Witnessed bad death(s)	4 (1-5)
Future mental confusion	3.5 (1-5)
Not wanting others to care for me	3 (1-25-5)
Worry about loss of sense of self	3 (1-5)
Future dyspnea	3 (1-5)
Ready to die	3 (1-5)
Future fatigue	3 (1-5)
Future loss of bowel/bladder control	3 (1-5)
Unable to pursue pleasurable activities	1 (1-4)
Life is pointless	1 (1-4)
Life tasks are complete	1 (1-4)
Perceive self as financial drain	1 (1-3-75)
Poor quality of life	1 (1-3)
Current pain	1 (1-2-75)
Unable to care for self now	1 (1-2)
Current dyspnea	1 (1-2)
Lack of support	1 (1-1)
Depressed mood	1 (1-1)
Current mental confusion	1 (1-1)
Current loss of bowel/bladder control	1 (1-1)

Abbreviation: IQR, interquartile range (25th percentile to 75th percentile).

^aParticipants marked the importance of their reasons for requesting physician aid in dying on a scale from 1 to 5: 1 was "reason not at all important in decision to request a lethal prescription" and 5 was "reason is very important in decision to request a lethal prescription." Marks not on an integer were estimated to the quarter interval.

reflect that our study participants were seen once, whereas Pearlman et al¹⁷ studied participants longitudinally, perhaps closer to death. Furthermore, our study focused on patients, not family members, as primary sources of information.

There are several limitations in our study. Our results focus on patients at the time they are first requesting PAD, yet 5 in 6 requests are ultimately not honored by physicians.¹¹ Furthermore, among those who are successful in obtaining a prescription, some may wait until they are more ill and symptomatic to take it. For example, 20 of 56 of our study participants (36%) were enrolled in hospice. Similarly, physicians reported that 32% of 141 Oregon patients were enrolled in hospice at the time of the first PAD request.¹¹ In contrast, 86% of Oregonians who die by lethal ingestion are ultimately enrolled in hospice.⁶ Although experienced physical symptoms were not a motivator for initially pursuing a lethal dose of medication, they may be cogent in the choice to ultimately die by a lethal prescription.

A second limitation is that only 47 of 166 clients (28%) invited by CCO to participate enrolled in the study; those who volunteered to participate in our study may not be representative of other Oregonians at the time they first request PAD. For example, in our study, 1 in 4 patients had limited self care or complete disability. In contrast, Oregon physicians reported that 59% of patients were con-

fined to bed or a chair for more than half their waking hours when first requesting PAD.¹¹ The very reasons that individuals may not have been able to participate in our study—lack of energy, poor motivation, disabling physical symptoms, or functional impairment—may have contributed to interest in hastened death. Despite the potential for selection bias, there is substantial agreement between the results of the present study and Oregon physicians' and hospice workers' previous reports of patients in Oregon who choose PAD.

The results of the present study may provide helpful approaches for patients who request PAD. Patients who actively pursue PAD appear, at least initially, to be motivated by worries about future physical discomfort and impending losses in autonomy and function. Having witnessed intolerable deaths, these patients need to have their sense of control supported. Health care providers should focus on reassuring patients that all efforts will be made to ensure that they will be able to die where they wish and that pain and other symptoms will be controlled.

If opposition to legalization of PAD is based on moral and religious beliefs about the value of life and ethical concerns about physicians' actions, then patients' reasons for hastening death may be irrelevant.¹⁹ However, for many policy makers and health care providers, judgment of Oregon's law is conditional and based on PAD being used as an option of last resort.²⁰ Lethal prescriptions should not substitute for competent end-of-life care.²¹ Our data support the assertion that initial pursuit of PAD does not appear to stem from lack of access to symptom management. Alternatively, for some, support of PAD legalization was based on the specter of patients with grave suffering from symptoms that could not be controlled even with good care. This support may wane faced with evidence that experienced physical symptoms are not paramount reasons for requesting PAD. However, as noted by Cassell,²² it is not the absolute level of pain, but the meaning of the pain, the prospect of its worsening, and its effect on one's sense of self that are the true components of suffering. Whether or not PAD can be justified, our findings clarify the source of these patients' suffering, which may lead to more compassionate care.

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Author Contributions: Drs Ganzini, Goy, and Dobscha had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. *Study concept and design:* Ganzini, Goy, and Dobscha. *Acquisition of data:* Ganzini and Goy. *Analysis and interpretation of data:* Ganzini, Goy, and Dobscha. *Drafting of the manuscript:* Ganzini. *Critical revision of the manuscript for important intellectual content:* Ganzini, Goy, and Dobscha. *Statistical analysis:* Ganzini. *Obtained funding:* Ganzini, Goy, and Dobscha. *Administrative, technical, and material support:* Ganzini and Goy. *Financial Disclosure:* None reported.

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"SDM-3"

This is the exhibit marked "SDM-3" referred to in the affidavit of **Alastair Donald Macleod** affirmed at Christchurch this 11th day of May 2015 before me:



Phillipa Frances Shaw
Solicitor,
Christchurch

A Solicitor of the High Court of New Zealand

PERSPECTIVE

Physician-Assisted Suicide — Oregon and Beyond

Susan Okie, M.D.

In February, the U.S. Supreme Court agreed to consider the legality of the Bush administration's effort to outlaw physician-assisted suicide in Oregon, raising the possibility that a ruling by the Court during its next term could effectively invalidate the controversial Oregon law known as the Death with Dignity Act. With the events leading to the death of Terri Schiavo focusing national attention on end-of-life decisions, the Court's acceptance of the case formerly known as *Oregon v. Ashcroft* is likely to heat up the public debate on assisted suicide. The justices will hear oral arguments in the case, now renamed *Oregon v. Gonzales*, soon after starting a new term next October. A decision is expected by July 2006. Whatever the future of the Oregon law, the state's seven years of experience with physician-assisted suicide have greatly influenced thinking about end-of-life issues and the practice of assisted suicide, both in the United States and elsewhere. This year, lawmakers in California and Vermont and in Britain are considering bills modeled on the Oregon law.

