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 SIMON ALLAN ON BEHALF OF THE DEFENDANT

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

CROWN LAW
TE TARI TURE O TE KARAUNA
PO Box 2858
WELLINGTON 6140
Tel: 04 472 1719
Fax: 04 473 3482

Contact Person:
Paul Rishworth QC
Email: paul.rishworth@crownlaw.govt.nz



I, Simon Gardiner Allan, of Palmerston North, Director of Palliative Care at Arohanui Hospice, solemnly and sincerely affirm:

- 1. I am a palliative care specialist and Director of Palliative Care at Arohanui Hospice, Palmerston North. I have a 25 year association with Arohanui Hospice and for most of this time I have been Medical Director and then Director of Palliative Care when the position was rescoped and renamed in 2005.
- 2. I am also the current President Elect for the Chapter of Palliative Medicine within the Royal Australasian College of Physicians.
- 3. My previous roles and positions include Medical Oncologist at Midcentral District Health Board (DHB) (I held this position for 20 years), Senior Clinical Advisor to NZ Ministry of Health between 2008-11 and a Clinical Advisor to Hospice NZ
- 4. I completed my undergraduate medical degree at the University of Aberdeen in 1977. I then attained by Membership of the Royal Colleges of Physicians (UK) in 1979 and my MD from the University of Aberdeen in 1986. I attained my Joint Committee on Higher Medical Training in Accreditation in Medical Oncology in 1988. I am also a graduate of and a Fellow of the Royal Australasian College of Physicians and a Fellow of the College of Physicians, Edinburgh (and an International Advisor to this College). I am currently a member of the Australia and NZ Society for Palliative Care and of the International Collaborative for the Best Care of the Dying patient.
- My curriculum vitae is annexed as "Exhibit SGA-1" to this affidavit.
- 6. In this affidavit I address a series of questions about palliative care in New Zealand in light of my experience.
- 7. I am familiar with the guidelines on the giving of expert evidence and I acknowledge that I have read and understood the Code of Conduct for Expert Witnesses and I agree to comply with it. Any opinions I express in this affidavit are within my areas of expertise and experience.



8. The evidence I provide is about palliative care in New Zealand in light of my personal involvement and experience.

What is palliative care?

- 9. Palliative Care is the active support of people diagnosed with life limiting conditions that involves an approach to the whole person, given the frequent existential, psychological, social as well as physical issues relating to both the terminal illness and the threat to life. Such a threat provokes a range of reactive responses from individuals. Some will respond (in a knee jerk way) with an immediate desire to depart this life quickly and can make analogies with Veterinary Science where animals are euthanised. Others will focus on any possible "curative" approach they perceive can better their outlook such as seeking overseas treatment (either allopathic or alternative) in various countries. The drive to seek alternative measures of treatment becomes very strong when one's life is threatened and the treatment scope is limited or zero. Many, indeed the majority adjust with time to their limited life span with an amazing acceptance (which in my experience is not negative, usually far from it) that allows them to re-orientate their life, their desires and their families towards support, early preparatory grieving and they seek to communicate, prepare and "gift" to others, both in the present and for the future, in a way which consolidates the memory and offers "permission" for their passing. Those who accept the communicated facts of their condition will generally adjust better and more rapidly than those who chase the "holy grail of cure".
- 10. Two human characteristics predominate in these circumstances. The first is the determination to be hopeful, the second is resilience which allows them to cope with the disappointments of dashed hopes and future life goals for example birthdays, family celebrations etc. A variable percentage of patients become depressed (perhaps 30% in my experience, but weighted against published studies showing an incidence of 25-60%) but many do not wish treatment and of those who receive treatment the success of anti-depressants is limited, even as low as 30 %. The identification of depression is partly by high suspicion of practitioners and also down to routine use of screening tools to identify such. The question "are you depressed" is one of the most potent tools for such identification. Patients will not necessarily have their depression.

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recognised because an assessment for depression has not been done or the patient refuses to have this explored.

11. The application of palliative care in New Zealand is at both the primary and secondary levels of health care. At the primary level there is a growing knowledge base and involvement in Palliative Care amongst General Practitioners and community nurses. Referral to secondary Palliative Care is either through Hospital Palliative Care Support Teams or to Hospice Services. Referrals to Hospice are for those who are entering their final 6-12 months of life (not an exact science) and who have significant symptom or existential distress. For example patients with complex and uncontrolled pain (or other distressing symptoms) or someone with significant expressions of self guilt and anguish from life events past. The provision of Palliative Care across NZ is improving with access to Specialist Palliative Care now being universal. The standard of access and service in NZ is still variable and this is a work in progress.

