

Submission ...End of Life Choices Inquiry

Thank you for establishing this important inquiry.

My attitude to 'end of life' matters is based on a statement from the great moral philosopher, David Hume, 1714-1776, a line from his book "On Suicide".

"I believe that no man ever threw away life while it was worth keeping." These profound words are irrefutable. Who has ever wanted to die when their life is good and offers peace?

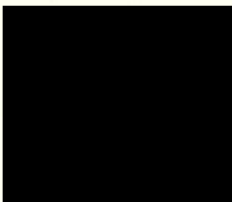
More than 80% of Australians support euthanasia. I hope that the Committee will consider, and choose to mitigate, the needs of our many Australians with a terminal illness who suffer intolerable pain which ends with a difficult death. Euthanasia, Physician-assisted death (PAD) and Physician-assisted suicide (PAS) provide the possibility of a painless, composed end of life.

My main focus regarding "end of life" matters is the unrelieved suffering and loss of normal life sustained by our severely mentally ill [SMI] . So serious is their problem that some seven, every day, choose to die by suicide, usually violently, always alone. Many of my comments are based on this concern, the frequent lack of psychiatric care in their lives, the total lack of dignity or help connected with their deaths.

May your decisions offer help and hope to all those who live with intolerable, incurable, physical, mental and psychological suffering.

I appreciate the opportunity to make this submission. I would like to be able to speak at a public hearing.

Mrs Caroline Storm



Respectfully submitted...



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Euthanasia in other nations

Netherlands...Passed a law in 2002 legalising euthanasia and PAS, under very specific circumstances. In 2004 a protocol was developed which set out criteria for child euthanasia.

Philippines and New Zealand...Assisted suicide and euthanasia are illegal.

Switzerland...Illegal drugs may be supplied to Swiss or foreigners.

Norway...Euthanasia remains illegal but a carer may be given a reduced punishment for taking the life of a person who consents or is hopelessly ill.

Ireland...It is illegal to contribute to a death. Life support may be removed, if requested. A 2010 poll showed 57% of adults believe PAS should be legal.

Belgium...Adult euthanasia was made legal in 2002. It has recently become the first country to allow euthanasia for terminally ill children of any age. The law was passed, 86 votes to 74. Christians, Muslims and Jews rejected the law.

Luxembourg...Parliament passed a Bill legalising euthanasia in 2008. A second reading decriminalised euthanasia in 2009.

Mexico...Active euthanasia is illegal. Passive euthanasia has been allowed since 2009.

Israel...The Penal Law forbids causing the death of another. Active euthanasia is forbidden by Jewish Law but has been accepted, in some cases, by Israeli Law.

Uruguay...Since 1932 the Penal Code has accepted "Compassionate Homicide".

Sweden...The Court ruled passive euthanasia is legal in 2010. Administering a lethal substance is illegal.

The United Kingdom...Euthanasia is illegal. Attempts have been made in the House of Lords to legalise voluntary euthanasia, unsuccessfully.

Euthanasia in other nations

Canada...the Supreme Court stated, 7/2/2015, “*The prohibition upon PAD infringes the right to fundamental justice, life, liberty and security of the person that is not in accordance with the principles of fundamental justice.*” The court believes mentally competent consenting adults who have intolerable physical or psychological suffering from a severe and incurable medical condition have the right for a doctor’s help to die. The Court agreed with a trial judge, the risks associated with PAD can be limited through a carefully designed and monitored system of safeguards. “*A theoretical or speculative fear cannot justify an absolute prohibition. Care for the dying is an entitlement for all.*”

The Canadian Supreme Court offers a simple and humane acknowledgement of a Canadian citizen’s rights. “*life, liberty and security of the person*” are paramount and a prohibition of PAD will infringe those rights. “*Care for the dying is an entitlement for all*” is a lesson for all nations.

The USA...Active euthanasia is illegal in the USA. Burdensome treatments such as life support systems may be removed. Assisted suicide is legal in the States of Washington, Vermont, Oregon, New Mexico, (one county only) and Montana (one county only).