The case now headed for the Supreme Court began in 2001, when Oregon's attorney general, along with a physician, a pharmacist, and several terminally ill state residents, sued to block the Justice Department from punishing Oregon doctors and pharmacists for providing lethal medications to terminally ill patients who wished to end their lives. In May 2004, the U.S. Court of Appeals for the Ninth Circuit in San Francisco ruled in favor of the plaintiffs, stating that drug-enforcement officials could not use the federal Controlled Substances Act to penalize Oregon health care professionals, provided that they had followed the requirements specified in the assisted-suicide law. This past November, on the day he announced his resignation as attorney general, John Ashcroft appealed that decision to the Supreme Court.

Dr. Okie is a contributing editor of the *Journal*.

In the past, the high court has allowed each state to determine the legal status of suicide. In a pair of 1997 decisions, the Supreme Court upheld laws in two states prohibiting physician-assisted suicide, but it left states free to legalize the practice. None except Oregon have done so. Thirty-eight states have laws that make it a crime to assist in a suicide, and several others treat such an act as a crime on the basis of their common law (precedent created by previously decided cases). Three states — North Carolina, Utah, and Wyoming — abolished the common law of crimes and have no statutes criminalizing assisted suicide. Virginia imposes civil but not criminal sanctions on anyone who assists in a suicide. The Ohio Supreme Court ruled in 1996 that assisted suicide is not a crime, although the state does not condone it.

In March, epidemiologists with Oregon's Department of Human Services issued their seventh annual report on state residents who have availed themselves of the Death with Dignity Act to end their lives. To use the law, a patient must be older than 17 years of age, capable of making and communicating health care decisions, and terminally ill with a life expectancy of less than 6 months. The patient's request for assisted suicide must be communicated to a doctor both orally and in writing, and both the prescribing physician and a consulting physician must confirm the diagnosis and prognosis as well as agree that the patient is capable of making an informed decision and is not clinically depressed. If either doctor is uncertain about the patient's mental competence, the patient must be referred for a psychiatric or psychological evaluation. People who are given a prescription for lethal medications must be able to take them orally; family members, friends, doctors, and other health care workers are forbidden to administer the drugs.

Oregon's seven years of experience with this law have been, for the most part, reassuring: medical and legal safeguards established during implemen-

tation appear to have prevented abuse, and most patients have had the expected outcome. Between 1998 and 2004, Oregon physicians wrote 326 prescriptions for drugs to be used in assisted suicide, and 208 people ended their lives by taking the drugs. In the years since legalization, the number of Oregonians hastening death in this way has increased, but it remains a tiny fraction of all terminally ill patients. According to the Oregon Department of Human Services, physician-assisted suicide was the cause of 37 deaths in 2004, about one eighth of 1 percent of all deaths in the state. Most frequently in such cases, the patient either drinks 10 g of liquid pentobarbital or swallows the powder from 9 to 10 g of secobarbital capsules (dissolved in water or applesauce). Patients are instructed to take an anti-nausea medication about an hour before swallowing the barbiturate. Despite this precaution, there have been some cases of partial regurgitation of the sedative, including a few in which the patients vomited one third to one half of the dose. However, in all cases but one for which information is available, the patients became unconscious — usually within a few minutes after taking the medication — and remained so until they died. The median time from ingestion to death was 25 minutes, but some patients survived for hours, including at least 17 who lived for more than 4 hours, 1 of them surviving for 37 hours and another for 48 hours. Once a patient swallows the prescribed dose, it is illegal to take any additional measure to hasten death. There have been no reported cases in which emergency medical services were summoned after a patient took the medication.

Earlier this year, in the first such case in Oregon since the law went into effect, a terminally ill patient apparently ingested the full prescribed dose of medication but did not die; instead, he awoke from a coma almost three days later and lived for two more weeks before dying of lung cancer. David E. Prueitt, 42, reportedly swallowed about 10 g of secobarbital powder mixed with water, applesauce, cinnamon, and a small amount of a sweet-tasting laxative. His wife told a reporter that he woke 65 hours later and asked, "What the hell happened? Why am I not dead?"¹ The Oregon Board of Pharmacy is analyzing

drug residue remaining on the empty capsules and investigating other aspects of the case, such as whether the laxative might have interfered with absorption of the barbiturate.

The law has not had the dire social consequences that some opponents predicted. There is no evidence that it has been used to coerce elderly, poor, or depressed patients to end their lives, nor has it caused any significant migration of terminally ill people to Oregon. As compared with Oregonians who died naturally from similar diseases in 2004, those who died by means of physician-assisted suicide tended to be younger (median age, 64 vs. 76 years), more highly educated, and more likely to have been divorced or never married. Seventy-eight percent had cancer. However, in the period from 1998 to 2004, the rates of assisted suicide were higher among people with amyotrophic lateral sclerosis (25 per 1000) and AIDS (23 per 1000) than among people with cancer (4 per 1000).

Only 2 of the 208 patients who died by means of lethal medication were uninsured, and 86 percent were enrolled in hospice care. Most died at home; only one died in an acute care hospital. The most frequent reasons for choosing assisted suicide, mentioned by more than 80 percent of patients, were loss of autonomy, loss of dignity, and loss of the ability to enjoy life. Thirty-six percent expressed concern about being a burden to family or caregivers; 22 percent cited inadequate pain control. Only 3 percent mentioned financial concerns. Researchers who have analyzed the personalities of patients choosing assisted suicide have found them to be exceptionally eager to control their own lives and remain independent. "I don't want to die not knowing if it's day or night, not knowing anybody in my family," Richard Holmes, one of the original plaintiffs in *Oregon v. Ashcroft*, told me in 2001. "I want to know what's going on and do it myself if I'm going to do it: say 'Adios.'" Holmes had obtained a lethal dose of barbiturates from a doctor, but like about 36 percent of the people who have done so under the law, he never used it; he died of cancer in September 2002.

Although relatively few terminally ill patients in Oregon actually make use of the law, recent find-



ings indicate that many more consider doing so. Medical ethicist Susan W. Tolle and colleagues interviewed the next of kin of 1384 Oregonians who died of natural causes. A total of 236 respondents (17 percent) reported that their sick relative had mentioned considering assisted suicide. However, only 25 said their relative had formally requested a prescription for lethal medication. In 17 cases, respondents said the doctor refused the request or dissuaded the patient.² "It is on the minds of more patients and families than physicians have any idea of," Tolle said.