What sort of fears do you encounter with patients who have diagnoses of terminal illnesses? How does palliative care deal with these fears?

12. It is a "normal" reaction to be fearful in the situation where one's life is threatened. Life is the one thing we can be sure of and the desire to hang on to it is strong, even in old age. From my experience troubles shared are troubles reduced and good knowledge and communication about what is happening, what is likely to happen and "how will I die?" are important to address with patients diagnosed with a terminal illness. Many issues in the past and present which relate to patients feeling lonely, lost, alone and with difficult to control symptoms (eg pain) can be found to arise from problems with communication, a lack of desire for some health professionals "to go there" in discussions and lack of an integrated approach to patient-centric care. Also a lack of knowledge of palliative approaches or treatments amongst health professionals may limit the application of early care for such patients. Explanations, reassurances and care provided can alleviate much of the fear which can be evoked in patients with terminal illnesses or facing the end of their lives. There is a need in society and among health professionals at large to have greater courage to discuss death and dying and to be better trained in

communicating. The challenge also is to improve the knowledge base of health professionals at under- and post-graduate levels.

- 13. Some fears become pathological and acute/chronic states of anxiety and depression can ensue. Post-traumatic reactions can be exposed with the added stress of a terminal diagnosis unmasking a troubling past experience. Treatment for these can be powerful, together with a coordinated and integrated care team approach to the patient and family.
- 14. People can vary in their opinions throughout the course of their illness. They may be reactive during periods of stress, but rethink their position when they are more relaxed and perhaps more aware of the facts surrounding them. They may reflect that the decisions they make have profound implications for others, especially their family, leading to a changed opinion on where they stand on the thought of euthanasia or suicide. There is no one similar journey for patients in these circumstances. However, many shared aspects exist including the reactions and the changing emotions which are encountered. The time line on these emotions is not a science, nor is the need for all patients to go through a chain of similar reactions. It is commonly accepted that patients have the ability and right to change their minds on a topic, on a treatment offered and about whether they might want to be euthanised or not. Most patients who voice a desire for assisted suicide do not mention this again when under care. My experience in 30 years of consultant practice is that I know (and do not consciously suspect any others) of one patient who has committed suicide and she had a past record of depression and suicide intent.
- 15. Dignity is a growing area of interest and research. There is no universally accepted definition when it comes to a person's care or experience. However, a few clinical basics are considered crucial to the achievement of dignity in patients' minds/experiences, namely the domains of:
 - 15.1 Autonomy;
 - 15.2 Communication;
 - 15.3 eating/drinking;
 - 15.4 privacy;

- 15.5 personal hygiene;
- 15.6 control of pain and other symptoms such as nausea/vomiting, intractable hiccups or cough, breathlessness/choking and constipation (which rarely can cause death);
- 15.7 social inclusion;
- 15.8 end of life care; and
- 15.9 safety (feeling safe in the holistic "space they are in").
- 16. Palliative Care is absolutely about maintaining dignity as it is deconstructed above and the meeting of such basic human need from the multi-disciplinary team is what gives Hospice the amazing reputation which it generally has with those families who have had direct experience of the care which it has provided.

Is it possible for palliative care to deal adequately with issues of pain and the other concerns of patients?

- 17. There have been great advances in the ability to give holistic care to terminally ill patients. Most symptoms can be well controlled, certainly to the satisfaction of our patients and families. While it is not possible to say that all symptoms and pain can always be treated and the patient maintain conscious with quality of life, given the agreement of the patient or lawful proxy, the use of sedation titrated to achieve control can be used effectively to give relief. In my practice in the Midcentral DHB area we might use such palliative sedation twice per year on average. We had 620 palliative care patient referrals over last year, to give some context to this number.
- 18. Terminal sedation is the use of medication adjusted to meet the agreed need of the patient/or appointed Executive Power Of Attorney to control symptoms with a degree of drug sedation, where the aim is to control the symptom not to cause death.
- 19. Palliative sedation is a term sometimes used to describe terminal sedation but in that some sedative drugs may be used to control restlessness or agitation at the end of life (a not uncommon final physiological state). I believe the term terminal sedation is better term. An example of the need for terminal sedation

might be patient who is going to die of choking from a tumour compressing a major airway and who has expressed consent that they need to be terminally sedated rather than struggle in final 1-2 days with a "natural strangulation". There is, therefore, no conscious experience of the "strangulation" when it occurs. When the situation begins to be unbearable in the final few days before death sedation is titrated to a point of comfort for the patient and this is usually at a level where they are no longer or only minimally conscious as the dying process occurs.