France...The National Assembly [17/3/2015], legalised euthanasia by a comfortable majority. Doctors may combine euthanasia with a deep and continued sedation.

Euthanasia and Physician-Assisted Suicide

There is a difference between euthanasia and physician-assisted suicide. The latter refers to a situation in which a doctor may prescribe a lethal drug but the patient is responsible for taking the drug. Euthanasia occurs when a health professional gives the patient a lethal dose of a chosen drug in order to end that patient's life. PAS, when/if legalised, may even become a new section of available social services.

"Providing good end of life care is an ethical duty of the medical professional. Good pain control should be a priority." From "American College of Physicians Ethics Manual, 1998".

Prime Minister Abbott, in 2014, promised a dying man that he will allow Liberal party members to vote with their conscience on a euthanasia bill being developed by Senator Richard Di Natale. The bill will make it legal for medical practitioners (the Senator is one) to help a terminally ill, mentally competent adult to end their life.

A multi-party Senate Committee recommended in 2014 that leaders allow MPs a free vote on euthanasia. Labor MPs have an automatic conscience vote.

Mr David Seymour, MP for the ACT, recently announced that he supports action which will relieve those suffering intolerable pain from irreversible medical conditions.

The following is the Melbourne Age editorial heading[11/5/2015]...*"Compelling case to enact right to assisted death"*. It ends... *"The Age holds that life is precious and should be protected. But not at all costs. There are clearly cases where the right thing to do is to recognise the right of terminally ill people who are suffering dreadful physical, psychological and emotional torment to die peacefully at a time of their choosing. Our politicians have a duty to do this without further delay."*

Christian Support for Euthanasia

Community support for PAD is 80%, A substantial majority of Christians support the right of doctors to provide terminally ill and suffering patients a lethal drug dose, according to a 2012 Newspan. Included in this support are nearly 9 out of 10 Anglicans and a surprising 3 out of 4 Catholics

Archbishop Tutu backs the right of the terminally ill to end life with dignity. He wrote “*I have been fortunate to spend my life working for dignity for the living. Now I wish to apply it to the issue of dignity for the dying. I revere the sanctity of life, but not at any cost*”.

Lord Carey, former Archbishop of Canterbury and head of the world-wide Anglican Church said in the House of Lords “*Today we face a terrible paradox. In strictly observing accepted teaching about life’s sanctity, the Church could actually be sanctioning anguish and pain; the very opposite of the Christian message.*”

“*In Quebec [the most Catholic province in Canada] an Act Respecting End of Life Care, which legalised assisted dying, was passed by the Quebec parliament, June, 2014, 94 votes to 22, to a standing ovation.*” [Posted in ‘On Line Opinion’ by Ian Wood 3/3/2015] Mr Wood is the National Co-ordinator for “Christians Supporting Choice for Voluntary Euthanasia

Dr Geoff Wall, a researcher, Sydney doctor and anaesthetist, posted to “On Line Opinion” 27/2/2015, “*Elect a dignified death...with state elections due in March, many voters may be overwhelmed by their options. One such cause affects any one of us: the basic human right to control one’s life and death. Consistently, over 80% of NSW citizens support voluntary euthanasia. Currently, 8% of Australians attend church regularly. The Church has every right to advise its followers...but none to override the rights and wishes of an 80% majority. For how much longer can a noisy minority overrule a massive majority of NSW citizens?*”

Dr Wall’s pre-election statement sets out the cause well...the basic human right to control one’s life and death; the basic human right to practise one’s religion .The former seems most likely to offer the way Australians want to move forward to legalised euthanasia.

RANZCP....Royal Australian and New Zealand College of Psychiatrists

The following notes are from a College Paper on PAS, May 2011.

“Recent legislative debate in Australia and New Zealand has focused on the possibility of legislation of PAS.

There is no consensus within the College membership as to whether or not PAS should be legalised. Nothing in this document should be taken either as an explicit or implicit position for or against PAS. This statement is not intended as any solution to the ethical debate. Members should note legalising an activity does not make it ethically correct. Ethical values are set to protect patients and to preserve trust in the profession.