There is suggestive evidence that the widely publicized debate about the assisted-suicide law and its enactment contributed to overall improvements in end-of-life care in Oregon. According to Tolle, Oregon has the lowest rate of in-hospital deaths of any state. Hospice admissions increased during the late 1990s, and the state adopted a standardized physician's order form for recording patients' wishes with regard to the use or limitation of life-sustaining treatment. Among Oregon physicians surveyed in 1999, 76 percent of those who cared for terminally ill patients reported having worked to improve their knowledge of pain treatment.³

Yet some Oregon physicians remain adamantly opposed to the law, maintaining that a patient's wish to hasten death may reflect unrecognized, treatable depression or a lack of support for other options. "When a patient says, 'I don't want to be a burden,' it may really be a question, 'Am I a burden?'" noted William L. Toffler, a professor of family medicine at Oregon Health and Sciences University and the national director of Physicians for Compassionate Care, a group that opposes assisted suicide.

Toffler made this comment in testimony before members of the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill, who traveled from the United Kingdom to Oregon this past December to learn about how the law has worked. The bill that the House of Lords has been considering, broadly modeled on the Oregon law, would legalize assisted suicide and euthanasia under specific circumstances, for patients who are terminally ill, mentally competent, and suffering unbearably. The committee was charged with investigating whether current British laws outlawing such practices should be changed.

British opinion on assisted suicide has shifted during the past decade, according to Mark Slattery

of the Voluntary Euthanasia Society in England and Wales. Cases in which seriously ill British patients traveled to Switzerland to obtain lethal medication in order to end their lives have been widely reported in the media. In a nationally representative poll conducted last September, 82 percent of respondents said terminally ill patients who are suffering unbearably should be allowed to receive medical help to die, if they want it. The British Medical Association, the nation's largest physicians' organization, opposes the Assisted Dying for the Terminally Ill Bill, but the Royal College of Physicians and the Royal College of General Practitioners recently dropped their opposition. The bill, which lacks government backing, is considered unlikely to pass this session. Earlier this month, the select committee issued its report, including a recommendation that "a clear distinction should be drawn in any future bill between assisted suicide and voluntary euthanasia in order to provide [Parliament] with an opportunity to consider carefully these two courses of action, and the different considerations which apply to them."⁴

Meanwhile, two California lawmakers held public hearings this past winter on another bill, closely patterned on the Oregon law, that they introduced in the state legislature in February. Democratic assembly members Patty Berg of Sebastopol and Lloyd Levine of Van Nuys brought witnesses from Oregon to the hearings in California to address concerns about how legalizing assisted suicide in this state might affect people with disabilities and how physicians evaluate the emotional state and mental competence of a terminally ill patient who requests lethal medication. A 1992 initiative to legalize euthanasia in California was voted down, and an assisted-suicide bill introduced in 1999 failed to pass the legislature, but Levine said he believes that the generally reassuring experience with the Oregon law has increased the chances of enacting a similar statute in California. "I would say this is not suicide," he said. "This is giving people dignity and control at the end of their lives." The state has already taken a number of measures to improve end-of-life care, including requiring that medical students be trained in pain management and that practicing physicians obtain continuing education in pain treatment and palliative care.

But Oregon's successful implementation of its assisted-suicide law might not be easily replicated in other states with more socioeconomically di-

verse populations and less inclusive health care programs, cautioned Joanne Lynn, a senior researcher with the RAND Corporation and director of the Washington Home Center for Palliative Care Studies in Washington, D.C. "There isn't a huge demand for assisted suicide in good care systems, but there could be a huge demand in much less adequate care systems," Lynn said.

Psychiatrist Linda Ganzini of Oregon Health and Sciences University agrees that her state's high-quality system of palliative care is the factor most responsible for keeping the number of assisted-sui-

cide cases low. "Your safety net is your end-of-life care and your hospice care," she said. "It's not the safeguards that you build into the law."

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Terri Schiavo — A Tragedy Compounded

Timothy E. Quill, M.D.

Related article, page 1710

An Interview with
Dr. Quill can be
heard at [www.
nejm.org](http://www.nejm.org).

The story of Terri Schiavo should be disturbing to all of us. How can it be that medicine, ethics, law, and family could work so poorly together in meeting the needs of this woman who was left in a persistent vegetative state after having a cardiac arrest? Ms. Schiavo had been sustained by artificial hydration and nutrition through a feeding tube for 15 years, and her husband, Michael Schiavo, was locked in a very public legal struggle with her parents and siblings about whether such treatment should be continued or stopped. Distortion by interest groups, media hyperbole, and manipulative use of videotape characterized this case and demonstrate what can happen when a patient becomes more a precedent-setting symbol than a unique human being.

Let us begin with some medical facts. On February 25, 1990, Terri Schiavo had a cardiac arrest, triggered by extreme hypokalemia brought on by an eating disorder. As a result, severe hypoxic-ischemic encephalopathy developed, and during the subsequent months, she exhibited no evidence of higher cortical function. Computed tomographic scans of her brain eventually showed severe atrophy of

her cerebral hemispheres, and her electroencephalograms were flat, indicating no functional activity of the cerebral cortex. Her neurologic examinations were indicative of a persistent vegetative state, which includes periods of wakefulness alternating with sleep, some reflexive responses to light and noise, and some basic gag and swallowing responses, but no signs of emotion, willful activity, or cognition.¹ There is no evidence that Ms. Schiavo was suffering, since the usual definition of this term requires conscious awareness that is impossible in the absence of cortical activity. There have been only a few reported cases in which minimal cognitive and motor functions were restored three months or more after the diagnosis of a persistent vegetative state due to hypoxic-ischemic encephalopathy; in none of these cases was there the sort of objective evidence of severe cortical damage that was present in this case, nor was the period of disability so long.²

Having viewed some of the highly edited videotaped material of Terri Schiavo and having seen other patients in a persistent vegetative state, I am not surprised that family members and others unfamiliar with this condition would interpret some of her apparent alertness and movement as meaningful. In 2002, the Florida trial court judge conducted six days of evidentiary hearings on Ms. Schiavo's condition, including evaluations by four neurologists, one radiologist, and her attending

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Review



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ANZJP

Assisted dying in liberalised jurisdictions and the role of psychiatry: A clinician's view

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Sandy Macleod

Abstract

Objective: Assisted dying is a contentious and topical issue. Mental disorder is a relevant influence on requests of hastened death. The psychiatry of dying is not a prominent component in the assessment of euthanasia and physician-assisted suicide (PAS) in jurisdictions with liberalised assisted dying laws. The literature on the assessment processes, with particular reference to mental status, involved in euthanasia requests is considered.

