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Should Australia Adopt the Groningen Protocol?

Considering the effects of legalising assisted dying on persons with disabilities who cannot consent.

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1. Introduction

With recent developments creating physician assisted suicide lawful around the world[1] and politician's Bills being introduced in Australia[2] and the United Kingdom,[3] it is not surprising the debate on euthanasia and assisted suicide is being constantly revived. Nancy Fitzmaurice was a 12 year-old child born with hydrocephalus, meningitis and septicaemia and was blind, could not walk, talk, eat or drink and was in need of constant care.[4] In late 2014 her mother, Charlotte Fitzmaurice, was allowed to euthanise her on the grounds she was in too much pain and was suffering.[5] This was despite being given morphine and ketamine to assist with the pain while she was being treated at London's Great Ormand Street Hospital.[6] Charlotte spoke of the 'light from her [daughter's] eyes'[7] leaving and being 'replaced with fear and a longing to be at peace.'[8] It was the first decision involving a child who was still breathing by themselves and not on life support being allowed to die.[9] It bears the question of whether the decision to terminate the life of a disabled person should be that of their loved ones and doctors, the courts or a combination of all.[10] The underlying issue lies with understanding when a person has capacity to make the decision for

[1] *Carter v. Canada (Attorney-General),* 2012 BCSC 886.
[2] Greens, *Committee Calls for Conscience Vote on Dying with Dignity* (10 November 2014) < http://greens.org.au/node/6469>.
[3] Campaign for Dying with Dignity, *Lord Falconer's Assisted Dying Bill* <http://www.dignityindying.org.uk/assisted-dying/lord-falconers-assisted-dying-bill/>.
[4] Cassy Fiano, *Mother wins case to kill her disabled* daughter (October 27, 2014) Live Action News< http://liveactionnews.org/mother-wins-case-to-kill-her-disabled-daughter/> .
[5] Ibid.
[6] Ibid.
[7] Ibid.
[8] Ibid.
[9] NBC News, *Juvenile Death with Dignity? U.K. Case May Hurt Aid in Dying Push* (7 November 2014) NBC News (Online) <http://www.nbcnews.com/health/health-news/juvenile-death-dignity-u-k-case-may-hurt-aid-dying-n242961>.
[10] The term 'court' will be used as an interchangeable term referring to the judiciary and administrative and other tribunals.

themselves or when substitute consent needs to be brought in;[11] and with capacity being fluid, how is this assessed?[12] Currently the law in Australia, seems to permit withdrawing and withholding treatment that may save a life is permissible with consent of either the patient[13] or through substitute consent.[14] If laws on euthanasia and assisted dying are passed in Australia, how will this affect Australian's with disabilities that also lack the capacity to consent?

Through a critical analysis of the legislative history and precedents of assisted dying, the views of opponents and proponents of legally being able to assist disabled persons who lack the capacity to consent to assisted dying will be discussed. The Dutch *Groningen Protocol* will be analysed to consider whether this method should be adopted in Australia, and if it is, the framework in which it would possibly operate. It will be demonstrated that abuse of vulnerable persons, such as those with disabilities, is unlikely to occur in the legal framework set out in Australia due to the existing safeguards present in statute and common law. The divide between the legislature and judiciary will demonstrate the ethical dilemma in determining whose decision ultimately it will be to assess the capacity of disabled persons seeking assisted dying for themselves or a disabled relative.

[11] Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Issues Paper 44, November 2013.
[12] Ibid.
[13] Adeline Tran, (Honours Thesis, Charles Darwin University, 2015) 21-25.
[14] See, *Guardianship and Management of Property Act 1991* (ACT); *Guardianship Act 1987* (NSW)*; New South Wales Trustee Guardianship Act 2009* (NSW); *Adult Guardianship Act 1988* (NT); *Guardianship and Administration Act 2000* (Qld)*; Powers of Attorney Act 1998* (Qld)*; Guardianship and Administration Act 1993* (SA); *Guardianship and Administration Act 1995* (Tas); *Guardianship and Administration Act 1986* (Vic); *Guardianship and Administration Act 1990* (WA).