- 20. It is unusual in cases of terminal sedation to offer artificial means of nutrition or hydration. Does the patient then have a degree of dehydration contributing towards death, the answer is yes. This is discussed in the prelude to terminal sedation. In practice the patient does not appear to suffer and with prior communication the family do not usually become concerned about this specific issue, more about the grief of losing their loved one.
- 21. The prime motivation for terminal sedation is that of comfort care, not the taking of life. That death will come a few days earlier than it might otherwise is one of the consequences of this means of symptom control which is taken account of in communicating with the patient and family.
- 22. Terminal sedation is a globally accepted and researched subject. It is accepted that there is more than one way such sedation can be achieved, several drugs can be used for this purpose but they are not necessarily available in all countries.
- 23. Communication is crucial to all palliative care, however terminal sedation is an area where clear decision making is required with as much empowerment and agreement of the patient and family as can be managed. Unfortunately concurrence within the family is not always able to be achieved, in these cases the prime decision maker is the patient when competent to do so.

What has been your experience with patients wishing to end their lives through suicide after diagnosis?

24. Most people who express a desire for euthanasia never mention the topic again when comprehensive care is provided. The average time under Specialist Palliative Care in NZ (from referral to death) for patients is around 2-3 months.

with a deteriorating physical state as time passes. A few do persist in their adherence to the principle of free choice in the matter of suicide, however, in my experience these patients are usually are well engaged in the journey they are on with strong family bonding, that I believe it unlikely that they would ultimately want to take a euthanasia as an option if it were available to them. Two members of a NZ voluntary euthanasia society have passed through our Hospice and both have explicitly refused visits from other members of that voluntary euthanasia society once they were under care and had experienced what Palliative Care had to offer. One was quoted as saying to me "Oh I am so enjoying my journey with you all here" with a large smile on her face.

A significant experience that does come to mind is one gentleman who was most fixed on his view of euthanasia over 6 months and would I believe have taken this option, if it existed, but without telling or involving his family of 5 grown children. I had the privilege of witnessing his death at home surrounded by his children and their families. He was in bed with a happy household, he called each member over to him, one by one, said something individually to each, closed his eyes and died. Strangely this is one of the most remarkable "death scenes" I have witnessed, in a man who was originally so adamant in his desire for assisted suicide. The memory of how someone dies remains forever in the minds of those who are left behind.

How would the legalisation of physician assisted death impact upon palliative care and hospice services?

26. Business as usual would be little affected in my view but the call to have physicians involved in performing this activity will bring some divide in the profession (with very few doctors only agreeing to participate). There would be strong resistance from the Hospice movement over any Hospice involvement in such activity and one wonders whether there would a Public or Private facility(ies) built to cater for this activity or whether it would be home-based activity. It may be that future coercion of doctors could occur (if this activity is deemed a human right and that doctors are duty bound to respond to that need) if only a few doctors are willingly to participate in doctor assisted death.

AFFIRMED

at Palmerston North this 2 th day) of April 2015

before me:

Simon Gardiner Allan

A Solicitor of the High Gourt of New Zealand A Justice of the Leace



CURRICULUM VITAE

SIMON GARDINER ALLAN

April 2015

This is the exhibit marked "SGA-1" referred to in the annexed Affidavit of SIMON GARDINER ALLAN affirmed at Palmerston North this 2 of April 2015 potree me:

Solicitor of the High Court of New Zentand
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CURRICULUM VITAE

SIMON GARDINER ALLAN

April 2015

This is the exhibit marked "SGA-1" referred to in the annexed Affidavit of SIMON GARDINER ALLAN affirmed at Palmerston North this 27 of April 2015 before me:

Solicitor of the High Court of New Zealand
A Justice of the Peaco

CURRICULUM VITAE

NAME:

Simon Gardiner Allan

DATE OF BIRTH:

31.3.54

CITIZENSHIP:

British & New Zealand (1994)

MARITAL STATUS:

Married

ADDRESS:

Arohanui Hospice,

PO Box 5349

Palmerston North 4441

MEDICAL COUNCIL OF NEW ZEALAND:

Full Registration No. 16168

UNDERGRADUATE AWARDS: (University of Aberdeen Medical School)

Strachan Medal in therapeutics 1976 Anderson Gold Medal in Clinical Medicine 1977 Class Prize in Medicine 1977

QUALIFICATIONS:

MB ChB Aberdeen University 1977

MRCP (UK) 1979

MD "Studies on the gastrointestinal toxicity of cisplatinum - Aberdeen University, 1986

JCHMT Accreditation in Medical Oncology 1988 (UK Specialist Training Qualification)

Fellow Royal Australasian College Physicians 1992

Fellow Royal College of Physicians (Edin) 1992

Fellow Australasian Chapter of Palliative Medicine 2000

PRESENT APPOINTMENTS: Commenced February 2012

1. Director of Palliative Care and Palliative Care Physician (0.9 FTE)

Arohanui Hospice, Palmerston North

2. Palliative Care Physician (0.1 FTE) Palmerston

North Hospital

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March 1989 - October 1996—Medical Oncologist 1.2 FTE

The Regional Cancer Treatment Service, Palmerston North Hospital provides oncology services for a large geographical area of the central North Island with a population base of 570,000. There are 3.5 Medical Oncologists, 5 Radiation Oncologists and 2.5 Haematologists in the Regional Service. Monthly Medical Oncology clinics are held in seven peripheral locations with chemotherapy given in four of these sites, under the direction of our Regional Service.

Research - We have had an active local, national and international involvement in clinical research studies. With the increasing trend to larger trials and international co-operation we have, in recent years, increasingly sought to participate in these multi-centre studies across a wide range.

October 1996 -2002

Medical Oncology 7 tenths position

July 2002-March 2010 Clinical Director of the Regional Cancer Treatment Service and part time Medical Oncologist.

Palliative Medicine

5/90 - 1/95

Part Time (0.1 FTE) Palliative Medicine

Physician.

1/95 - 10/96

Acting Medical Director, Arohanui Hospice following the resignation of the then Medical Director. This position was held while still fulltime Oncology, due to prevailing circumstances

at the time.

11/96 - 9/05

Medical Director, Arohanui Hospice. changed configuration of medical staffing at the Hospice allowed for my appointment to this position on a part-time basis. This varied throughout this time- 14-20 hours per week.

9/05-present

Director of Palliative Care, Arohanui Hospice.

Responsible for clinical quality, education and research in Palliative Care with strategic input to the vision and direction of Palliative Care Services. This role includes

clinical oversight and clinical work.

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Arohanui Hospice is a regional Hospice serving 180,000 people, has 10 beds and a Palliative Care Liaison Nurse Service. The medical staffing is 3.6 F.T.E., with 1.2 Specialist FTE and one training registrar. There is a Hospital based Palliative Care Team and each week the Service looks after 200 patients. (around 700 new referrals per year).

11/2008-11/2011

Senior Clinical Advisor (Palliative Care) NZ Ministry of Health

2007-2012

Co-Clinical Director Central Cancer Network

2012-2013

Clinical Adviser for Health and Disability Commissioner- (Medical Oncology) and Palliative Care

PREVIOUS APPOINTMENTS:

1977-78 -General registration Aberdeen Royal Infirmary 1978-1979 -SHO Medicine Aberdeen Hospitals. 1979-1982 -Registrar General Medicine, Aberdeen Hospitals

Lecturer:

Western General Hospital

Medical

3/82-1/84

Hospital Edinburgh

Oncology

<u>Clinical Research Fellow</u> - Imperial Cancer Research Fund, Medical Oncology Unit, Edinburgh, 2/84-4/86 MD 1986 (University of Aberdeen)

April/May 1986 Clinical Haematology Western General Hospital, Edinburgh

<u>HONORARY SENIOR REGISTRAR - 5/86 - 2/89</u> - Lothian Health Board, Edinburgh.

Paediatric Oncology: 4 months

(Dr O B Eden, Royal Hospital for Sick Children, Edinburgh).

Medical Oncology:

(Prof J F Smyth; Dr R C F Leonard; Dr M A Cornbleet)

Radiotherapy: November/December 1987

General Medicine:

(Prof C R W Edwards and Dr P Padfield)

During 1988 I participated in a monthly general medical receiving rota with post-

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receiving ward rounds in the Western General Hospital.