Methods: An experienced palliative medicine specialist and psychiatrist selectively reviewed the recent literature published about the mental health issues involved in euthanasia and PAS.

Results: Assessments of competency, sustained wish to die prematurely, depressive disorder, demoralisation and 'unbearable suffering' in the terminally ill are clinically uncertain and difficult tasks. There is a growing psychiatric and psychological literature on the mental status of the terminally ill. As yet psychiatry does not have the expertise to 'select' those whose wish for hastened death is rational, humane and 'healthy'. Rarely in those societies with liberalised assisted dying laws are psychiatrists involved in the decision-making for individuals requesting early death. This role is fulfilled by non-specialists.

Conclusions: There remain significant concerns about the accuracy of psychiatric assessment in the terminally ill. Mental processes are more relevant influences on a hastened wish to die than are the physical symptoms of terminal malignant disease. Psychiatric review of persons requesting euthanasia is relevant. It is not obligatory or emphasised in those legislations allowing assisted dying. Psychiatry needs to play a greater role in the assessment processes of euthanasia and PAS.

Keywords

Euthanasia, physician-assisted suicide, depression, competency, suffering

Introduction

Over recent decades in several jurisdictions, including for a brief period the Northern Territory of Australia, there has been legislation for assisted dying for severe terminal medical illness. Legalised euthanasia and/or physician-assisted suicide (PAS) are currently practised in the Netherlands, Belgium, Estonia, Luxembourg, Albania, Switzerland and the US states of Oregon, Montana and Washington (Field and Curtice, 2009). Assuring mental competency and the exclusion of current psychiatric illness are tasks expected of medical assessors, who are rarely specialist psychiatrists. Ryan (1995) advocated mandatory psychiatric review of persons requesting euthanasia, a view supported by the RANZCP Section of Consultation-Liaison Psychiatry's Working Group on Euthanasia (1996). This was obligatory in the Northern Territory but is not in the law of the other

jurisdictions. Psychiatry needs to play a greater role in the ongoing debates about euthanasia and contribute from the clinical, scientific, and ethical points of view (Naudts et al., 2006).

Euthanasia is the deliberate ending of another person's life at his or her request. Physician-assisted suicide (PAS) is defined as 'a doctor intentionally helping a person to commit suicide by providing drugs for self-administration, at

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the person's voluntary and competent request' (Materstvedt et al., 2003). Withholding and withdrawing futile treatments and palliative or terminal sedation are not considered euthanasia (Materstvedt et al., 2003). There are philosophical, religious, medical, financial and political arguments opposing and supporting killing on request. Reports about those countries and states with liberalised assisted dying legislations are becoming available and provide important insights into this practice.

The author has attended an estimated 10,000 terminally ill hospice patients over the last two decades. Clinical practice moulds professional opinion. It is impossible not to be influenced and biased by clinical experience. This article is not a comprehensive review of the literature on assisted dying. It is a selective review of published literature from jurisdictions with assisted dying legislations by a clinician working within a legal system prohibiting euthanasia and PAS, and with an interest in the psychiatric state of the terminally ill.

Over the last 50 years, medicine became scientifically capable of artificially sustaining life. For the first time the very sick have options of living or dying. Assertive oncological treatments, aimed only to prolong life for weeks to months, are allowing cancer patients to live longer. Critical care and emergency medicine are able to salvage persons suffering horrendous injuries and illnesses. The survivors, however, may endure major disabilities including psychiatric disorders. Cancer and AIDS have been converted into chronic illnesses, allowing the accumulation of disease in multiple organs, including the brain. The process of dying is becoming increasingly fraught and difficult. Euthanasia debates do not occur in societies without health services sufficiently affluent to be able to keep persons artificially living (Spence, 2003). The fear of dying 'badly' (dysthanasia), rather than a fear of death, is a dominant concern of developed societies. This is a new driver of euthanasia for which modern medicine is responsible. The psychology and psychiatry of dying is becoming increasingly relevant in those individuals whose quality of remaining life is deteriorating and who are experiencing ideations about hastening death.

Legalised PAS and euthanasia

In 1996, for the first time in history, a democratically elected government in the Northern Territory made both euthanasia and PAS legal. The following year the Australian government overturned this territory law. In 9 months, seven patients had made formal use of this law and four died under it. In the Netherlands, euthanasia and PAS have been sanctioned and practised openly since 1991. The Dutch criteria for euthanasia include competency but not the exclusion of mental illness as prerequisites (Table 1) (Field and Curtice, 2009; KNMG, 2011). In 2001, 2.8% of all Dutch deaths were by euthanasia and PAS (van der Heide et al., 2007). This percentage had fallen to 1.8% in 2005 (van der Heide et al., 2007). Of a yearly average of 8400 requests, approximately 2400 are actually carried out (KNMG, 2011). In most cases the estimated shortening of life was rarely more than 1 month (van der Heide et al., 2003). In 1994 the US state of Oregon legalised PAS but not euthanasia. This law was enacted in 1997. Terminally ill persons suffering 'incurable' and 'irreversible' disease considered to be in the last 6 months of life, who are capable of making a voluntary decision about their health care, understand the information provided, communicate a choice, and not have a mental health condition that impairs judgement, may request PAS. The patient is prescribed a supply of lethal medication (a barbiturate) to be consumed orally. About 50–60 persons/year die of PAS (about 0.2% of all deaths). Between 1998 and 2004 only 326 prescriptions were written, and 208 ended their life this way (36% dying naturally) (Okie, 2005). In 2010, 96 patients were recipients of lethal medication prescriptions and 59 are known to have died ingesting the medications (Oregon Public Health Division, 2010). Similar legislation was passed in Washington in 2008. Since 2010 doctors in Montana are protected from prosecution for helping the terminally ill die, providing the patient is competent. Belgium legalised euthanasia in 2002, but not PAS or any other forms of life-shortening action (Field and Curtice, 2009). Belgium is the only country in which mental suffering from either somatic or mental disorder is explicitly acknowledged in law as a

Table 1. Dutch euthanasia criteria, 2002 (Field and Curtice, 2009; KNMG, 2011).