2. Background

Euthanasia is a term commonly used to describe a variety of scenarios which some argue should be separated and treated differently.[15] The word euthanasia is believed to have derived from the Greek words '*eu'* and '*thantos'* meaning 'well/good' and 'death' as a term used to describe mercy killings of loved ones suffering enduring illnesses during the sixteenth century.[16] Hippocrates developed the medical ethics code around 400BC, which demonstrates the killing of another human being has been considered immoral[17] even when the other person has requested to end their own life.[18] The Code states: 'I will neither give a deadly drug to anybody if asked… nor will I make suggestions to this effect.'[19] Despite this there is evidence that support for voluntary euthanasia has risen in Australia to an astonishing 85% in recent years.[20] Numerous Australian States[21] have attempted to pass laws on euthanasia unsuccessfully, usually stemming down to the belief there are not enough adequate safeguards in place to protect vulnerable persons.[22] This paper will prove these fears are unfounded in Australia's medical-legal framework through adequate safeguards, although it should be improved.

[15] John Griffiths, 'Physician-Assisted Suicide in the Netherlands and Belgium' in Dieter Birnbacher and Edgar Dahl (eds), *Giving Death a Helping Hand*: *Physician-Assisted Suicide and Public Policy. An International Perspective* (Springer, Volume 38, 2008) 77-86.
[16] George J.Marlin, *The Politician's Guide to Assisted Suicide, Cloning and Other Current Controversies* (Morely Books, Washington DC, 1998) 66.
[17] Peter Tyson, *The Hippocratic Oath Today* (27 March 2001) Public Broadcasting Services < http://www.pbs.org/wgbh/nova/body/hippocratic-oath-today.html>.
[18] Ibid.
[19] Fr. Paul Marx O.S.B, Ph.D., *And Now… Euthanasia* (Washington, DC, 2nd Ed, 1985) 10.
[20] Australian Associated Press, '85 per cent Support Voluntary Euthanasia – Poll' *The Australian* (online) 26 October 2009 <http://www.theaustralian.com.au/news/latest-news/per-cent-support-voluntary-euthanasia-poll/story-fn3dxiwe-1225791455181>.
[21] See, eg, *Dying with Dignity Bill 2009* (Tas); *Ending Life with Dignity (No 2) Bill 2013* (SA); *Rights of the Terminally Ill Bill 2013* (NSW); *Medical Treatment (Physician Assisted Dying) Bill 2008* (Vic).
[22] Southern Cross Bioethics Institute, *Non Voluntary Euthanasia*, Southern Cross Bioethics Institute <http://www.bioethics.org.au/Resources/Online%20Articles/Other%20Articles/Non-voluntary%20euthanasia%20in%20Australia%20-%20Brian%20Pollard's%20fourth%20Document.pdf>.

The debate over euthanasia is a heated discussion weighing in and raising a myriad of intertwining ethical, legal, social, political and moral issues.[23] The crux of the debates typically turn to the right of autonomy[24] over one's own body combined with the perceived right to choose when to die[25] verse the competing right to life.[26] Additionally, the assessment of mental capacity of the patient is a complex undertaking[27] which must not be taken lightly. Intellectual disability is the most common primary disability reported in Australia[28] as the concept of disabilities has widened from individual insufficiency to 'functional and environmental considerations' of the person.[29] Furthermore, the fluctuating nature of capacity[30] needs to be assessed as a patient may be able to make decisions at certain times of the day and not others, due to their ability to comprehend simple decisions versus decisions with high consequences.[31] The case of Nancy mentioned above, illustrates a potentially troubling precedent where a person not on life support and not diagnosed with a terminal illness[32] was allowed to be euthanised by their loved one. Cases such as Nancy's push the discussion on euthanasia from the question of legalising it to the logistics of who decides whether the patient has the capacity to consent for themselves, or whether substitute consent is needed. Should courts hear all matters where capacity is an issue to

