
IN THE HIGH COURT OF NEW ZEALAND
WELLINGTON REGISTRY

CIV-2015-485-235

UNDER

The Declaratory Judgments Act 1908 and
the New Zealand Bill of Rights Act 1990

BETWEEN

LECRETIA SEALES

Plaintiff

AND

ATTORNEY-GENERAL

Defendant

AFFIDAVIT OF BARONESS ILORA FINLAY ON BEHALF OF THE
DEFENDANT

6 MAY 2015

Judicial Officer: Justice Collins
Next Event Date: Hearing commencing 25 May 2015

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I, ILORA GILLIAN, BARONESS FINLAY OF LLANDAFF, domiciled and residing at 19 Cathedral Green, Llandaff, Cardiff CF5 2EB, United Kingdom, make oath and say:

1. I am a consultant physician, a professor of palliative medicine and member of the House of Lords (the Upper Chamber of the UK Parliament)

Qualification and Expertise

2. My *curriculum vitae* is attached to this affidavit as **"Exhibit IGF-1"**.
3. I have been a qualified physician since 1972. After working as a hospital doctor and a general practitioner, I specialised in care of the terminally ill and was appointed in January 1987 to establish the hospice in Cardiff and was the first consultant in palliative medicine in Wales. In 1987 palliative medicine was recognised in the UK as a clinical speciality, requiring four years dedicated specialist training and experience and assessment prior to attainment of consultant status. In 1989 I established the Diploma/Master of Sciences course in Palliative Medicine at the University of Wales College of Medicine (now Cardiff University), in which 1,439 doctors graduated between 1990 and 2011. Similar courses have subsequently been developed, with my guidance, at King's College London, Bristol University, the University of Melbourne and in South Africa. I have taught palliative medicine to SCEN (euthanasia screening) doctors in The Netherlands, where I held a visiting professorship at Groningen University, and supported development of education courses for doctors, including assessing consultation communication skills. I chaired the Association for Palliative Medicine (APM) of Great Britain and Ireland from 1995-98, having previously been the founder chairman of the APM Ethics Committee (1991-95). From 2006 to 2008 I was President of the Royal Society of Medicine. I am a founder member of the Scientific Advisory Committee of the Cicely Saunders International Institute (2005 onwards) and a current member of the British Medical Association Ethics Committee. I am president of the British Medical Association. From 2008 – 2014 I chaired the Palliative Care Strategy Implementation Board and since 2014 I am the clinical need in palliative care for Wales, producing quality standards and clinical guidelines including on integrated care priorities for the last days of life, 'do not attempt cardiopulmonary resuscitation (DNACPR)' documentation, and establishing

staffing levels to ensure a seven-day specialist palliative care service is available across the whole of Wales that supports all other services (cancer, neurology, renal, care of the elderly, paediatrics etc) in their care of patients with life-limiting conditions. I continued to work on the rota for out-of-hours on call until late 2014.

4. In 2001 I became an independent Crossbench Member of the House of Lords (the Upper Chamber of the UK Parliament). I played a significant role in the development of the Mental Capacity Act 2005 (England and Wales) and the Code of Practice accompanying that legislation, particularly in relation to Advance Decisions to Refuse Treatment and the concept of an Advance Statement of Wishes. This has led to further work on care plans for the terminally ill.
5. From July 2004 to April 2005 I was a member of a UK parliamentary select committee established to examine a draft Private Member's bill for legalisation of 'assisted dying' for the terminally ill - 'assisted dying' being defined as physician-assisted suicide or physician-administered euthanasia. The select committee, which included experts in the law, medicine and other disciplines relevant to the subject under consideration, conducted a thorough examination, involving six months of evidence-gathering in the UK, the US State of Oregon, The Netherlands and Switzerland. Its report was published in April 2005¹. The select committee did not offer a view on whether 'assisted dying' should be legalised (there was no consensus on this within the committee) but it drew attention to a range of issues concerning the safeguards proposed in the draft bill. In the following year (2006) a similar Private Member's bill was rejected by Parliament after an eight-hour debate.
6. In 2010, together with Lord Carlile, who is a Queen's Counsel practising at the Criminal Bar and a Liberal-Democrat member of the House of Lords, I founded *Living and Dying Well*, a body which researches and analyses the evidence surrounding the subject of 'assisted dying'. In February 2012 *Living and Dying Well* published its analysis of proposals by a 'commission on assisted dying' which had recommended the legalisation of 'assisted dying' for

¹ House of Lords Report 86 (Session 2004-05)

terminally ill people. This 'commission', notwithstanding its name, was not an official body: it had been instigated and funded by proponents of legalisation and its membership consisted largely of persons taking that view. The critique by *Living and Dying Well* was based on careful analysis of all the published evidence given to the 'commission'. A copy is submitted as "Exhibit IGF-2".

7. I have opposed the legalisation of 'assisted dying' in the UK. While many people are opposed to legalisation on grounds of personal morality, my opposition stems from considerations of public safety and from my professional experience of caring for dying people for over 25 years as well as on personal experience of caring for my father and close friends with terminal malignancies and of my own mother's terminal illness and death. I do not contend that 'assisted dying' is unnecessary because palliative care is a panacea for terminal illness: no form of medicine can be that. I do contend, however, that the advances in palliative care (in pharmacology, communication techniques, aspects of personal and family support etc) which have been made over the last 30 years, and which are still being made, are capable of relieving much of the suffering that once accompanied the dying process and that the case for legalising 'assisted dying' is less strong today than it was when I was a young doctor and when much of the suffering of terminal illness could not be effectively relieved.
8. I have been asked by the defendant, the Attorney-General of New Zealand to express my opinion on a number of matters relating to my areas of expertise which arise out of this case.
9. I have read and agree to comply with the Code of Conduct for Expert Witnesses.

The impact on the doctor-patient relationship of any move to allow physician-assisted suicide or euthanasia

10. The term physician-assisted dying needs to be considered in its component parts: physician-assisted suicide (PAS), where a patient self-administers lethal drugs supplied by a doctor, and voluntary euthanasia, where a doctor administers lethal drugs to a patient at the patient's request.

11. The distinction is important because the relationship between the patient and the doctor is different in the two scenarios. In PAS the patient has to undertake a positive action: he or she must lift the glass of barbiturate to drink it. Euthanasia is far more passive: the patient simply lies down, whilst the doctor injects the lethal drugs into a vein; the active role is taken by the administering doctor.
12. The drugs are important to consider here. For PAS 9-10 grams of a barbiturate is usual; this is about 50 times the dose used clinically as a powerful sedative. As the barbiturate is not highly soluble the volume of liquid to be taken is about a tumbler-full. It is taken after swallowing metoclopramide, used as an anti-sickness drug, to try to avoid the lethal barbiturate being vomited back up. For euthanasia the drugs are similar to those used in judicial executions in the United States: usually a short acting anaesthetic agent plus pancuronium. The latter completely paralyses the patient who then dies of asphyxia. It is not known whether there is any regaining of consciousness in terminally ill patients who have had euthanasia, but there is evidence that in 43% of executed prisoners the blood levels of the anaesthetic agent had fallen by the time of death to such an extent that may have regained a degree of consciousness; as the recipients were completely paralysed by the pancuronium this would not be evident to the official observers.²
13. It is also of note that PAS and Euthanasia are not without complications. In a Dutch study, there were difficulties in administering the lethal drugs in 10% of PAS and 5% of euthanasias; complications such as vomiting and muscle spasms occurred during the process in 7% of PAS and 3% of euthanasias; and death took an unexpectedly long time, of up to 7 days, in 15% of PAS and 5% of euthanasias.³ Reports from the Oregon Public Health Division (OPHD) also describe very long intervals from ingestion to death, with a range up to 104 hours (median 25 minutes) until death; six patients were reported to have re-awoken.⁴ None re-attempted PAS.