The patient's request must be voluntary, enduring and well considered.
The patient's suffering must be lasting and unbearable.
The patient must be well-informed about the current situation and prospects.
All other options for care must have been exhausted, or refused by the patient.
Euthanasia must be carried out by a qualified physician with due care.
The physician must consult at least one other physician.
The physician must inform the local coroner that euthanasia has occurred.

valid basis for euthanasia (Naudts et al., 2006). The mentally ill person must be competent, continuously suffering unbearably, repeatedly express and record a wish to die, and be experiencing a severe and incurable disorder. Euthanasia represented 1.9% of all Flemish deaths in 2007 (Smets et al., 2010). Since 1942 the penal code in Switzerland has not criminalised assisted suicide provided the person who assists is 'motivated by "unselfish" reasons' (Field and Curtice, 2009). The Swiss law, when created, did not envisage assisted suicide from a medical perspective (Guillod and Schmidt, 2005). Active euthanasia is illegal. A medical practitioner must assess the patient's decisional capacity and prescribe the lethal dose. The patient must directly administer the lethal barbiturate to themselves. The person seeking assistance does not have to be terminally ill. They do need to be 'unbearably suffering' or 'unreasonably disabled', and consistently wish to die. Since 1998 nearly 1000 deaths have occurred under this arrangement including nearly 100 British citizens, for the patient does not need to be a Swiss national (Field and Curtice, 2009; Joffe, 2009). Of 1800 Swiss requests for PAS each year, two-thirds are rejected after screening and half of the remaining die by natural causes, leaving about 300 assisted suicides each year (or 0.45% of deaths in Switzerland) (Hurst and Mauron, 2003). In the UK assisting suicide remains illegal, however encouraging suicide may not necessarily be prosecuted if the assistance is 'minor, reluctant and wholly motivated by compassion' (Director of Public Prosecutions, 2010). However the Director of Public Prosecutions (DPP) gives no specific assurance as to how it may respond, emphasising the uncertainty still existing regarding assisted suicide in the UK.

Requests for assisted dying

It is uncertain how frequent the occurrence of unsanctioned doctor-assisted dying is in countries in which euthanasia is illegal. Even anonymously, few clinicians are prepared to reveal an illegal act. Many relatives (and some doctors) presume an analgesic dose several hours before death caused death, rather than easing pain until the imminent natural death occurred. The classical example of this phenomenon is Dr Schur's 'voluntary euthanasia' of the 83-year-old Sigmund Freud, dying of a jaw malignancy (Schur, 1972).

Public opinion polls suggest over 80% support euthanasia legalisation in the UK (Branthwaite, 2005). In most developed countries a majority of the general population appear supportive. There is however a trend that as an individual moves from the street, to oncology outpatients, and to hospice care, their attitude toward liberalising euthanasia mellows. In the Netherlands 7% of all people whose death is expected request euthanasia preceding their death (Onwuteaka-Philipsen et al., 2010). Having initiated the process, 13% then withdraw (Jansen-van der Weide et al.,

2005). About 17% of Oregonians are potentially interested in aid in dying, though only 1–2% actually request it (Ganzini et al., 2008) and 36% provided a lethal prescription die naturally (Okie, 2005). In Canadian palliative care patients 63% believed euthanasia should be legalised, yet only 6% would wish to initiate the request (Wilson et al., 2007). The proximity to the death bed contaminates opinion. This may also apply to medical practitioners. Doctors are less often in favour of actively shortening life than are the general public and nurses (Gielen et al., 2008). Specialities such as palliative care, geriatrics and oncology appear more strongly opposed than intensive care physicians and medical students (Gielen et al., 2008; Marini et al., 2006). The UK House of Lords (2005) summarised doctors' views as 'The closer their experience of end-of-life patients, the less sure professionals are about the prospect of a change of the law in favour of euthanasia'.

Requests for euthanasia are not uncommon in medical practice. It is reported that 47% of Australian doctors have received at least one request for euthanasia (Stevens and Hassan, 1994). GPs are the recipients of most requests, palliative medicine physicians probably the least. Patients cared for at home are more inclined to request assistance dying than those in hospital, who are more likely to request non-treatment (Cohen et al., 2007).

Acceptable criteria

It might be reasonable to presume that those requesting a hastened death would be frail and suffering severe (cancer) pain or other unpleasant symptoms. In the Netherlands cancer is the most common diagnosis (74%) of the requesters, 7% have cardiovascular disease, and 5% severe pulmonary disease. However relatively more patients (20%) with motor neurone disease (MND) die due to euthanasia or PAS compared with patients with cancer (5%) or heart failure (0.5%) (Maessen et al., 2010). In 2000/01, 2.9% of the requests for PAS were for psychiatric disease and 4.5% for 'weary of life' (Rurup et al., 2005). The major specific reasons for the requests were fear of pain (37%), deteriorating physical status (31%), hopelessness (22%), and dyspnoea (15%) (Marcoux et al., 2005). The most important concerns were non-physical (Marquet et al., 2003). Usually the concerns were multifactorial and included fears of dependence, loss of autonomy, loss of dignity, being a burden on others, and social isolation (Marquet et al., 2003). Loss of control appeared to be a core influencing factor. The personal and social factors were more relevant in encouraging the request than the physical and psychiatric ones (Rietjens et al., 2009). The characteristics of the 'weary' patients were old age (average 81 years), 'reasonable' health, aloneness, social isolation, and 'through or tired of living and physically deteriorating' (Rurup et al., 2005). These discontented citizens request 'suicide-by-doctor'. In only 20–30% of those who request euthanasia is it performed, though none

in the psychiatric group and 1% in the 'weary' group (Rurup et al., 2005). Thirty-nine per cent had died before the request could be granted and 38% did not meet the necessary criteria to allow euthanasia (Onwuteaka-Philipsen et al., 2010).