[23] Alexander Smith, 'Euthanasia: The Strengths of the Middle Ground' (1999) 7 *Medical Law Review* 194, 195.
[24] Michael Douglas, 'An Absurd Inconsistency in Law: Nicklinson's Case and Deciding to Die' (2014) 21 *Journal of Law and Medicine* 627, 638.
[25] Leon R. Kass, 'Is There a Right to Die?' (1993) Volume 23 No. 1, *The Hastings Center Report*, 34-43.
[26] See, Dieter Birnbacher and Edgar Dahl (editors), *Giving Death a Helping Hand*: *Physician-Assisted Suicide and Public Policy. An International Perspective* (Springer, Volume 38, 2008).
[27] Claudia Camden-Smith, 'Mental Capacity and Assisted Suicide: To what exent can mental capacity be reliably assessed in patients seeking physician-assisted suicide?' (2010) *Living and Dying Well (Online)* <http://www.livinganddyingwell.org.uk/sites/default/files/Report%20-%20Mental%20Capacity%20and%20Assisted%20Suicide.pdf>.
[28] Australian Institute of Health and Welfare, 'Disability in Australia: intellectual disability' (2008) 67 *Australian Government (Online)* <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442452891>.
[29] Ibid.
[30] Rebecca Jacob, Michael J Gunn and Anthony Holland (eds), *Mental Capacity Legislation: Principles and Practice* (RCPsych Publications, 2013) 99.
[31] Ibid.
[32] Andy Jones, *Disability rights group responds to Nancy Fitzmaurice case* (5 November 2014) Rooted In Rights <http://www.rootedinrights.org/disability-rights-group-responds-to-nancy-fitzmaurice-case/>.

ensure the patient's best interests are being met? [33] Or should it be left up to the patient's doctors and their loved ones?

I. DEFINITIONS

'Euthanasia' is used to describe acts where the physician injects the patient with a lethal drug directly causing the death of the patient.[34] The term is also frequently, and arguably incorrectly, used to describe 'physician assisted suicide'[35] where the physician gives the lethal drug to the patient to take themselves.[36] Many argue the distinction between the two is irrelevant to the moral evaluation of the acts[37] whilst others believe the distinction is critical[38] as patients who are not capable of taking the lethal drug themselves cannot have physician assisted suicide as an option for ending their lives.[39] Furthermore, euthanasia can be 'voluntary', 'involuntary' or 'non-voluntary' depending on the level of competence of the patient.[40] The term 'assisted dying' has been used to mean acts of physician assisted suicide and euthanasia in all of its forms.[41]

The terms of 'doctrine of double effect' and 'advanced medical directive' should also be noted. The doctrine of double effect is where palliative care for a patient is taken and death is hastened *unintentionally*[42]*;* this method is arguably considered legal in Australia.[43]

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[33] *Secretary, Department of Health and Community Services v JWB and SMB (Marion's Case)* [1992] 175 CLR 218.
[34] John Keown, *Euthanasia, Ethics and Public Policy: An Argument Against Legislation* (Cambridge University Press, 2002) 10-11.
[35] John Griffiths, above n 14, 77.
[36] John Keown, above n 33.
[37] John Griffiths, above n 14, 77.
[38] Ibid.
[39] Ibid.
[40] BBC, *Voluntary and involuntary euthanasia,* BBC (online) <http://www.bbc.co.uk/ethics/euthanasia/overview/volinvol.shtml>.
[41] *Assisted Dying for the Terminally Ill Bill* (2004) United Kingdom.
[42] George Williams, *Changing mind on the right to die* (25 February 2015) The Drum <http://www.abc.net.au/news/2015-02-25/williams-euthanasia/6261884>.

Advanced medical directives have been implemented in certain Australian jurisdictions, such as the Northern Territory,[44] to provide persons with capacity to make a decision about their health, finance and end of life circumstances before they lose capacity.[45] For the purposes of this paper non-voluntary assisted dying will be the focus; where the act can be aided by the patient's physician or their loved ones without the consent of the patient.

3. The Groningen Protocol

I. NETHERLANDS HISTORY

Although Australia currently does not have any laws allowing for either euthanasia or physician assisted suicide, the Netherlands has prided itself on its innovative laws allowing for both.[46] In the 1990s both acts of euthanasia and physician assisted suicide were liable for prosecution unless strict guidelines were adhered to in the Netherlands.[47] Despite the illegality of euthanasia and physician assisted suicide it seems that Dutch courts have not provided a clear judgement on the matters since 1984[48] when the Supreme Court allowed the doctrine of *force majeure* to be applied in circumstances.[49] Due to the view of the 'physician's duty to assist a terminally ill patient outweigh[ing] his or her duty to adhere to the law'[50] the Dutch Medical Association combined with the Nurses Association developed