Under the quashed N.T. law, a psychiatrist was required to certify that the patient was not suffering a treatable, clinical depression or other mental illness which may have impaired judgement. Psychiatrists have specific skills in identifying psychiatric illnesses and understand the aetiology of suicidal ideation in the terminally ill; any legislation involving PAS should require a mandatory psychiatric review of the patient before the request is acceded to.

The College believes that unrelievable psychiatric illness is rare and the difficulties of securing capacity in these situations so great that any putative benefits could not be outweighed by associated risks”.

Obviously, the College wants no role in any PAS/PAD discussion. It suggests a patient review before PAS is acceded to. The Committee needs to consider this very carefully. The College states, offering no evidence, “unrelievable psychiatric illness is rare”. This has no relationship to reality. Suicides occur! Death is usually violent and the person alone. The College has ignored SMI defunding, loss of acute care and acute care beds, lower life expectancy [56-58 years] and dereliction of duty of care. More SMI have died since medication superseded crucial psychotherapy. The medication causes increased metabolic problems, hence obesity and severe cardiac illness, both increase SMI patients’ medical deaths, thus lowering life expectancy...to some 20+ years below the norm.

Palliative care in Australia

State and Federal Governments fund palliative care organisations and patients, carers and families are well-provided for. Palliative Care Australia (PCA) aims to improve quality of life for patients, carers and families who face problems of a life-threatening illness.

PCA aims to do this by addressing physical, social, emotional and cultural needs. This enables clients to live as well as possible. Help is always offered to patients and, when necessary, to the bereaved.

PCA offers a “Palliative Care Directory”. It is available to ensure that patients and families receive the expertise needed at home, in hospital, an aged care home or a hospice. PCA also has available “Multicultural Palliative Care Guidelines, 2009”. This is of great support to older immigrants and their families.

Palliative care, in its broadest sense, encapsulates specialist and general care. The “National Palliative Care Projects” is supported by the Australian Department of Health. It aims to improve the palliative education and training of the health and aged-care workforce and identify quality improvements that can assist in the delivery of better palliative care services across Australia.

Dr Rodney Syme wrote in his book “A Good Death”, “If you and your family are struggling with your illness, ask about palliative care”.

Palliative care appears to be better than the normally good care found in our public hospitals. It identifies the patient, the family, the carer, and works to allow all to come together for the best care of the central person, the seriously unwell patient who is approaching death. The simplest definition of palliative care seems to be “The care given to the terminally ill and family and carers, especially that provided by ordinary health services.”

Suicide and Euthanasia

Dr Jamison, the famous US psychiatrist and author wrote the following paragraphs in her book, "Night falls Fast". She suffers from manic-depression and this appears to intensify her ability to make clear the struggles and difficulties which our severely mentally ill endure.

Schizophrenia is the most severe and frightening of psychiatric illnesses. Like manic-depression, it hits when the individual is young and is devastating to relationships, education and aspiration.

Numerous studies in Europe, the USA, Asia and Australia show the unequivocal presence of severe mental illness in those who die by their own hand; indeed, in all the major studies to date, 90-95% of people who died by suicide had a diagnosable psychiatric illness. It is striking that more suicides are linked to psychiatric illness than to terminal physical disorders. Schizophrenia is the most severe and frightening of psychiatric illnesses. Suicide is common enough to make it a very lethal disease. It is malevolent and will kill 10% of its victims through suicide.

Silvano Arieti, 1914-1981, was a psychiatrist, regarded as one of the world's foremost authorities on schizophrenia. He wrote, in "A Personal Journey", of the truth and history of schizophrenia...a history which has not changed in the 101 years since his birth. Speaking for those who suffer this treatable but seemingly forever intractable mental illness, he said :
"No war in history has produced so many victims, wounded so many people. No earthquake has exacted so high a toll. No other condition has deprived so many people of the promise of life."

