**,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 ELIZABETH ANN SMALES
AFFIRMED 23 APRIL 2015

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I, ELIZABETH ANN SMALES, doctor, of Hawke's Bay, sincerely and solemnly affirm:

Introduction

1. I am a Palliative Care Physician, who practiced primarily at Cranford Hospice in Hawke's Bay.

2. I have been asked to give evidence on:

   (a) what palliative care is;

   (b) how palliative care works in New Zealand;

   (c) the limits of palliative care;

   (d) whether palliative care is likely to be able to alleviate Lecretia's end of life suffering; and

   (e) my experiences regarding premature death.

3. To the extent in this affidavit I express opinions, I confirm that such matters are within my areas of expertise and experience. I note that I have been involved in a number of aid in dying meetings over the last decade, including, for example, giving a talk at the Voluntary Euthanasia Society of New Zealand in June 2013. I confirm that I have read the High Court Code of Conduct for Expert Witnesses as set out in schedule 4 of the High Court Rules. I agree to comply with the provisions of the Code, and recognise my duty to assist the Court impartially on relevant matters within my area of expertise.

4. For the purpose of preparing this affidavit, I have been provided with and reviewed copies of the affidavits of Lecretia Seales, [redacted] and the draft affidavit of [redacted]

Personal profile

5. I trained at St Bartholomew's Hospital in London, the Royal Children's Hospital and Adult Medical Centre in San Francisco and at the Scott and Devonport Hospitals in Plymouth.

6. My qualifications are:

   (a) MRCS - Member of the Royal College of Surgeons UK (August 1969);

   (b) LRCP - Licentiate of the Royal College of Physicians UK (August 1969);

   (c) MBBS – Bachelor of Medicine, Bachelor of Surgery, University of London (October 1969);

   (d) FAChPM - Fellow of the Australasian Chapter of Palliative Medicine (2000).

7. I have held a variety of roles since coming to New Zealand in 1979, including:

   (a) founding medical officer at Cranford Hospice in 1982;

   (b) medical director at Cranford Hospice from 1984 to 2001;

   (c) president of Hospice New Zealand from 1992 to 1994;

   (d) director of the Central Regional Health Authority Establishment Board from 1992 - 1993;

   (e) member of the Royal Australasian College of Physicians - Specialist Advisory Committee (Palliative Care) from 1994 to 2007;

   (f) sensitive issues reviewer at ACC from 1998 to 2007;

   (g) honorary treasurer of the Asia Pacific Hospice Network from 1998 - 2001;

   (h) working part-time at Cranford Hospice from 2001 - 2004, and 2005 - 2006;

   (i) tutoring palliative care at Cranford Hospice from 2006 - 2008;

   (j) member of the National Ethics Advisory Council from 2008 - 2011; and

   (k) member of the Royal Australasian College of Physicians - Fellows in Difficulty Committee from 2013 - 2014.

8. I was made a Companion of the New Zealand Order of Merit in December 2003, for services to the Hospice movement.

What palliative care is

9. The word "palliative" is derived from the Latin word for shield; one of the aims of palliative care is to shield the patient from the physical, emotional, intellectual and spiritual impacts of their disease. The focus is not only on the patient who is dying, but also their family and friends, and those who care for them.

10. Palliative care is about acknowledging and managing dying, and enabling people to live as fully as they can until they die. It seeks neither to hasten nor postpone death. Although the word holistic has become hackneyed, it is an appropriate word here – palliative care seeks to address needs in all 'four quadrants': physical, intellectual, spiritual and emotional. To care for each person as a whole person, to work out with them what matters as distinct from what is the matter, within the context of their family, their social setting and their religious beliefs.

11. My experience as a hospice doctor for more than two decades has taught me that many people are not frightened of being dead, they are frightened of what they might have to go through before they die.

12. Very often, a patient referred to the hospice for palliative care presents with an acute issue that needs urgent attention, such as unaddressed pain. So, we deal with that urgent issue and then move on to the next one. The acute issue is not always a physical symptom like pain - sometimes a person is confused or terrified and doesn't understand what is going on. The situation can be overwhelming for the patient and for the family.

13. Palliative care is challenging. By the time people get referred to a hospice programme they often have multisystem disease with multiple co-morbidities, requiring careful and accurate diagnoses. For example, there are many different kinds of pain, requiring different medications and/or different modalities of treatment. Much of the skill in palliative care revolves around the constant juggling of medications, their effects, side effects and the way they can interact with each other to enhance therapeutic effect or cause problems.

14. An example of the way that palliative care works from my experience was a patient named Mary (not her real name). She was admitted to Cranford when she was 62, she had been previously very fit and active. Mary was dying of aggressive metastatic breast cancer which had spread to her lymph nodes, bones, lungs and liver. She had been out of the district for palliative radiotherapy to assist with painful bony secondary deposits. Mary arrived alone in an ambulance, after a three hour journey on a hard stretcher, curled up like a child, crying. Over the next few days, we managed her pain, cleared her bowel, sorted her nausea, dealt with pressure areas and she managed to sleep, something she was desperate for after a spell in a noisy busy ward. We also worked with her family.