[43] Adeline Tran, above n 11, 21-25.
[44] *Advance Personal Planning Act 2014* (NT).
[45] Northern Territory Government, *Advanced Personal Planning* (24 November 2014) <http://www.nt.gov.au/justice/pubtrust/app/index.shtml>.
[46] George J. Marlin, above n 15, quoting W.C.M Klijn Dutch Professor of Medical Ethics, 80.
[47] David Jeffrey, *Against Assisted Suicide: a palliative care perspective*, (Radcliffe Publishing United Kingdom, 2009) 69.
[48] See, Felipe E. Vizcarrondo MD, MA, FCP, *Neonatal Euthanasia: The Groningen Protocol* (February 2014) American College of Paediatricians <http://www.acpeds.org/the-college-speaks/position-statements/life-issues/neonatal-euthanasia-2>.
[49] Parliamentary Library Research Service, 'Medical Treatment (Physician Assisted Dying) Bill 2008' (Current Issues Brief No. 2,2008, Parliamentary Library, Victoria, June 2008) 31.
[50] Ibid.

the 'Guidelines for Euthanasia' in 1986.[51] In 2002 both forms of assisted dying were legalised for patients who are 'suffering unbearably'[52] with the enactment of the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act*. It should be noted that under the Dutch Penal Code,[53] and the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act,* euthanasia and physician assisted suicide are criminal offences[54] unless conducted by a physician[55] who satisfies the relevant requirements[56] for patients 12 years and older.[57] This means that to avoid prosecution the act of assisting death must be conducted by a physician.

The primary requirement of suffering unbearably[58] is in stark contrast to the primary concern with patients of physician assisted suicide in Oregon, and proponents in Australia, who are largely concerned with autonomy.[59] A problem with this is that suffering is a subjective[60] and what may be unbearable to one person may be tolerable to another.[61] David Jeffery stated that 'Dutch physicians appear to have the power to decide whether the suffering is unbearable even if the patient is not requesting or cannot request euthanasia or physician assisted suicide.'[62] He goes on to remark in *Against Physician Assisted Suicide: a palliative care perspective* that in 2005 there were 2,297 deaths as a result of euthanasia and 113 due to physician assisted suicide with 452 of these deaths resulting from patients

[51] Ibid.
[52] *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* (Netherlands) ch 4-A.
[53] Parliamentary Library Research Service, above n 48.
[54] *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* (Netherlands) chs. 4-A, 4-B.
[55] Ibid, chs 4-A.
[56] Ibid.
[57] Ibid.
[58] Ibid.
[59] Oregon Public Health Division, *Oregon's Death with Dignity Act- 2014*, Death With Dignity National Centre, 2014 Report.
[60] Dr Verhagen and Dr Sauer, 'The Groningen Protocol- Euthanasia in Severely Ill Newborns' (2005) *The New England Journal of Medicine* (online) <http://www.nejm.org/doi/full/10.1056/NEJMp058026#t=article>.
[61] David Jeffrey, *Against Physician Assisted Suicide: a palliative care perspective* (Radcliffe Publishing, 2009)17.
[62] Ibid, 70.

who had no given consent.[63] Alarmingly, the State Commission on Euthanasia in 1987 argued that non-voluntary euthanasia should not be an offence in an already euthanasia accepting society[64] despite consent, whether by the patient directly or through substitute consent, is clearly a requirement for assisted dying to not constitute murder.[65]

The Netherlands have debated extensively on the medical treatments open to incompetent patients, particularly in light of end of life treatments.[66] The striking difference in the Netherland's approach compared to all other jurisdictions is however, that they seem more accepting of euthanasia and physician assisted suicide in all its forms.[67] As will be discussed below, the Netherlands have adopted a protocol which enables physicians to, in circumstances,[68] euthanise children with disabilities.[69] Although it is argued that the Protocol is misunderstood and is 'both ethical and also the most humane alternative for these suffering and dying infants'[70] practice has shown that the Protocol has led to unintended abuse and the termination of life of children with non-severe disabilities.[71] If the Protocol were to be adopted in Australia, would existing laws aide in ensuring abuse found in the Netherlands does not occur? In the case with Nancy Fitzmaurice, under the Protocol, Charlotte Fitzmaurice would have been able to euthanise her non-terminally ill child without