The late Dr John Cade, a Melbourne psychiatrist, was a brilliant man who discovered the values of lithium and its use as a medication for the severely mentally ill. Lithium began to be used globally for the mentally ill and Dr Cade defined their suffering. *"Depression is the most painful illness known to man, equalling even the most exquisite physical agony".*

The Heart of the Matter

The World Health Organisation (WHO) states the seriously mentally ill [SMI], suffering schizophrenia, bipolar and other affective disorders, make up 1.5 to 2% of the global population. Australia, then, has some 345,000 SMI with these disorders.

Last month the Australian Institute of Health and Welfare reported 89,500 hospital beds were available in Australia. It stated Victoria has one psychiatric hospital for our 5,000,000 people. There are 790 psychiatric beds for our 345,000 seriously mentally ill. The late Dr Jean Lennane wrote of our SMIs' treatment "It saves a lot of money if you don't treat them. They end up homeless, on the streets or in jail or dead by preventable suicide. It's an enormous amount of money saved quickly". The most common factor in suicide is mental illness. Suicide among our young and very ill increases as funding and care deteriorate.

The RANZCP states "The College believes that unrelievable psychiatric suffering is rare.". Many of us, having lost a son or daughter to suicide after years of suffering, after previous attempts to die by suicide, watching their pain as capacity disappears, talent disappears, creativity disappears, are appalled by that statement. What does the College believe has happened to the 2,550 who yearly die by suicide? It occurs, College Fellows, because they have endured so much unrelieved psychiatric suffering that "life is not worth keeping"! It is not rare, it exists until their death allows peace...A peace you did not and could not give them.

Dr Jamison describes schizophrenia in "Night Falls Fast". *"The gradual disintegration of a mind is almost incomprehensible. To observe its unwinding from within is surely intolerable. To be frightened of this world, to be walled away from it, harangued by voices, to see life as assorted shapes and colours, to lose constancy and trust in one's brain: the death by suicide is not a gentle death-bed gathering. It rips apart beliefs and sets the survivors on a prolonged and devastating journey. The core of this journey has been seen as an agonising question".*

This, I have escaped. I have never, since being told of my daughter Anne's death by suicide, asked "why". I knew. She had lived with schizophrenia for more than ten years. This was her third attempt to find peace. Our family's life, the lives of many people I know who have lost a child to suicide, would be quite different if our children had aid such as PAS. Indeed, PAS may be described as a panacea for all to whom it is given, Do not stint its gift of peace.

The Heart of the Matter

The Committee has the opportunity, by approving PAS, of not only offering a desired death without violence or solitude, but also a final day of quiet intimacy, enclosed by loved ones, a wholly contented passing from an intolerable life to its peaceful end in an environment of choice; this enables parents and family to lead a life, certainly of loss, but without the permanent, painful memory of a solitary death by violent suicide.

I believe PAS will become a legal manner of death. The “Matter” of concern is that our SMI must be a part of this, as much a part as those who suffer an intolerable, terminal physical disease. Their case is as sound! “No other condition has deprived so many people of the promise of life”.

Every year, 5,000 more parents face the suicidal, lonely death of their child. You, our Committee, cannot lower the number of suicides. But your final decision re PAS has the potential to enable thousands of people to find a life of peace and acceptance. That final day of love and care, when their child died, accepting of peace, will also give parents and family peace.

A major problem re PAS legislation for our mentally ill may well be the attitude of the RANZCP and other professional bodies; opposition based on the ‘mentally incompetent’ point of view. Our children were mentally ill, but that does not preclude sanity. Even at her most depressed, Anne was mentally competent, rational and sensible; though periods of paranoia and psychosis came, they were lived through. She succeeded in winning an art prize after 7 years of schizophrenia. That talent was gradually lost. Our last long day together, two days before her death, we spent talking, writing a letter to be placed in her medical file, asking she not be discharged...she was concerned about waiting one more week before leaving.

After I obtained her medical file I found she was discharged the next day without a medical risk assessment, that her doctor had written nothing about her condition in that file for the prior 16 days. The letter was not placed in the file. Anne, after 10 years of schizophrenia, died the next day, having made the mentally competent decision to leave her life, at this time “not worth keeping”. All the parents I know agree with me, our child decided rationality, “I can’t take any more”.