² Koniaris IG, Zimmers TA, Lubarsky DA, Sheldon JP. Inadequate anaesthesia in lethal injection for execution. *Lancet*. 2005 Apr 16-22; 365(9468):1412-4.

³ Groenewoud JH, van der Heide A, Onwuteaka-Philipsen BD et al. Clinical problems with the performance of euthanasia and physician-assisted suicide in The Netherlands. *New England Journal of Medicine* 2000; 342: 551-6

⁴ Oregon Public Health Division "Oregon's Death with Dignity Act 2014", Table 1

14. The relationship between doctor and patient directly affects patient decision making. For any decision to be valid, it must be based on accurate information, be taken voluntarily and the person must have mental capacity commensurate to the decision. I will deal with each of these in turn and then deal with the influence of the doctor on patients' thinking.

Issues of, prognosis, whether disease is terminal, capacity, mental health concerns, patients who suffer neurological disorders, discrimination against people with disabilities

15. Two key pieces of information for a patient's decision to end life are the diagnosis and prognosis.

Diagnostic accuracy

16. The fallibility of diagnosis was brought to the attention of the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill, of which I was a member in 2004-05, by the Royal College of Pathologists, who stated that "*post mortem research and clinical audit studies performed in the UK, Europe, USA and many other countries consistently show a c.30 per cent error rate in the medically certified cause of death*" and that "*significant errors (i.e. misdiagnosis of the terminal illness resulting in inappropriate treatment) occurs in c. five per cent of cases*".⁵

Prognostic accuracy

17. There are a large number of papers published in the medical literature on attempts to find prognostic markers in advanced disease; they reveal that none have high accuracy. Although the average, median and range of life expectancy across a population with a condition can be stated, it is impossible to predict where an individual's life expectancy lies within this range; there are always exceptional cases, where individuals live longer (sometimes very much longer) than the range documented in the literature. Over years of clinical practice I have come to realise that the only honest answer to the question 'How long have I got?' is 'I honestly cannot tell'.
18. I have provided care for many terminally ill patients who have lived far longer than any medical prognosis they were given prior to palliative care referral. One vivid example is a patient referred in 1991 with a prognosis of three

⁵ House of Lords Report 86 (Session 2004-05), Volume 2, Page 730

months to live (as determined independently by the Consultant Oncologist, Consultant Surgeon and General Practitioner and with which I concurred). He was insistent that he wanted help to end his life prematurely but agreed, albeit reluctantly, to accept specialist palliative care. He is alive and well today, over 24 years later. In 2001 his wife died unexpectedly and he was left to bring up their three children alone (the youngest son being just 11 years old when his mother died). Another terminally-ill patient, who sought my help to travel to Switzerland for assisted suicide, lived for a further seven months and, with the support of specialist palliative care, was able to live life to the full during this time, including undertaking holiday cruises before dying naturally and without distress.

19. Fifteen years of data from Oregon, where PAS was legalised in 1997 by the 'Death with Dignity Act' (DWDA), supports the impossibility of accurate prediction of the course of a disease. The OPHD reports show that, between 1998 and 2014, the median interval between requesting lethal drugs and using them to commit suicide was 47 days, with a range of 15 days to nearly 3 years (1009 days), which is far longer than the six month prognosis required by the DWDA.⁶

Voluntariness

20. Detecting coercion is extremely difficult. Doctors are not in a position to do this. There are a range of coercive forces on people who are terminally ill, including a sense of an obligation to die. Last year in Oregon, 40% of PAS cases cited 'being a burden' among the end of life concerns behind their request.⁷
21. I have misjudged families on several occasions, believing them to be loving; later they were revealed to have other motives, usually financial, for wishing for their relative's death. One family in particular I will never forget because I was convinced that they were very caring and upset about their mother's illness. But, after her birthday, they visited less and a short time later the patient disclosed to one of our nurses that her fixed term life insurance policy had expired on her birthday.

⁶ Oregon Public Health Division "Oregon's Death with Dignity Act 2014", Table 1

22. Another example is of a couple: the clinical team all believed that the husband was loving and caring. His wife, the patient, was going home and he learnt how to do all her care, which was complex. After the patient died, her sister came to see me because apparently a couple of days after the patient had got home, her husband had called a solicitor to the house. The patient changed her will to leave everything to him and write her natural children out of her will. None of us thought that might happen when she went home from the hospice.
23. It is notable that many cases of elder abuse go undetected because clinicians are not trained to search for signs of financial or emotional abuse, even physical bruising often fails to trigger awareness of abuse occurring.⁸ A doctor who regularly visits a patient in his or her home may perhaps be able to catch a glimpse of family dynamics but home visits are now increasingly the exception rather than the rule; and, when they do occur, they are not always by the same doctor.

Influence of the doctor

24. The influence of a doctor's attitude on a patient's thought-process is important.⁹ A doctor who is depressed or feels hopeless about a situation will convey that attitude to a patient; a doctor who is emotionally warm and empathic, emanating an ability to cope, is more likely to instil confidence.
25. The manner in which a doctor responds to a patient has a profound influence. A request for help to 'end it all' is almost invariably an expression of the patient's worst fears; it is an attempt to get a clearer view of what lies ahead, seeking reassurance that they will not be abandoned to their condition. Such doctor-patient conversations, when undertaken with the aim of helping the patient to deal with his or her problems, generally reveal that the wish for death is unstable. A doctor's reaction to a request for help to 'end it all' is more than just a response: if the doctor explores and processes such a request the message the patient receives is that the doctor agrees that the patient's outlook is every bit as bad as the patient fears and that the patient would be

⁷ Oregon Public Health Division "Oregon's Death with Dignity Act 2014", Table 1

⁸ Fitzgerald G. Hidden Voices: Older People's Experience of Abuse. Action on Elder Abuse 2004

'better off dead'. The doctor-patient relationship is not a simple customer/supplier relationship. It is a far more complex and intimate relationship than that, with the potential for life or death, and it needs to be understood as such.

26. Research¹⁰ suggests that an important factor in the vulnerability of terminally-ill patients is the way in which care is given to them, which can either enhance or undermine their sense of dignity and personal worth. Patients who receive the message that their situation is devoid of any hope for restoring their dignity and respect are more likely to lose a sense of meaning or worth, feel they are simply a burden on others and question the point of their continued existence. The attitude of health care professionals is of key importance here. As I have argued above, a doctor who concurs with a patient's wish to 'end it all' can all too easily send the subliminal message that the patient's condition is hopeless and that continued existence is pointless. It is here, rather than in simple socio-economic groupings, that vulnerability lies.