The Oregonian data suggest that patients do not request PAS because of unrelieved physical symptoms, or inadequacy of palliative care services (most are simultaneously enrolled in hospice programmes), and neither are they depressed or socially vulnerable (Ganzini and Back, 2003). They request assisted suicide for psychological and existential reasons: they value control, dread dependence on others, are ready to die, and assess current quality of life as poor (Ganzini and Back, 2003). The most important reasons for their requests concerned loss of control, wishing to die at home, loss of dignity and independence, concerns about future pain, poor quality of life and self-care ability (Ganzini et al., 2009). Significantly the requests did not relate to distressing physical symptoms, financial concerns or poor social support. The concerns were about future worries of declining welfare. The majority who request PAS are in their seventh decade, well educated, middle-class, white, married, with cancer diagnoses, and complaining of loss of enjoyment and quality of life. The poor, the ill-educated, the uninsured and those without access to palliative care are not those who request PAS. In Oregon approximately one in two PAS requests are declined, usually because the patient does not suffer cancer (Ganzini et al., 2000).

Contrary to what may have been predicted (and is perhaps assumed by the general public), people request assisted dying, if they have the legal opportunity to do so, because of psychosocial, and not physical, symptoms.

Psychiatry in PAS jurisdictions

A critical component of the legal requirements introduced for assisted dying is that of the role of the medical profession. Doctors are asked to assess the patient and opine upon prognosis and mental status. In the terminally ill these are not simple and straightforward clinical determinations.

In the Northern Territory the patient under the law had to be certified to be of sound mind and making the decision freely, voluntarily, and after due consideration (Field and Curtice, 2009). A psychiatrist was required to examine the patient and confirm that they were not suffering from a 'treatable' clinical depression. Four of the seven patients considered (two died before the law came into effect, one after its repeal) had some symptoms of depression. One, despite current depressive symptoms and a probable sub-therapeutic dose of antidepressant, was considered to be 'depressed consistent with her medical condition'. The other three to die were considered competent and not depressed. The psychiatric assessment was mandatory, raising concerns regarding cooperation, honesty and trust

issues (Kissane et al., 1998). Indeed one patient assessed withheld relevant history. No ongoing assessment or psychiatric treatment was offered or proposed.

In the Netherlands physicians ask for a psychiatric evaluation for patients requesting PAS in only 3% of cases (Ganzini and Lee, 1997). However if a psychiatrist or psychologist has already been involved in a patient's terminal care it was twice as likely that a request for euthanasia be made (likewise for palliative medicine involvement) (Onwuteaka-Philipsen et al., 2010). This may merely be an indication of case complexity. Since the law change in 2002 the person does not need to be competent when 'euthanased'. An advance request can be made, which remains valid despite altering health status. In 2005, 20% of cases of euthanasia and PAS went unreported and 0.4% of all deaths were the results of the ending of life without any explicit request by the patient (van der Heide et al., 2007). The Dutch medical fraternity believe that a person can have a death wish and not be clinically depressed (Maessen et al., 2010). To date most requests for those suffering mood disorders have been declined as there were still psychiatric treatment options remaining (Field and Curtice, 2009). Objective criteria assessing suffering are neither available nor indeed possible. How the suffering is determined to be 'unbearable' rests upon the impression of the assessing doctor for there is no formal definition of this term (Dees et al., 2010). Ultimately the decision to enact PAS rests on how the doctor considers the patient's suffering. It could be argued that it is not patients exerting autonomy, but doctors exercising power.

In Oregon if the primary physician believes a psychiatric disorder is present, the patient must be referred to a psychiatrist or psychologist. The limited ability by primary care physicians to detect psychiatric disorder is well recognised. Only 6% of Oregon psychiatrists were confident that on a single consultation they could determine if mental disorder was influencing the request (Ganzini and Lee, 1997). In 2010 only one of the 65 persons who died of PAS had been referred for formal psychiatric or psychological evaluation (Oregon Public Health Division, 2010). Depression (in Oregon) may or may not invalidate a voluntary request, and treatment of depression only improves the desire for life-sustaining therapy in a minority (Ganzini and Lee, 1997; Ganzini et al., 1994). The key task for psychiatry in Belgium is the assessment of capacity. Normally the treating doctor will assess competency, except in those whom the doctor thinks will not die in the foreseeable future (Naudts et al., 2006). A mandatory psychiatric referral then occurs. These are generally those patients with mental illness (and without a terminal illness). Mental disorder does not necessarily imply incompetence and there are no established criteria for determining whether a patient is competent to choose death by suicide.

The current provision of psychiatric assessment, as legislated in these jurisdictions, would appear to be inadequate

to perform the difficult tasks expected. Not only is psychiatry rarely consulted, the limited knowledge of the psychiatry of terminal illness raises the probability that the legal expectation of psychiatry is not achievable.

The psychiatry of dying

The prevalence of psychological distress and psychiatric illness in the dying is significant (Macleod, 2011). Affectations of the brain and mind influence judgement and decision making. Most terminally ill people are at times fearful and anxious. Serious emotional turmoil is commonly associated with incapacity (David et al., 2010). At least 15% of terminally ill cancer patients are experiencing major depression (Hotopf et al., 2002), though this prevalence falls as death approaches (Macleod, 2011). A similar number are dysthymic, dysphoric and demoralised (Kissane and Kelly, 2000). Depression in the terminally ill is a complex and difficult diagnosis to make and depressed and demoralised patients are not necessarily competent (Kissane and Kelly, 2000). Delirium is a common, if not inevitable, syndrome during the final phase of a malignant illness. In the terminal phase of life up to 80% become delirious (Lawler et al., 2000).

Assessing capacity in those requesting PAS is difficult as the cognitive capabilities required to decide on rational suicide are contestable. In the Netherlands consent is not invariably given prior to assisted death. Euthanasia without an explicit request from the patient amounted to 0.7% of all deaths in the Netherlands in 2001, and 0.4% in 2005 (van der Heide et al., 2007). There had been discussion about the act, or a previous wish of the patient for the act, in 60% of these patients, as compared to 26% in 2001. Discussions with relatives had occurred in 80% and with colleagues in 65% of these cases, 10% of whom were unconscious at the time of the decision and 14% incompetent owing to young age. Termination of life without request is more common in Belgium, with 1.8% dying without an explicit request (a weighted prevalence) in 2007 (Chambaere et al., 2010). In a sample of 208 deaths under the euthanasia law, representing 12% of the deaths during 2007 in Flanders, 32% were administered life-ending drugs without their explicit request (Chambaere et al., 2010). The decisions to terminate the lives of these elderly, hospitalised patients in comatose or demented states, who had previously indicated a wish for life not to be needlessly prolonged, were made by medical staff in agreement with the family, usually following a sudden decline in the patient's health, leaving them unable to communicate.