Locum Consultant Duties:

A total of three months of locum consultant physician duties have been undertaken in the Caithness General Hospital, Wick which entailed general medical clinics, receiving, ward rounds and administration.

Member of Societies:

Royal College of Physicians, Edinburgh
Royal Australasian College of Physicians
Association of Cancer Physicians
British Association for Cancer Research
American Society of Clinical Oncology
New Zealand Society of Oncology
New Zealand Cancer Society
Australia & New Zealand Society for Palliative Medicine
Hospice New Zealand
NZ Association of Cancer Specialists

Committee Work:

- a. Animal Users Committee of the Western General Hospital, Edinburgh, (1984-1986).
- Regional representative for Junior Committee of Association of Cancer Physicians, UK (1986-1989).
- c. Chairman Working Party on Hospital Notes System, Palmerston North Hospital (1990-1991).
- d. Honorary Secretary Physicians Committee, Palmerston North Hospital (1989 1993).
- e. On executive of Combined Medical Staff Committee, Palmerston North Hospital (1990 1992).
- f. Secretary of local branch of Association of Salaried Medical Specialists (1991 1996).
- g. Manawatu-Wanganui Area Health Board Committee on Notes and Stationery (1993).
- On executive of Manawatu branch of Cancer Society and on Medical Sub-committee (1991 present).
 Chairman of Medical & Health Promotion Committee (1994 -1997 and 2000-present)
 Chair Medical Committee (1997- present), Vice President (1999-current).

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- Vice president of Central Districts Cancer Society-2011-present.
- Overseas (NZ) representative of Royal College of Physicians (Edin). 1995present
- j. Member/Chair of National Health Promotion Committee, Cancer Society(1995-current). Chair of said committee January 2002—March 2007
- K. Chair NZ Committee and Vice President Australia & NZ Society(ANZSPM) for Palliative Medicine 5/1997- 2000.
- Chair Specialist Advisory Committee for Palliative Medicine [RACP] 1997present. NZ representative Australasian Chapter of Palliative Medicine Education Committee.
- m. Member of Interim Council of the Australasian Chapter of Palliative Medicine and on the Foundation Fellowship Committee of the Chapter-1999-2001
- n. Member of the Council of the Australasian Chapter of Palliative Medicine 1999-2001.
- Chairman Palmerston North Hospital Combined Medical Staff Committee 2001-2004, and by right, member of Medical Reference Group and the Palmerston North Medical Trust.
- p. Member of Palmerston North Hospital Credentials Committee 2000-2008
- Member Palmerston North Hospital Clinical Board 2001-2007
- r. Member of the Palliative Care, Research Group of Hospice NZ-2004-2006
- Clinical Advisor to Hospice NZ 6/05-4/11.
- t. Chairman of the Palliative Care Collaborative-towards a NZ National Body in Palliative Care.
- U. Chair of the District Management Group (Cancer) Midcentral DHB, 2006-2011, now member-present
- v. Member of Palliative Care Partnership governance/management group 2005-present
- W. Member ex-officio of the Palliative Care Advisory Group- ended 2011.
- x. Member (FRACP portfolio) of combined SAC of Australasian Chapter of Palliative Medicine

y. Chairman of the Palliative Medicine Education Committee, RACP 2008-2012

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- z. Clinical Director Central Cancer Network- 2007-2012
- aa. Health Workforce NZ Chair of Palliative Care workgroup
- bb. Chair of Palliative Medicine Training Co-ordination Committee 2008-2012
- cc. Branch Advisory Body member, RACP 2002-present
- dd. Member AChPM Council
- ee. Member of Health of Older People (HOP) Group- (Lower North Island)
- ff. Member PHO Board (Midcentral DHB)-2013-present
- gg. Member Clinical Leader ship Council (Midcentral DHB)- 2014- present
- hh. Deputy Chair Manawatu Cancer Society
- ii. Vice president Central Districts Cancer Society
- jj. Member International Collaborative for End of Life Care
- kk. Member of Midcentral District Health Board Clinical Leadership Council 2014-present
- II. Member of the Council of the Chapter of Palliative Medicine 2012-present
- mm. Member of governing body for Final Days of Life- NZ Jan 2014-Sept 2015
- nn. President elect for the Chapter of Palliative Medicine May 2015

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cancer.

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