Vulnerability

27. An individual's vulnerability to influence and to being made to feel despairing is highly personal and context-specific. Vulnerability can relate to learning difficulties, age, isolation, lack of mobility and many other factors.
28. It is sometimes claimed that there is no evidence in Oregon of heightened risk to vulnerable groups of people, such as the elderly or racial minorities or persons who lack mental capacity, as a result of legalisation. This claim has been made by Margaret Battin and others¹¹ in "Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in vulnerable groups", *Journal of Medical Ethics*, 2007; 33: 591-597, a true copy of which is attached and marked **Exhibit IGF-3**.
29. The evidence on which such claims are based and the method of analysing the evidence have been called into question. I attach as **Exhibit IGF-4** the paper

⁹ Mamede S, Schmidt HG. The twin traps of overtreatment and therapeutic nihilism in clinical practice. *Medical Education*. 2014; 48(1):34-43.

¹⁰ Chochinov HM "Dignity and the Essence of Medicine: the A, B, C and D of Dignity Conserving Care" *BMJ* 2007; 335(7612): 184-187

¹¹ Battin M, van der Heide A, Ganzini L, van der Wal G, "Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in vulnerable groups", *Journal of Medical Ethics*, 2007; 33: 591-597

I wrote with Professor Robert George in which we critiqued the paper by Battin and others "Legal physician-assisted suicide in Oregon and The Netherlands: evidence concerning the impact on patients in vulnerable groups - another perspective on Oregon's data", *Journal of Medical Ethics* 2011; 37: 171-174.

30. The official annual reports on Oregon's DWDA show that resort to PAS is predominantly among the over-65s, who in 2011 accounted for more than two in three of those who died by ingesting legally-supplied lethal drugs, and that the median age for those who took their own lives in this way between 1998 and 2011 was 71 years. While this does not of itself mean that the elderly are at heightened risk from Oregon's PAS law, it does indicate where the main take-up of PAS lies and it calls into question confident assertions that the elderly are not at risk from legalisation.
31. There is no evidence that standard socio-economic groupings provide an appropriate measure of vulnerability in end-of-life decision-making. Vulnerability in this context is linked, not with economic or social status, but with factors such as personality (e.g. proneness to experience psychological distress¹²), personal and family situation, ability to communicate, or experience of effective symptom relief. One grouping, however, which is certainly vulnerable in this context is that of persons, whatever their social or economic status, who are clinically depressed.
32. Evidence from Oregon, from a prospectively monitored group of 18 patients, showed that amongst those who died after ingesting legally-supplied lethal drugs for PAS, one third had been suffering from clinical depression which had not been diagnosed or referred for expert psychiatric or psychological assessment and treatment.¹³ Further evidence, again from Oregon, confirms the strong correlation between depression and hopelessness amongst those requesting PAD.¹⁴

¹² Chochinov HM, Wilson KG, Enns M, Lander S "Depression Hopelessness and Suicidal Ideation in the Terminally Ill", *Psychosomatics* 1998;39(4):366-370

¹³ Ganzini L, Goy ER, Dobscha SK. Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey. *BMJ* 2008; 337: a1682

Mental Capacity

33. There is no absolute test for mental capacity. A patient may have capacity for certain decisions, but not for others. An example is people with dementia, who can still live independently. They know what they want to do, to eat and to wear, but are not safe with major financial and other decisions because they can't follow through and recall the complexities involved, making their decisions unsound.
34. To end your life is the biggest decision that you could make and is cognitively demanding. But detecting cognitive impairment is very difficult. In evidence given to the Select Committee we heard from neurologists that about 30 percent of patients with motor neuron disease (ALS) will appear to be completely mentally competent but actually, on careful neuropsychological testing, are shown to be cognitively impaired [House of Lords Report 86-II, Page 366]. In this case this is relevant because of the neurological damage from the patient's surgery and treatment, as well as from the tumour.
35. Doctors are not specifically trained in assessing mental capacity. Psychiatrists, particularly those specializing in care of people with life-threatening illness, are better equipped to detect cognitive impairment, particularly as individuals adapt to illness and suicidal thoughts fluctuate. Moreover, when doctors assess capacity, they do it with a view to protecting the patient concerned from harm, not to clearing the way for their suicide. Indeed, a doctor who has reason to suspect suicidal intent in a patient will normally make arrangements for the patient's protection. Legalised PAS stands this aspect of the doctor-patient relationship on its head.

My experience as to suicidal thoughts in persons suffering from a terminal illness

Suicide in palliative care and hospice patients

36. Suicidal ideation is a common, and usually transient, thought process occurring in up to one third of palliative care patients, and is associated with clinical depression.

¹⁴ Smith KA, Harvath TA, Goy ER, Ganzini L. Predictors of pursuit of physician-assisted death. *Journal of Pain and Symptom Management*. 2015;49(3):555-61

37. In my own clinical practice I have had discussions with patients about their desire for death, their acceptance of impending death and their thoughts of suicide; in the latter group, suicidal ideation has had associated markers of depression and a sense of hopelessness. Their expression of wanting to die disappears when their fears and concerns are recognised and addressed, with support to adjust to the adversity of their situation and find value in living.
38. I have only encountered three suicides in palliative care patients during my practice in the discipline since 1987; in all three cases there was no warning of the suicide detected by clinical staff.
39. To explore suicides in terminally ill patients, I undertook a survey of 43 UK hospices in 1994. This survey had a high response rate (79%) and revealed an incidence of one suicidal case per 1,252 hospice referrals in 1994 (21 suicides; 37 attempted suicides; 72633 hospice referrals), giving an incidence of one completed suicide per 3,459 patients referred.¹⁵
40. This data contrasts starkly with demographic data from The Netherlands which suggests that over one in 30 of all deaths are through PAD (in 2013: 4,829 PADs reported; deaths all causes 141,245).¹⁶
41. A desire for death is known to be linked to depression and a sense of hopelessness. These are independent, but mutually reinforcing, factors in patients with advanced cancer who express a desire for death.¹⁷ High disease burden, insecure attachment, low self-esteem, and younger age are known risk factors for depression; low spiritual well-being is a known risk factor for hopelessness. In a prospective study of cancer patients expressing a clear desire for death, 11% showed instability in their expressed desire.¹⁸

The concept of rational suicide

42. Some patients view their future as so bleak that logical argument takes them to view death as a preferable option. They do not appear to have any other

¹⁵ Grzybowska P, Finlay I. The incidence of suicide in palliative care patients. *Palliative Med.* 1997; 11(4): 313-6.

¹⁶ Dutch Regional Euthanasia Review Committee, "Regional Euthanasia Review Committee's Annual Report, 2013"

¹⁷ Rodin G, Lo C, Mikulincer M, Donner A, Gagliese L, Zimmermann C. Pathways to distress: the multiple determinants of depression, hopelessness, and the desire for hastened death in metastatic cancer patients. *Social Science and Medicine.* 2009; 68(3): 562-9.

¹⁸ Wilson KG, Chochinov HM, McPherson CJ, et al. Desire for euthanasia or physician-assisted suicide in palliative cancer care. *Health Psychology.* 2007; 26(3): 314-23.

mental disorder prior to suicide; for these cases a few psychiatrists have used the term 'rational suicide'. However, there is much dispute about the concept of rational suicide, which cuts across a physician's duty of care and responsibilities that underpin suicide prevention policies. There are also suicides in patients with mental illness who are determined to end their life despite all prevention endeavours; such patients could be classified as terminally ill through mental illness.