The accuracy of the figures on euthanasia is complicated by how palliative sedation is defined. Palliative sedation refers to the intentional clinical practice of suppressing consciousness to control refractory symptoms (delirium, pain, dyspnoea, nausea, acute haemorrhage) during the last days or hours of life, in a manner that is ethically acceptable

to the patient, family and healthcare providers. When there is no other medical means of relieving an unendurable symptom, sedation may be the humane clinical option. Palliative sedation is not euthanasia; the intent is to relieve suffering, not to kill. In Belgium since 2001 the rate of using continuous and deep sedation until death increased from 8.2% of all deaths in 2001 to 14.5% in 2007 in one study (Bilsen et al., 2009) and fell from 7% in 1999/2000 to 1–2% since 2001 in another (Broeckaert et al., 2011). In the study by Chambaere et al. (2010), opioids were used for sedation in 83% of the cases (often as the sole agent). This suggests a very broad definition of palliative sedation. There is solid evidence that the dose of opioid and its rate of increase do not influence survival at the end of life (Good et al., 2005), and indeed indications are that the duration of life is actually prolonged by palliative sedation. Appropriate opioid, neuroleptic and benzodiazepine prescribing does not constitute the use of 'life-ending drugs'. Barbiturate administration, however, does. Palliative sedation and the doctrine of double effect are issues potentially able to be manipulated by advocates and/or critics of assisted dying. In the Netherlands in 2001, 5.6% of deaths involved the practice of 'continuous deep sedation', and in 2005 this figure was 7.1% (van der Heide et al., 2007). In palliative care settings worldwide about 25% of dying patients receive palliative sedation (Macleod, 2011).

It is claimed that there is no evidence from the Netherlands or Oregon to justify concerns about the negative impact of assisted dying legislation on potentially vulnerable groups, such as older, uninsured, ethnic minorities, minors and disabled people (Norwood et al., 2009). The only group identified to have a heightened risk were people with AIDS (Battin et al., 2007). While in the Netherlands it is more likely to talk about euthanasia than to die a euthanasia death (Norwood et al., 2009), as yet there is no compelling information from countries allowing assisted death that competency and consent issues are rigorously adhered to.

High desire to die is present in up to 17% of the palliative care population (Nissim et al., 2009). In severely ill patients, the will to live fluctuates (Cochinov et al., 1995). The will to live is determined more strongly by psychological variables until the last few days, when it is supplanted by physical variables such as pain and dyspnoea (Cochinov et al., 1999). In terminally ill cancer patients, psychological distress rather than pain and functional status is the most influential factor determining the desire for hastened death (Mystakidou et al., 2005). The strongest factors are hopelessness, depression and anxiety (Mystakidou et al., 2005). The wish to die is not stable, especially if mental health problems are evident (Ganzini et al., 2000). Major depression was diagnosed in 59% of hospice patients who persistently desired a hastened death, but in only 8% of those who did not (Cochinov et al., 1995).

In Oregon it is estimated that about 20% of those requesting aid for dying are depressed (Ganzini et al., 2000,

2008), an expected incidence. Concerned that the professionals and family members involved with Oregon patients who pursued assisted dying did not believe depression had influenced their choice, and that in 2007 none of those who died of PAS had been seen by a psychiatrist or psychologist, investigators studied the prevalence of depression and anxiety in terminally ill people requesting aid in dying (Ganzini et al., 2008). Although the investigators struggled to recruit subjects, of 58 Oregonians 15 met the criteria for depression (HADS and Beck, SCID-I), six of whom being of the opinion that their depression influenced their preference for PAS. By the end of the study 42 had died, of whom 18 had been prescribed a lethal dose, and nine had died by this method. Three (17%) of these 18 decedents had met the criteria for depression, though one had been successfully treated for depression before her death. It would appear that some cases of depression are missed or overlooked in the medical assessments. Elevated prevalence of depression has been determined in Swiss people seeking assistance to die. The largest right-to-die organisation in Switzerland (Exit) found 27% of those requesting assisted suicide were 'depressed' according to their volunteer assistants (Bossard et al., 2008), and 36% of hospitalised palliative care patients demanding death were depressed (Moynier-Vanteghem et al., 2010). However in neither of these studies was depression diagnosed according to accepted research criteria.

Those Oregonians who received substantive intervention such as control of pain, hospice referral, psychosocial and antidepressant medication, were more likely to change their mind about PAS. They also had less advanced disease. Eleven per cent had a change of mind after an antidepressant trial. Those whose decision altered were more ambivalent and unstable with regard to the initial request, not as hopeless, and had a few treatment options still available (Ganzini et al., 2000). In Oregon, no PAS patient has contacted emergency services after consuming the lethal medication, though this would need to be done within 25 minutes (Okie, 2005). In the Netherlands 13% had a change of mind (Jansen-van der Weide et al., 2005). This was less likely in the terminal phase and more likely if there were mental health problems. Instability of attitude concerning PAS, generally toward rejection of an earlier supportive view, occurred in 8–26% of non-terminally ill hospitalised elderly American patients, particularly if depression lifted (Blank et al., 2001). A study of depressed geriatric patients' preference for life-sustaining therapy found that 25% showed an increased desire for such therapy after treatment for their depression (Ganzini et al., 1994). In AIDS patients with desire for hastened death, 27% of whom had major depressive illness, those who responded well to antidepressant treatment after 2 months dramatically reduced their wish for an early death (Breitbart et al., 2010). The 37% of patients whose depression did not respond had no major alteration in their desire to die early. Depression does not

inevitably account for desire for death but there is a possibility that treatment of depression may alter significantly the incidence of PAS requests. Existential variables may have a stronger effect on the desire to die than psychological and psychiatric ones (Cochinov et al., 2005). The desire for death may be driven by the intolerable future rather than the intolerable present (Sullivan, 2005). Spiritual well-being (a sense of meaning and peace) is an important modifier of the desire to die, and even if depressed, it is protective (McClain-Jacobson et al., 2004). The percentages of patients changing their view about PAS, perhaps 10–15%, whilst small, would be considered to be an unacceptably high operating mortality in surgical practice. Of additional concern is the clinical impression that by offering further treatment options (such as chemotherapy for the cancer patient), the patient's view about euthanasia may alter. This underlines the fickleness of hastened death ideation.