This morning, July 23rd, several of us had the pleasure of hearing from Professor Paul Komesaroff, Professor Sweressin and our Committee. Statements, questions and answers were most interesting. His telling words made a connection to what this page contained.

He told us “People once wanted to die at home. We now have a different trajectory for death than we did 100 years ago”. The complexities of medical care do change. The 20th century was a period of great medical research . It was also a century full of change...perhaps the greatest ones being in health care and an increased life expectancy.

This change was explored, with great patience, by the Australian New Zealand Health Policy. In July 7th, 2010, the organisation published a research paper “The trend in mental health-related mortality rates in Australia, 1916-2004: implications for policy”. 1916 was the first year that statistics were available concerning the welfare of Australia’s mentally ill people. This is a painstaking work of some 30 pages covering 88 years of medical record and history. The authors are Darrel P. Doessel, Ruth F G Williams and Harvey Whiteford.

In the five years since the Report was published I have been unable to find, in the media or medical papers, any comments on this research.

The authors’ conclusion is harrowing...“This study finds the temporal trend in mental health-related mortality rates (which reflects the longevity of people with a mental illness) has worsened through time. There are no gains.”

The authors note “PYLL [potential years of life lost] calculation shows mental health-related mortality is a proportionately greater cause of death compared with applying headcount metrics”.

In 88 years of the 20th and 21st centuries...There are no gains, and years of life lost increase.

The different trajectory for death, noted by the Professor, has in no way touched our severely mentally ill. Australia, land of the ‘fair go’. But not for all.

The New York Times, “Choosing How We Die”, July 24th, 2015

<http://www.nytimes.com/2015/07/24/opinion/choosing-how-we-die.html>

Written By Theresa Brown

“Patients have little guidance re end of life choices and doctors have little incentive to offer it. On July 8th the Centers for Medicare and Medicaid Services proposed a rule that would reimburse physicians for discussing “advance care planning” ... with Medicare patients. After a public comment period, it is proposed to go into effect by January 1st...

There are no “right or wrong” answers - only what is right or wrong for each individual patient – and physicians should be paid for discussing these options because they are hard, long conversations to have. [As Professor Swerissen said]...

The new proposal arguing for reimbursement acknowledges that... payment is much more likely to make these conversations happen when they should... the reigning presumption in our health care system is that treatment, no matter how hopeless or torturous, must be pursued, and that life, no matter how compromised, must be preserved...

Life is precious, so such attitudes are understandable. The problem is... that many ill patients would choose differently if their choices were truly informed...

And that’s what all this comes down to. The new rule has the potential to give the sickest among us the ability to say “This is what I want.”...

We all have only one life and one death. There is so much about life’s end that we can’t control; surely we deserve the chance to learn about and plan for the part that we can”

Theresa Brown, a hospice nurse, is the author of “Critical Care: A New Nurse Faces Death, Life and Everything in Between.”

NYT “Medicare to Try a Blend of Hospice Care and Treatment”

“Most older Americans close to death have to make a difficult choice; continue with traditional medical treatment or with hospice care.

Now Medicine is testing a third alternative: both. The new pilot program, designed to affect the care of about 150,000 Medicare patients over the next four years, will allow patients with terminal diseases to receive hospital care to manage suffering, and counselling to plan for end of life--but still see doctors and get medical treatments like chemotherapy and hospitalization, intended to fight their illnesses.

The test program is based on research which shows that patients with access to palliative care and traditional medicine often end up with a better quality of life and less expensive, intense medical treatment. The approach may even offer the patients a longer life span than those treated with traditional medicine alone.

The question of how to mix palliative care, intended to manage patients' symptoms, and curative care to fight disease, has been studied in 3 randomized trials of cancer patients. All showed benefits to the approach.

There are risks...that hospice providers may sign up patients who do not need these services.

Written by Margot Sanyer Katz. NYT, 27/7/2015