The implications for society if PAD is legalised

43. Suicides have occurred in societies throughout history. The trauma for those left behind usually is associated with thoughts of 'if only' and a sense of failure at having been unable to avert the suicide. In her evidence, Dr Smales suggests that the suicides she cites would not have occurred if PAS had been available. She does not give evidence from conversations with the victims to support her supposition.
44. I refute this on the grounds that Oregon has shown an increase in suicides (excluding physician assisted deaths) since 2000 (two years after their Death with Dignity Act came into force), has a suicide rate 41% higher than the national average and the trend is of increases not decreases. Men were 3.7 times more likely to die by suicide than women; 62% used firearms.¹⁹
45. A similar trend is seen in The Netherlands, where the suicide rate is higher than in the United Kingdom. The legislation citing unbearable suffering as a qualifying factor for PAD in The Netherlands would have been expected to have the reverse effect on their suicide rates.

Routinisation and normalisation of PAD in society

46. Current legal prohibition of PAD provides the security of a 'bright line'. Doctors know what they can do and what they cannot do. Patients know that they can safely expect the doctor treating them to strive to improve their current situation without endangering their lives; they can discuss their fears about dying and about wanting to 'end it all' safe in the knowledge that they will not be taken at their word. People with severe disabilities have voiced

¹⁹ Suicides in Oregon 2012 report- trends and risk factors. Oregon violent death reporting system. Oregon Public Health department. <http://www.oregon.gov/oha/amh/CSAC%20Meeting%20Shedule/Suicide-in-Oregon-report.pdf>

fears that the discriminatory negative attitudes in care, already experienced by many, will worsen if PAD is seen as a legitimate option. Such negative attitudes in society as a whole are already evident.²⁰ They exist in medicine too.

47. The rise in suicides in countries where PAD is legal practice suggests that normalisation has occurred; the normal response to seemingly inescapable, enormous difficulties in life is to consider disposing of that life itself. Thus normalisation of suicide, as an effect of introducing PAS, runs counter to the Human Right to Life.

Contagion

48. There is a process in society whereby behaviours spread through repetition and imitation. It is seen with 'copy-cat' suicides and clusters of suicides, which are the contagion of suicide as a way of coping with problems in life.²¹ An expectation develops of the way a person will behave; such behaviour of suicide clusters is sometimes called the 'Werther' effect. This is similar to peer pressure, it is a spreading expectation of how a person appropriately responds to distress.
49. This means that others around (friends, family or even health care workers) may ask someone who is ill whether they have asked about assisted suicide or euthanasia, or even when they are going to go for it. I have encountered this anecdotally in the Netherlands particularly amongst young people when their friend has a devastating diagnosis. The question itself reinforces the view that a time will come when PAD should be sought. This mounts a subtle coercive pressure, from the expectations within society, and creates a subtle internal pressure within the patient.
50. Acclimatisation is likely to occur amongst many physicians who are deliberately foreshortening life. Dutch doctors have described their first euthanasia as particularly difficult but easier as it is repeated. Such acclimatisation is normal: as doctors we all get used, indeed inured, to things we do, whether it is sticking a needle in a child, or performing an uncomfortable examination. Such loss of sensitivity is a coping mechanism for the doctor, but a doctor should always

²⁰ Murray J. My mother wasn't drunk she had Parkinson's. The Guardian April 2015

²¹ InfoExchange 10: Suicide Contagion and Suicide Clusters. Centre for Suicide Prevention, 2013

maintain awareness of the enormity of the impact of each medical action. It is of concern that some doctors performing PAD are not troubled by it.

Routinisation

51. The routinisation of PAD in clinical practice is vivid in Dutch and Belgian figures, which exhibit escalating numbers of cases of PAD. Belgian official reports show a rapid escalation of PAD, from 259 reported PAD deaths in 2002-03, to 1,432 in 2012, and then 1,807 in 2013.²²
52. There are similar incremental rises in reported PAD deaths in The Netherlands year on year, from 2636 deaths reported in 2009, to 4829 reported in 2013.²³ . In The Netherlands around one death in every thirty deaths now is the result of PAD in one form or another. There were 1882 PAD deaths reported in the first year of the Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act; Dutch authorities expected no rise when they legislated for PAD in 2002, having had a period of non-prosecution prior to enactment during which time it was thought that the numbers had plateaued.
53. In Oregon the incidence of legalised PAS has risen steadily since the law was changed. The number of persons who ended their lives in 2014 by ingesting legally prescribed lethal drugs was six and a half times the number who did so in the first year of the law's operation (1998), and the upward trend shows no sign of abating. In neighbouring Washington State, which legalised PAS with effect from 2009, a similar upward trend is discernible in the five official annual reports so far published. The number of persons who ended their lives there in 2013 was nearly three and half times greater than the number who did so in 2009.²⁴
54. It is of note that referrals for psychiatrist assessment in Oregon were about 30% in the early years, but have dropped to near zero.²⁵ This decrease in referrals is unlikely to have occurred because general physicians have become better at assessing capacity. It is more likely that people have got used to requests for PAS; they have become routine. It is also possible that a factor in

²² Commission fédérale de contrôle et d'évaluation de l'euthanasie. Sixième rapport aux chambres législatives. 19 August 2014, page 32

²³ Regional euthanasia review committees. 2013 Annual Report. The Netherlands

²⁴ Washington State Department of Health "Washington State Department of Health 2013 Death with Dignity Act Report", Figure 2

²⁵ Oregon Public Health Division "Oregon's Death with Dignity Act 2014", Table 1

the decrease is that there is 'doctor shopping' taking place in Oregon; patients whose doctors refuse to participate in assisted suicide find, or are sign-posted to, more compliant doctors, who know little of the patients beyond their case notes and may view assisted suicide as a rational response to terminal illness.

Illegal Acts

55. It is sometimes argued that an increase in applicants is to be expected following legalisation and that much of this increase can be attributed to acts being declared which were once concealed because they were illegal. Since 2007, however, the incidence of declared (and legal) cases of PAE in Belgium has risen steeply. Whereas in 2007 there were 495 declared cases, by 2011 the number had risen to 1133 - nearly five times the number for the year following legalisation (2003).
56. The actual numbers of PADs may be higher. Official reports on deaths from PAS and PAE contain caveats that they can only report on declared actions that ended life. The Belgian official report for the biennium 2010-2011, for example, states that the commission compiling the report "*was unable to assess the number of declared euthanasias compared with the number that actually took place*".²⁶ The Oregon Public Health Department has given a similar caveat, stating "*our numbers are based on a reporting system for terminally ill patients who legally receive prescriptions for lethal medications, and do not include patients and physicians who may act outside the law.*"²⁷

Expected numbers of PAD's

57. The few jurisdictions which have legalised these practices to date have different populations, and it is easy to overlook the impact which the death rates they have experienced would produce in other jurisdictions. For example, Oregon's current death rate from PAS, if replicated in England and Wales, would produce over 1,500 legal physician-assisted suicides annually, whereas under current (prohibitive) English law less than 20 cases a year are recorded of people receiving assistance (usually from a family member or friend) to go to the Dignitas facility in Switzerland; many of these cases could

²⁶ Commission Fédérale de Contrôle et d'Evaluation de l'Euthanasie, Cinquième Rapport aux Chambres Législatives, Page 14

²⁷ "Oregon's Death with Dignity Act: Three years of legalized physician-assisted suicide", Oregon Health Division, February 22 2001

not be defined as terminally ill. The death rate from PAE and PAS in The Netherlands is the equivalent of around 18,000 such deaths annually in Britain. Any jurisdiction contemplating legalisation would be well-advised to consider how the experiences of Oregon, Washington, The Netherlands or Belgium would be replicated in their own populations.