15. The change in her was dramatic, she became again the competent woman she had been all her life. In spite of multiple limitations, she was able to explore her new reality and express very clearly what she wanted and what she did not.

16. On Friday night I stopped to say goodnight on my way home and we talked about how she was, "fine", and agreed to review things on Monday. She thanked me, said goodnight, held up her arms for a hug (gentle because of sore bones) and said "you look tired dear go home". In other words she was enough herself to move from adult to parent, acting like the good mother she always had been. For me those moments are privileged and special and absolutely what palliative care is all about.

17. In New Zealand, palliative care takes place in hospices, in rest homes, hospitals, and in the home. What matters is that the patient feels safe in that location, and comfortable with the people around them – their family and friends, and the medical professionals. Often, patients would come into the hospice, get their symptoms, relationships and worries under control, their questions answered, and then go home for a period of time, knowing they could come back if they needed to and that we would care for them wherever they decided to be.

18. Dying patients can and do sometimes change very rapidly, they may be on multiple medications via several routes. Changes in their needs require re-calibration of all medications, doses and routes of administrations. This is sometimes impossible to achieve except in the

hospice. The level and frequency of review is not possible at home. Some patients will trade less effective symptom control in order to stay at home. This is one of the many 'trades-offs' that can happen; even though pain may be intense, the patient might decide it is worth holding off increments in dose or terminal sedation because, for example, someone important is coming from overseas.

19. Many people experience an "Indian summer" once their symptoms are controlled and the emotional turmoil and the existential issues dealt with. It is then possible to make very good use of the time that is left.

Limitations of palliative care

20. For most dying people in most situations good palliative care is absolutely what they need. Palliative care teams work exceptionally hard to address the emotional, physical, intellectual and spiritual issues associated with the dying process and are in most cases successful. But, there is a small percentage of people who face pain and suffering that we are unable to control while keeping the patient conscious.

21. We can often make a difference to even these people, but at every hospice meeting, formal or informal and every conference I've been to there is much discussion about patients with unremitting problems and the various attempted interventions.

Physical suffering

22. Some pain is extremely difficult to control. For example, some patients who have multiple bony deposits may be reasonably comfortable at rest due to good pain management. However, any sort of movement provokes agony, vulnerable bones can break very easily and will not heal. For these patients, even extra doses of pain relief before moving / toileting can be far from adequate. The head pain caused by an expanding lesion inside the rigid skull is also sometimes unmanageable. Where pain cannot be controlled, palliative sedation is often all we have to add.

23. There are many other problems which are difficult to manage: the spiral of breathlessness causing anxiety which exacerbates the breathlessness, causing panic; fits due to a tumour in the brain; loss of function; loss of independence; incontinence; loss of dignity; loss of one's mental faculties; blindness; confusion; the sometimes overwhelming fatigue of end stage malignancy; the inability to eat, drink, or swallow one's own secretions; loss of speech; the situation of fulminating tumour; and flu like symptoms caused by excess circulating cytokines, when everything aches and it hurts to move or be touched.

Psychological suffering

24. Physical pain and other symptoms are often accompanied by psychological symptoms. Patients in this situation are facing incremental loss and may become "overwhelmed" by the disease. They are slowly losing everything that makes them, them. Such psychological suffering is complex and intense. Patients can experience hopelessness (not clinical depression, which can also occur) but justifiable hopelessness at their situation and the suffering they are enduring. For some patients, having

their loved ones see them in this way is extremely difficult - the dying are witnesses to their family's pain just as the family are witnesses to theirs. The lack of independence, reliance on others and loss of function can also cause suffering, particularly for the young and independent.

Side effects of drugs

25. The drugs used to manage symptoms all have side effects. If you're giving a patient several drugs, then you have several side effects to juggle. Morphine is a brilliant drug for some pain, but it's incredibly constipating. It can also cause nausea and hallucinations. Steroids, can make you hungry, cause weight gain and diabetes, make you spotty, moody and even aggressive, and cause sleeping difficulties. Omeprazole which is often used to protect the gut from non-steroidal anti-inflammatory drugs and/or steroids, and metoclopramide a commonly used anti-emetic are not tolerated by some people. Side effects may need to be treated by further drugs, which can themselves have further side effects. At times, it is a choice between managing one physical symptom and accepting that there will be other suffering caused by the side effects, or not managing the original physical symptom. We try to get the maximum benefit for the minimum negative impact.

26. Opiates/opioids may work well for some soft tissue pain, but not all, and have side effects such as nausea, which requires anti-emetics, and constipation, which requires laxatives and careful attention to bowels. Opiates can also cause other problems, including drowsiness, confusion, dry mouth, hallucinations, restlessness and urinary retention, all of which need addressing.

Palliative sedation

27. We try to manage a patient awake as long as we can, and then - subject to the patient's wishes - they can be managed by palliative sedation.