Suicidal thoughts occur in as many as 45% of terminally ill patients, though these are usually fleeting and often associated with feelings of loss of control and anxiety about the future (Bloch, 2000). The frequency of completed suicide in the cancer population is about twice that in the general population (Misono et al., 2008), with the highest risk in the months after diagnosis (Crocetti et al., 1998). Suicide is the cause of death in less than 1% of the cancer population and the risk is very low in the terminal phase (Nissim et al., 2009; Ripamonti et al., 1999). 'Psychological autopsy' studies suggest that 80% of persons with cancer who committed suicide were clinically depressed, about the same as for those suicides without cancer (Henrikson et al., 1995). Relatively few terminally ill patients kill themselves, yet some wish to be killed by their doctor. Finlay (2003) suggests that suicide and euthanasia are driven by fundamentally different needs, the former by depressive illness, the latter by a desperate way to gain the last vestige of control over a situation. Historically society has viewed suicide as a mortal sin, a criminal offence, a mental illness, and since the 1970s Western society has started to consider suicide as a calculable category of risk (McManus, 2005). Identifying and attending to these risk factors, thereby preventing suicide, has become a major public health issue. To dissuade the general community from committing suicide, and yet allow it in specific instances, risks complicating suicide prevention education.

Conversations about dying, death and suicide are important components of the practices of palliative medicine and psychiatry. For some 'euthanasia talks' (the negotiations around the request and the process) are in themselves apparently therapeutic. Euthanasia practice in the Netherlands typically involves extensive deliberations with the patient, the majority of which do not end in a euthanasia death (Norwood et al., 2009). Paradoxically, these discussions tend to affirm social bonds, social life and life. This is consistent with the findings that advance care planning can

positively enhance rather than diminish patients' hope (Davison and Simpson, 2006). The provision of a 'lethal bullet' may result psychologically in an enhancement of the patient's control over their desperate predicament, an improvement of their esteem and a reinvigorated wish to live until nature determines otherwise. Referring to Oregonians who decide not to ingest the prescribed barbiturate, Quill (2005) commented that: 'Perhaps the knowledge that they could end their life if they so desired makes them feel less trapped – therefore freer to keep going'. It may be that a planned and orchestrated death, and the avoidance of an uncomfortable death-bed vigil, may facilitate less traumatic grief reactions for family and friends (Swarte et al., 2003). However most working in palliative care observe the helping and healing dynamics of families during those final days, but there is no doubt that some individuals and families may prefer ordered and sanitised death.

Assisting dying

Doctors may buckle with the psychological issues associated with their dying patient. The fatigued, hopeless and despairing doctor confronted by a patient requesting assisted suicide may more easily acquiesce or subtly encourage the act. Clinicians burdened with the care of the very sick, who are frustrated by therapeutic impotency, struggling to communicate effectively, and seduced by the apparent rationality of the request, may become, like their patient, supportive and implicit in quickening death (Kelly et al., 2003).

Killing patients is a role most doctors appear neither to wish nor want. It may be, not surprisingly, distressing for the practitioner. In the 1990s 75% of Dutch doctors expressed feelings of discomfort following euthanasia, 58% following assisted suicide, and 34% following life ending without an explicit consent (Haverkate et al., 2001): 'Many physicians who had practiced euthanasia (in the Netherlands) mentioned that they would be most reluctant to do so again' (van der Maas et al., 1991). In Oregon doctors attending persons requesting PAS report being intimidated by patients to assist, and of being powerless to influence the decision-making process (Stevens, 2006). In the USA 53% of physicians who reported participating in euthanasia or PAS were comforted from having helped the patient, 24% regretted being involved and 16% reported that the emotional burden of performing euthanasia or PAS had adversely affected their medical practice (Emanuel et al., 1998). Oregon doctors who had participated, particularly those involved in the early years, acknowledged the difficulties it aroused emotionally. They consider themselves insufficiently prepared, fearful of making errors, and being personally damaged by the experience (Dobscha et al., 2004). It appears that the personal and professional experience of therapeutically killing is discouraging doctors from accepting these patients

onto their books and they are withdrawing from the process. For their own self-protection some doctors in the Netherlands apparently attempt to avoid involvement in euthanasia cases (Stevens, 2006).

Euthanasia and psychiatry

Relatively rarely do patients request assisted dying in jurisdictions in which it is legal. If they do so the clinical problems initiating the request are psychosocial and existential rather than medical. There are psychiatric concerns about euthanasia and PAS, yet psychiatry is infrequently consulted and involved in the decision-making processes. Literature from countries and states with liberalised assisted dying laws and the palliative medicine literature are indicative of some specific areas of concerns regarding the mental status of those requesting hastened dying. The oscillations of the wish to die of the terminally ill, the difficulties of diagnosing major depression toward the end of life, the effect of depression and demoralisation on euthanasia requests, and of what constitutes fitness to commit on rational suicide are significant and as yet unresolved clinical issues. Concerns of a 'slippery slope' remain, for competency determinations appear not to be strictly adhered to in some jurisdictions. Subjective medical impressions of suffering need to be supplanted by solid objective evidence-based literature and clinical guidelines. Medical practitioners of euthanasia and PAS appear reluctant and increasingly unenthusiastic participants in the processes. 'Euthanasia talks' may be therapeutic but medicinal killing, despite the informative experiences of jurisdictions in which it has been legalised, remains a controversial practice.

Every doctor has attended patients whose quality of life is poor and where no effective treatments are known or available. Psychiatrists are familiar with resistant affective disorders, chronic unremitting psychoses, and intractable anorexia nervosa. If legal liberalisation occurs the obvious evolution of pro-euthanasia advocacy is towards addressing those with intractable mental disorders and those weary with life in general. Psychiatry should be forewarned.

The euthanasia debate will not vanish from modern society. Society and politics will ultimately determine the legality of assisted dying in any community. As yet psychiatry does not have the expertise or the will to 'select' those whose wish for a premature death is rational, humane and 'healthy'. Whether the profession will ever achieve this knowledge is uncertain. But until this is obtained doubts and concerns about assisted dying within psychiatry (and medicine) will persist.

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