58. It is estimated that a Dutch-style law in New Zealand would result in over 1,200 PAD deaths per year and rising, judged on current European data.

Societal protection of all citizens by the law

59. The year-on-year increases in the incidence of PAD illustrate that legalisation does not simply reproduce the status quo in legal form, but leads to an increase in these practices. Enabling laws tend to encourage the acts they enable because they change the underlying social message. The criminal law exists not only to prosecute offenders, but also to state clearly those acts which society considers to be unacceptable. Creating a licensing system for PAD sends the message that, while deliberately bringing about someone's death is normally seen as criminal behaviour, in the case of certain people (in this case, those who are terminally or otherwise seriously ill) it is acceptable. Implicit in this is a value judgement: that the lives of those who are deemed terminally ill are worth less, and should be afforded less protection in law, than the lives of other citizens.
60. Proponents of PAD advocate that defining the type of illness or disability would be a safeguard. Yet many profoundly disabled people contribute enormously to society but need help with all aspects of daily living from feeding through to evacuation and cannot move unaided. Relating a safeguard to any kind of illness or disability discriminates against people who have a disability and who find it hard enough to get the adequate care that they need anyway. It is a sad reality of much clinical practice that a value judgment is projected onto patients by care staff thinking 'if I was like that, I wouldn't want to go on', which can influence thinking in clinical teams. Any proposal that an inability to live independently should be linked to PAD sends a very clear message to all the people who are severely ill, disabled and need support from others that their lives are of less worth than people who are living independently. Such prejudices should not risk being reinforced in law.

Doctor's views

61. Consistency and objectivity are not evident in any of the systems in the world that have legislated for PAD. Some doctors view the death of the patient as the solution to the problem they present, giving them a low threshold to accede to requests for PAS; this is evident from Oregon data showing a small number of doctors who have issued multiple prescriptions for lethal drugs while others have never prescribed such lethal drugs. However, the majority of doctors are resistant to involvement in PAD; they feel that their duty of care requires them to redouble their efforts to enhance dignity and relieve distress, not to deliberately end life. The difficulties presented by PAD for hospice and palliative care staff who are providing care for such patients has been clearly described to me by palliative care doctors in the Netherlands and in Belgium, and in literature from the USA.²⁸ Staff distress at involvement in PAD inevitably distracts them from providing care to other patients; in a time of pressures on health care systems, such considerations are particularly important.
62. Repeated surveys of doctors in the UK have shown that the majority are opposed to the legalisation of PAD.

The concept of “intolerable suffering” and the concerns with this being a criteria for qualifying for PAD

63. Intolerable suffering is a concept that some suggest is a rational reason for PAD. The difficulty is that it cannot be assessed or measured objectively. It is not like body temperature. Suffering depends on a vast array of factors and is experienced by different people, at different times in life and for different reasons. It is a purely subjective perception; the degree to which suffering is unbearable cannot be discerned by those around. It is no safeguard as a controlling factor in eligibility for PAD as the sufferer's description must be taken at face value and therefore it effectively creates a situation of on-demand PAD.
64. For example, those who are acutely and traumatically bereaved can find their suffering so unbearable that they become physically or mentally ill, or even commit suicide. Yet for such people we have suicide prevention policies in

²⁸ Courtney CS, Black MA. Dignity, Death, and Dilemmas: A Study of Washington Hospices and Physician-Assisted Death. *J Pain Symptom Manage* 2014; 47: 137-153.

place in society, even though there is evidence that for some they will never emerge from their overwhelming sense of suffering in grief. Perhaps the greatest overwhelming suffering I have witnessed was the unbearable suffering of parents whose child had been murdered.

65. Disease and injury evoke a sense of devastation and the prospect of what lies ahead can look unbearable. Among those who sustain spinal cord injury such despair can last for years before a new meaning and purpose in life emerges. In my own clinical experience I have found that depressed over-medicated patients with chronic fibromyalgia pain are more likely to describe their plight as 'intolerable' than those who are extremely ill and facing dying.
66. A subjective test of intolerable suffering cannot be regarded as a reason for a physician to assist in the deliberate foreshortening of life. My view is that there must be a constant pressure on physicians to do all they can to relieve that suffering, which is different to relieving the patient of their life itself.
67. It is worth examining the reason why people seek PAD. Oregon data shows year-on-year that the three most frequently mentioned end-of-life concerns in those who died by PAS were: loss of autonomy (over 91%), decreasing ability to participate in activities that made life enjoyable (89%), and loss of dignity (81%). Losing control of bodily functions was cited by 50%, being a burden on family, friends/caregivers by 40% and inadequate pain control or concern about it by 24%; 3% expressed concerns at the financial implications of treatment.²⁹
68. There is another aspect to the issue of suffering which is often overlooked by the advocates of PAD. Suffering for whom? Under the law as it stands, to some (the strong-willed, no-nonsense patient) this may perhaps seem a denial of choice. But it is necessary to consider the majority of terminally ill people, who may be depressed, worried about the impact of their illness on those around them and struggling to come to terms with their mortality. Legalised PAD presents such people, at a highly stressful time of life, with an ongoing choice to be made day after day - should I do this to spare the family? Would it be better to get it over with? Most people's experience of life is less about

²⁹ Oregon Public Health Division "Oregon's Death with Dignity Act 2014", Table 1

asserting their autonomy than about coping with what life throws at them. Legalised PAD has the potential to increase suffering for these people.

The concepts of autonomy and dignity – how do terminally ill patients’ views of these vary throughout the course of their illness

69. Dignity is sometimes claimed to be a useless concept in medical ethics.³⁰ The basis for this claim is that the term is impossibly multifocal; its content is so reliant on individual circumstances that it is not responsible or feasible to use it as the basis for policy-making. Similar claims have been made about the concept of autonomy, due to the various conflicting definitions it has and continues to be given.
70. In the context of PAD, Baroness O'Neill has suggested that appeals to autonomy are probably concerned with something like 'patient choice'.³¹ Viewed as such, we must consider whether anything should be done to restrict or assess the validity of a choice. If one considers the presence of such restrictions and assessments ("safeguards") as integral to responsible law making – as I do – then safeguards must be robust in any legislation. In this context the foregoing discussion of diagnosis, prognosis, mental capacity, etc. is of crucial importance. I do not believe safeguards can be implemented within a physician-assisted suicide scheme.
71. This concept of autonomy can be distorting, however. Its narrow focus on the individual means that autonomy tends to be equated with what Linda Ganzini, et al, refer to as 'dismissive attachment,' meaning an 'attachment to others characterised by independence and self-reliance'.³² Ganzini's research suggests that those who pursue PAD exhibit, on average, a higher-rate of this attachment style.³³ It is irresponsible to change the law based upon the attachment style of a particular group of individuals.
72. Baroness O'Neill has pointed out³⁴ that autonomy, in its origins in classical Greece, was a political, not a personal, concept. It was used to denote states

³⁰ See Macklin R, "Dignity is a useless concept", *BMJ*, 2003; 327: 1419 - 1420

³¹ O'Neill O, "Autonomy and Assisted Suicide", <http://www.livinganddyingwell.org.uk> (accessed 29.04.2015)