28. Palliative sedation is used where a patient has so much pain and suffering that the only way it can be managed compassionately, is to sedate the patient into unconsciousness. The expectation is that the patient will not wake up. We continue treating the patient with pain relief and other drugs (such as for nausea), and wait until they die. Often, when a patient is at this stage, they have already stopped eating or drinking. They are too ill and tired to want food or drink, other than to moisten the mouth. We do everything we can to keep them comfortable. The patient's heart continues to beat and they breathe, but they are unconscious. At this time, mouth care, pressure area care, and management of bowels and bladder are extremely important.

29. The concept of palliative sedation does not suit everyone. It is something we discuss with patients and families. Some patients do not want it because they would prefer to be alert and conscious when they die, or do not want to make their loved ones sit by their bed while they lie unconscious, dying slowly, albeit peacefully, over the course of days.

Lectretia's circumstances

30. I have read Lecretia's affidavit setting out her current condition and the effect it is having on her, as well as her anxiety for the future. I have also

read Dr [redacted] affidavit concerning Lecretia's condition and the effects that she is presently suffering from as well as the additional effects that may manifest as the tumour advances. I have also read the draft affidavit of Dr Ashby. I agree with his views on the palliative care that Lecretia would be likely to receive in New Zealand, and the effectiveness of that palliative care. In short, it is possible that palliative care will be unable to address Lecretia's suffering.

31. The problems caused by brain tumours can be many, varied and appalling. The pain is sometimes unmanageable. After all the chemotherapeutic / radiation therapy options are exhausted, all we can offer in addition to often ineffective analgesia is high dose steroids, drugs which have significant side effects (as detailed above). The steroids do not stop the tumour growth, but merely have a limited and often short lived effect on the peri-tumoural oedema. The issues of weakness, neurological deficits, loss of mental acuity, independence, and the inability to move, talk and swallow all continue to worsen, usually requiring sedation.

32. As the brain tumour expands it forces the brain stem down through the foramen magnum, (coning) which is usually the cause of death. Facing this sort of prognosis with no hope of anything 'fixing it' other than sedation when it becomes unbearable creates a level of suffering it is hard to imagine.

Premature death and suffering

33. I have been asked whether I have experience of people who have attempted to commit suicide rather than face the suffering of the terminal phase of their diseases.

34. An example was a woman in her 50s, who was grieving for her husband who had very recently died of motor neurone disease. He had been a rally driver. The progress of the disease had been hugely challenging. When he lost the use of his legs he got a mobility scooter. One day he drove this over a cliff on their rural property; he did not die, but added fractured ribs and bruises to his problems. Her suffering was not merely related to his death, more to what they both endured before he died. She felt coerced into accepting a PEG on his behalf when he could no longer swallow, something they had discussed and which he did not want. This had, in her opinion, prolonged his dying for three more wretched weeks.

35. I have also seen examples of patients prematurely taking their lives rather than suffer the effects of the disease outside of my professional work.

36. In 2014, I went to the funeral of a friend. This man had chosen to end his life with a shotgun. He was dying of liver cancer. He had a wife and four young children when diagnosed; he stopped drinking, changed all sorts of things and had amazingly lived for 10 years before he began to decline rapidly. He shot himself to end the suffering for himself and his family.

37. I believe, from listening to his family, that had the option of assisted dying been available, he would not have needed to shoot himself, but could have waited and lived longer. When he shot himself, he was ill and already frail, scared of becoming too frail to be able to end it. His family, who were not with him when he died, were upset by the violent manner

and loneliness of this death. Both Hospice and the Police were acknowledged at his funeral.

38. Earlier this year one of my friends chose to end her life by stopping eating and drinking. Arterial insufficiency in her legs, particularly on one side, had made walking extremely painful (it was rapidly becoming impossible) and she could no longer drive. The possibility of a stent was explored and was not possible. Various analgesics were tried, unsuccessfully: they made her feel ill and did not fix the pain. The likelihood of amputation was discussed, along with the concerns about gangrene.

39. Highly intelligent, fiercely independent and aged 84, she looked at her options, discussed them at length with her cardiologist, her general practitioner, her friends, and her only living relative, her sister-in-law, in Germany. Her mind was made up; she had done her research and based on all available information had made an informed unshakeable decision based on the combination of intractable disease, uncontrollable pain and a sense of a completed life.

40. I think, that because she was such a vital woman, had she been given the option of assisted dying, she would not have stopped eating and drinking to end her life when she did; she might have been able to live a while longer, secure in the knowledge that she could ask for help to end her life when she needed to. She made a decision to kill herself by stopping eating and drinking, because that was the only means available to her to avoid what lay ahead. She chose to spare those of us who loved her, the complications of suicide by other means.

AFFIRMED at Hawke's Bay this 23rd day of April 2015 before me:

E Smales.

Elizabeth Ann Smales

A Solicitor of the High Court of New Zealand

KIRSTY JANE KUPA
Solicitor
HASTINGS