³² Ganzini L, et al, "Predictors of Pursuit of Physician-Assisted Death", *Journal of Pain and Symptom Management*, 2015; 49.3: 555

³³ Ganzini L, et al, 'Attachment styles of Oregonians who request physician-assisted death', *Palliative and Supportive Care*, 2011; 9.2: 123 – 128; Ganzini L, et al, "Predictors of Pursuit of Physician-Assisted Death", *Journal of Pain and Symptom Management*, 2015; 49.3: 555 - 561

³⁴ Autonomy and Assisted Suicide, Living and Dying Well 2010, available at www.livinganddyingwell.org.uk

which made their own laws. Some may argue that, if the Greeks defined autonomy in that way, that is no reason why the concept should not be expanded to include personal as well as political autonomy. But that raises the important question of where the individual sits in relation to the wider community, a question that lies at the heart of this whole debate. It may sound libertarian to suggest that we should be free to behave as we wish provided that in doing so we do not cause harm to others. But who makes these judgements as to the harmlessness of individual actions? Such decisions cannot surely be left to the person who is taking the action and has a vested interest in overlooking the collateral harm which may result from it. That is why we have laws made by Parliament rather than by autonomous individuals. The argument that we should be free to behave as we wish provided that we do not harm others in the process is not of itself a serious basis for changing the law.

73. Relational autonomy – the effect of one person's actions on the autonomy of others – requires balancing the rights of the individual against those of the wider community, both in the patient's family and beyond. The concept of relational autonomy reflects the interconnected nature of people in society. It is a better description of autonomy than one that portrays each individual as if in isolation, not acknowledging the effect on others of actions and decisions.

The efficacy of palliative care in managing pain and symptoms in terminally ill patients

74. Palliative care aims to relieve distress in those with life limiting progressing illnesses; it has developed particular specialist expertise in the management of distress around the end of life. A concise definition is given in the Australia and New Zealand Palliative Medicine Association statement.
75. I have read the affidavit of Dr Rajesh Munglani. There are several aspects that are open to challenge. I have run a chronic pain management programme in Cardiff in parallel with the palliative care service; those patients with chronic apparently intractable pain were a very different cohort to those in need of palliative care. Patients with chronic pain are the group that develop long term tolerance, whose myalgia and neuropathic pains (caused by muscle injury and spasm, and by nerve damage) are often poorly responsive to opioids and who almost invariably had a great deal of accompanying psychosocial distress. For

some, serious abuse or trauma of some kind contributed to or caused the onset of their pain state.

76. However, in cancer patients I have found that patients with severe complex pain that did not appear to respond to pain relief intervention, there was an underlying cause that had not been previously diagnosed. In some cancer patients, reinvestigation revealed the site of a previously unknown metastatic deposit, amenable to targeted radiotherapy, surgery, chemotherapy or local injection. The concept of total pain was first described by Cicely Saunders; it is the magnification of the physical pain experience by emotional distress, fear, interrelation or financial difficulties or spiritual distress. It is whole person care, which lies at the heart of good palliative medicine that can help patients adjust to their adversity and tackle problems that seemed insurmountable. To illustrate this, one young woman I was asked to see on a hospital ward had terrible pain, particularly at night. She had multiple additional doses of morphine through the night and spent most of the day drowsy and disconnected from the world. When I sat with her and listened to her background, her personal history and her fears, she told me she had been bereaved aged 18 by the suicide of her boyfriend whom she adored. She had never disclosed the searing pain of that grief and now was deeply fearful of inflicting similar pain on her 11 year old son by her own impending death. She asked her husband not to bring her son in, hoping he would grow distant from her. But each evening she thought of him. We discussed the need to prepare her son for loss, to avoid the sudden pain of grief. I promised to return that evening to see her, which I did late at night, tucked her in and sat for a time with her. That night she slept, her morphine requirements plummeted and she later went home and died at home some weeks later, having made provision for her son.
77. In another woman with advanced cancer her 'unresponsive pain' required 1000mg of morphine a day. After a few days in the hospice she revealed being in an abusive relationship. She then was able to plan with support how to spend her last months; without any physical pain intervention she had good pain relief on 60mg a day of morphine. Her total pain had been addressed.

78. There is no intervention in medicine that is 100% effective all the time. Even the miracle of penicillin for meningitis sometimes fails. When tackling symptoms that can have multiple causes, the clinician needs to analyse the cause of each symptom, in the context of the complexity of the patient's situation, and apply the best diagnostic skills to guide appropriate management and prescribing.
79. Palliative medicine clinicians are not simply 'symptomatologists'; much of our work involves managing complexity and supporting people to help them re-adjust their hopes and aspirations in the face of their new reality, while working to improve their experience of their reality and supporting them as they interrelate with those important to them. For many, illness is the first time they have seriously confronted the uncertainty of life itself and their own mortality.
80. Research in lung cancer patients has shown that patients proactively referred to specialist palliative care lived longer and better than those whose oncologist only referred to palliative care when significant problems arose.³⁵
81. Some proposed assisted dying legislation in the UK has stated that a patient should be told of the alternatives to assisted suicide or euthanasia, including palliative care. But just being told about something is very different to experiencing it. I have often seen patients who are in despair, sceptical about any hospice-type care and disbelieving that they could feel better than they do; after receiving appropriate care for their complex needs, they have said with astonishment that they never believed they could feel better, never believed they could enjoy life again.
82. Evidence from Oregon has shown that pain and distress in dying patients in the last week of life, as reported by relatives, was worse after Oregon's PAS legislation than in the 1996-1998 period prior. In the two year period of 2000-2002 after enactment, decedents were approximately twice as likely to be

³⁵ Temel JS, Greer JA, Muzikansky A. et al. *New England Journal of Medicine* 2010; 363:733-42

reported to be in moderate or severe pain or distress during the last week of their lives.³⁶

83. Dr Munglani has listed some side effects of strong opioids. In my experience these can usually be controlled by very careful titration of the dose needed for pain relief against unwanted effects and by judicious use of other medication. I disagree with the emphasis in his submission. Somnolence often wears off after a few weeks, nausea and vomiting may require antiemetic (anti-sickness) medication for about two weeks and then usually wears off; in some it responds to changing the opioid rather than stopping it. In my experience intractable nausea and vomiting is usually due to other causes, not all opioids per se. Depression that needs treatment can be revealed and usually accounts for changes in cognition, memory and affect. I have not seen personality changes from opioids alone.
84. Some proponents of PAD have suggested that patients are being sedated to death and that doctors are hiding behind so called 'double effect'. That is a largely obsolete concept as palliative medicine has become expert at titration of medication to achieve an effective dose with minimal risk to life. However, in overdose opioids can depress respiration. In the event of an unintentional overdose that resulted in death this unintended, harmful effect is defensible (e.g. an early death) if: (a) the nature of the act is itself good (e.g. the relief of pain and distress); (b) the intention is for the good effect and not the bad; (c) the good effect outweighs the bad effect in a situation that is sufficiently grave to merit the risk of that bad effect (e.g. overwhelming suffering in a dying patient); and (d) the good effect (the symptom relief) is not through the bad effect (death).
85. In palliative medicine practice over 27 years I have seen several patients who had an accidental overdose, usually through an administration error; none have died as a result of the accidental overdose.

Treatment cessation versus PAD

86. Treatment cessation decisions need to be clearly differentiated from PAD. In treatment cessation, the intervention is either stopped because it is achieving its

³⁶³⁶ Fromme EK, Tilden VP, Drach LL, Tolle SW. Increased family reports of pain or distress in dying Oregonians: 1996 to 2002. *Journal of Palliative Medicine* 2004; 7:431-442

therapeutic goal or withheld because its administration would be futile or because the patient has refused consent for the intervention proposed. Intent is key to this: in treatment cessation the doctor is respecting the inevitability of death and the failure of interventions to stop the patient dying of the underlying disease. On ceasing a treatment some patients die rapidly, many die sometime soon afterwards but a few show a dramatic recovery and it is only with hindsight that the clinicians become aware that the person was dying from the adverse effects of treatment rather than directly from the underlying condition. PAD is completely different from treatment cessation in both intent and practice. In PAD the doctor's intention is to end a life - a life that might have otherwise continued for weeks months or even years.

87. Elements of the debate around PAD appear to be deliberately attempting to blur the boundaries of the distinction between the two situations, but a death following treatment cessation results from the underlying disease; In PAD there is a deliberate intention to end life.

If PAD were to be legalised safeguards would be required to mitigate the risks associated with PAD, including resolving the inadequacy of currently proposed "safeguards" in protecting against risks

88. I have studied this subject extensively as a member of the House of Lords, and I have practised in the area of palliative medicine as a specialist since 1987 and prior to that as a GP. I have not come across sufficiently reassuring safeguards within a physician-assisted suicide scheme because of the influence of the physician on the patient, the fallibility of diagnosis and prognosis, and the inability of a doctor to detect coercion.
89. It is worth briefly discussing a few frequently proposed safeguards that have not arisen in my evidence so far.
90. Having two or more physicians sign off a euthanasia or assisted suicide request is often proposed as a safeguard. However, we know from other situations requiring a second doctor's opinion that human nature is such that doctors seek a second opinion from a doctor who is likely to concur with the original assessment. A physician who agrees with euthanasia or physician assisted suicide is likely to seek a second opinion from a like-minded individual.

91. Certain physicians will make writing lethal prescriptions part of their practice. For example, in 2010 Oregon there were eleven prescriptions for lethal drugs written by one doctor alone [Oregon Health Dept. Report]. In evidence to the Select Committee the pro-euthanasia group in Oregon described themselves as 'stewards of the law', who will act as an agent to put patients in touch with a doctor who would help them obtain a lethal prescription [House of Lords Report 86-II (Session 2004-05), Page 310].
92. 'Doctor shopping' raises the specter of superficial assessments by physicians being used to validate processing of euthanasia or physician assisted suicide.
93. So-called "cooling off periods" are sometimes proposed as a safeguard. This does not acknowledge that the desire for hastened death fluctuates greatly over time and is not consistent across patients, in terms of length of time. Nor does a cooling off period protect a patient from coercive influences.
94. An additional grave concern is that patients can get locked into the process they initiated. When a pre-arranged time for taking lethal drugs arrives, a person has to be strong to say "I have changed my mind" or "I'm not certain, I really don't quite know whether I want to go through with this". Hesitancy is normal in people who undertaking any major event. Subtle coercion from those who might benefit from the death, or are tired by providing care, would be very difficult to detect.

Reflections on the legalisation of PAD in the Netherlands and Oregon

95. It has been a privilege to work with physicians in the Netherlands, where there is a very high standard of general medical and surgical skills and good training programmes.
96. I worked with some Dutch GPs to set up teaching programs on palliative care. The Netherlands does not recognise palliative medicine as a distinct specialty, unlike the UK where there is a four-year specialty training program. Courses from the UK have been adapted and shortened; they raise awareness of palliative care, but they do not provide specialist competency training.
97. Whereas in the UK today, consultants in palliative medicine have gone through a particular curriculum in a structured and assessed training program.

98. When teaching in the Netherlands I have found that the euthanasia question is dominant; issues around requests for euthanasia can detract from training in other clinical skills. Euthanasia is a constant background difficulty because there is always the question - at what point do you opt out of any further efforts to improve quality of life and default to euthanasia or ending life. The doctors there have good communications skills training; their medical education programs are to a high standard, but I believe the effect of their law greatly influences their thinking.
99. Where euthanasia is legal, as in The Netherlands, the premises and assumptions underlying care for the dying can become very different. A physician caring for a patient, working through protocols processing a request for euthanasia, is working in the opposite direction to a physician who is working to improve the quality of the patient's life. This is because the underlying assumption in processing a request for euthanasia is that this is a life that's no longer worth living, whereas the premise underlying a desire to improve quality of life is that the patient has a life worth living. That difference in the intention behind clinical behaviour has struck me powerfully.
100. For example, one hospice doctor in The Netherlands related to me his horror at seeing patients whose basic symptoms had not been adequately controlled, but whose euthanasia was being processed.
101. I have also seen first-hand how imaginative and creative thinking in caring for the dying is not compatible with processing a request for death. This is because working to find a way forward for a patient requires imagination. This is completely different from a bureaucratic procedure with a series of so-called checks which focuses the consultation in a completely different direction, towards PAD.
102. It is also instructive that a respected Member of one Holland's Regional Euthanasia Review Committees spoke out³⁷ last year in public and warned other jurisdictions about the unforeseen dangers of going down the PAD road.

³⁷ <http://www.dailymail.co.uk/news/article-2686711/Dont-make-mistake-As-assisted-suicide-bill-goes-Lords-Dutch-regulator-backed-euthanasia-warns-Britain-leads-mass-killing.html>

Conclusions

103. PAS and PAE sit uneasily within clinical practice. Given that the majority of doctors are uncomfortable with these practices, legalisation effectively drives those seeking PAS (or PAE) towards a minority of doctors who, in many cases, have been acquainted with them as patients for only a very short period of time and who are not on that account well-placed to have any in-depth knowledge of their emotional and mental states or of any personal or family circumstances which may be influencing a request. Moreover, the asymmetry inherent in the doctor-patient relationship and the consequent trust which patients invest in their doctors confer upon any doctor considering a request for PAS (or PAE) the power to influence, however unintentionally, the patient's decision-making. Indeed, it is the trust which is such an essential ingredient of the doctor-patient relationship that makes PAS (or PAE) within this setting particularly fraught with risk.

Comments on affidavit of Dr Elizabeth Smales

104. At paragraph 21 she describes the discussion of difficulties encountered in clinical care as if this represents failure of palliative care. This appears to me to be disingenuous. The reflective practice and clinical audit processes in such meetings, where complex issues are discussed and shared, demonstrate clinicians striving to find ways to improve practice and learn from each other and from their own experience.
105. No two patients are alike. The delivery of palliative care requires addressing the complexity of the human condition of our patients in all domains, not just physical. Palliative care is not like a simple course of antibiotics that either works or does not work.
106. At paragraph 22 she describes some pain as extremely difficult to control but fails to address the critically important step of diagnosing the cause of the pain. In my experience, difficult pains have almost always needed a review of the precise cause of each component of the pain before relief is achieved.
107. Her statement that "palliative sedation is often all we have to add" is of concern. In my experience specific sedation for pain relief is very rare. I have seen the overuse of sedative drugs by clinicians insecure in their diagnostic

skills, insecure in listening to the anguish of patients grieving for the life they have lost or are losing, and helping them find resolution in adapting to the uncertainty they face.

108. Sadly, resorting too easily to prescribing excessive sedation may be a marker of a clinician who is overstretched or who is becoming burnt out.
109. At paragraph 28 the description of sedating with “the expectation that the patient will not wake up” is of great concern because it implies that the patient is sedated with the intent to end life, not to titrate sedation and review until pain relief is obtained.
110. In less than a handful of patients I have used a period of sedation to achieve pain control; the sedation has been decreased after one to two days. The exhausted patient needed to sleep; after complete rest the pain control was more easily achieved. In one man I recall this pain relief was not achieved; reinvestigation revealed a small metastasis of cancer that had been missed and responded to radiotherapy – we had wasted days trying different analgesic combinations and doses before he had a repeat MRI scan.
111. At paragraph 29 Dr Smales describes her experience of palliative sedation in patients as taking days to die. Again this concerns me. In general, sedative drugs such as midazolam may be needed in low dose in a patient who is already actively dying and restless. The intention of the low dose is to achieve calm and settle agitation, not to induce coma so that the patient dies days later through lack of hydration or nutrition. Such deaths in the UK were subject to the inquiry into the Liverpool Care Pathway, chaired by Baroness Neuberger. The subsequent consensus document *One Chance to Get It Right* outlines five priorities in care of the dying that can be summarised as:
 - (a) This possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly.
 - (b) Sensitive communication takes place between staff and the dying person, and those identified as important to them.

- (c) The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
 - (d) The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
 - (e) An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.
112. This approach aims to ensure that every person dying has care delivered in a way to enhance and respect their personal integrity and dignity, to minimise distress and respect their needs. It does not involve excessive sedation. It respects death as a natural process at the end of life and that the person is dying. It is not euthanasia.
113. At paragraph 30 the statement that “it is possible that palliative care will be unable to address Lecretia’s suffering” is applicable to every patient. The possibility always exists that some will have causes of suffering that are beyond the narrow realms of medicine. But it does not follow that existential suffering is a reason for deliberately foreshortening a patient’s life by assisting suicide or euthanasia in someone who is terminally ill.
114. The patients who I have seen with the greatest existential suffering had longstanding issues in their lives (e.g. previous abuse either as victim or perpetrator, loss of children etc.) that no amount of medical intervention could rectify.
115. As to paragraph 32 I would dispute the nature of death in such patients. In my experience their final days and hours are not distressing in the way this paragraph portrays.
116. At paragraph 34 Dr Smales describes a patient whose wife was coerced into accepting a PEG before her husband died. I suggest that this is bad clinical care and was disrespectful of the patient, and was a futile intervention. No

PEG should have been inserted; the patient should have been kept comfortable while dying.

117. As to paragraph 38, Dr Smales' friend died by denying herself nutrition and hydration. The evidence from Oregon is that such intentional suicides are better deaths, as reported by relatives, than those from PAS.
118. However, I note with concern that this woman's severe ischaemic pain was not apparently offered a sympathetic nerve block (to dilate narrowed blood vessels) or an epidural to achieve better pain control.

Comments on evidence of Dr Michael Ashby

119. At para 13 Dr Ashby states that "palliative care is unable to relieve suffering in all circumstances for all people". Of course no system of human endeavour can relieve all suffering. Across the world there are millions dying every year without access to any pain relief at all or even to the simplest care. But humility is required to strive to improve our ability to care. In recent years there have been great advances in medicine that have happened precisely because clinicians have sought newer and better ways to control disease and distress. Dr Ashby's statements assume there is no more to discover in palliative medicine. That is certainly not the case and research efforts continue to improve quality of life for patients who are facing their death.
120. At paragraph 20 Dr Ashby rightly points to the inadequacies of some palliative care teams when faced with psychological and emotional suffering. There has been a tendency for a physical symptomatology agenda to overshadow the holistic 'whole person care' that lay at the root of modern hospice care. The Asia Pacific Hospice Congress this month in Taiwan, attended by over 1300 delegates, spent much time focusing on the need to empower staff and volunteers when with people facing distress and adversity.
121. As to paragraph 21, in my experience patients who express a wish to have assistance with suicide or euthanasia have many factors underlying their anguish. Often it is relatively small things that can restore a sense of personal worth yet are not easily found in modern healthcare systems, such as the

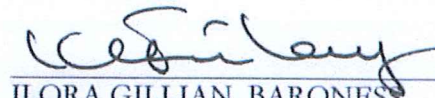
impact of a hairdresser or barber on wellbeing. For some there are issues in their past, revealed by the statement "I've never told anyone this before". Each person needs to be listened to carefully and sensitively. In my experience, I respond to such statements of despair by exploring whether there is anything at all, however trivial, that can be done to improve the day. A commitment to care and redouble efforts on behalf of the patient results in such requests fading as meaning to the person's life is restored.

122. As to paragraph 22 I have been struck how often patients find new meaning by being supported to pursue an aim which gives life meaning. One example was a man I met in a personal capacity, not clinically. Despite near total paralysis from motor neurone disease, he mounted a campaign to allow patients to offer themselves as 'guinea pigs' for new drugs for devastating diseases and to speed up drug licensing systems. He had enormous presence despite his total dependence for all care and has certainly left an important legacy from his activism.
123. As to paragraph 23 I draw a different conclusion from the description of Lecretia Seales' character to that of Dr Ashby. She has shown great resilience and is a woman of creative intellectual ability. Such patients can find creative ways to continue to live well, despite illness and disability. This may continue and be of benefit. Her intellectual ability to mount her action provides a challenge to the palliative care professionals to improve provision, and allows the complexities around PAD to be aired.
124. As to paragraphs 30-34, steroids are powerful drugs with severe metabolic side effects, which include increased appetite (leading to weight gain), protein catabolism (leading to muscle wasting) and emotional lability. This altered emotional response to situations is important and usually resolves when the dose is tailed off. In my own clinical practice I recommend review after 48 hours with a view to gradually decreasing the dose to a minimum maintenance dose or stopping if there is no benefit at all. Some side effects are dose related, not all or nothing as implied by Dr Ashby.
125. As to paragraphs 37-39, I addressed sedation in my comments on Dr Smales' affidavit. Dr Ashby's description of drug titration is a more accurate description of the way sedation should be used, if resorted to.

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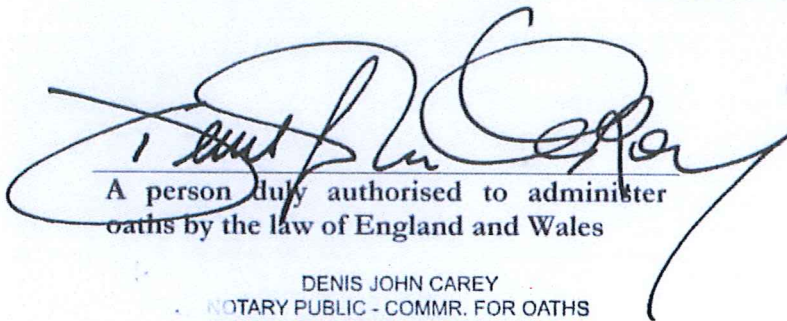
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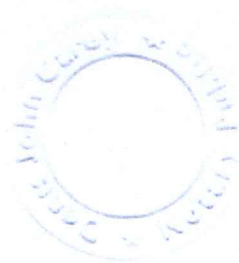


ILORA GILLIAN, BARONESS

FINLAY OF LLANDAFF


A person duly authorised to administer
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