[63] Ibid.
[64] Southern Cross Bioethics Institute, above n 21.
[65] Ibid.
[66] Sjef Gevers, 'Euthanasia: law and practices in The Netherlands' (1996) 52 (No. 2) *British Medical Bulletin* 326-333, 1.
[67] George J. Marlin, above n 15, 81.
[68] Dr Verhagen and Dr Sauer, above n 59.
[69] Ibid.
[70] B A Manninen, 'A case for justified non-voluntary active euthanasia: exploring the ethics of the Groningen Protocol' (2006) 32 (11) *J Med Ethics* Online < http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2563300/>.
[71] Mark Leach, *Gosnell, after-birth abortion, and Down Syndrome* (May 16, 2013) Down Syndrome Prenatal Testing < http://www.downsyndromeprenataltesting.com/gosnell-after-birth-abortion-and-down-syndrome/ >.

going to the courts for permission first.[72] Is this the method Australia should adopt when legalising assisted dying?

II. THE PROTOCOL

In 2005 the Groningen Protocol ('the Protocol') was developed in consultation with the Dutch District Attorney and the University Medical Center Groningen in the Netherlands to ensure strict guidelines were in place for physician assisted suicide of infants with illnesses and disabilities.[73] The Protocol outlines the medical requirements[74] along with the information needed[75] to support the making of the decision by the parents and the medical team, combined with an independent practitioner, [76] in the ending of the infant's life.[77]

Although the Protocol, as used within the Netherlands is for the purpose of deciding whether seriously ill neonates[78] should have their life terminated,[79] for the purposes of this paper the Protocol will be analysed with reference to all persons who do not have the capacity to consent to assisted dying due to disabilities.

[72] Dr Verhagen and Dr Sauer, above n 59.
[73] Dr Verhagen and Dr Sauer, above n 59.
[74] Ibid.
[75] Ibid.
[76] James E. Wilkinson, *Position Paper on the Groningen Protocol: Disability Stereotypes, International Human Rights and Infanticide* (2011) International Federation for Spina Bifida and Hydrocephalus <http://www.ifglobal.org/images/stories/groningen-d.pdf>.
[77] Felipe E. Vizcarrondo MD, MA, FCP, *Neonatal Euthanasia: The Groningen Protocol* (February 2014) American College of Paediatricians <http://www.acpeds.org/the-college-speaks/position-statements/life-issues/neonatal-euthanasia-2>.
[78] Ibid.
[79] Dr Verhagen and Dr Sauer, above n 59.

Dr Verhagen, the clinical director/attorney, and Dr Sauer, chairman of the paediatrics department of the University Medical Center Groningen state the Protocol only applies to persons in three categories:[80]

1. Persons with no chance of survival;
2. Persons with a poor prognosis and are dependent on intensive care; and
3. Persons with a hopeless prognosis who experience what family and medical experts deem to be unbearable suffering.[81]

Table 2 of the Protocol, in Annexure 1, sets out the requirements which must be filled in order to use the Protocol as well as the supporting information which must be provided to ensure that justification of the termination of life is present to avoid prosecution.[82] Within the Netherlands persons over the age of 16 may request euthanasia in circumstances similar to that proposed by the Protocol.[83] The Protocol requires that 'all possible measures must be taken to alleviate severe pain and discomfort'[84] before determining the life of the disabled patient cannot have suffering relieved[85] and no improvement can be expected of their condition.[86] In determining this, the Protocol requires that the patient's physician, along with an independent physician's second opinion on the prognosis of the patient, must come to the same conclusion that assisted dying is acceptable in the circumstances.[87] The consultations must also provide the method of assisted dying to be prescribed as well as the

[80] Ibid.
[81] Dr Verhagen and Dr Sauer, above n 59.
[82] Ibid, Table 2.
[83] Ibid.
[84] Ibid.
[85] Manninen,, above n 69.
[86] Dr Verhagen and Dr Sauer, above n 59.
[87] Ibid.

time, place and participants of the procedure and reasons for the method chosen.[88] In order to make the decision to terminate of the patient's life, there does not need to be a terminal illness – only that there is suffering which is '[h]opeless and unbearable'.[89] An issue with this is there is no definition of the terms 'suffering' and 'unbearable pain' within the Dutch framework.[90] Evidence suggests the Dutch understand the implied meaning of the 'soft or vague criteria in the law'[91] despite their subjective nature. As argued by slippery slope opponents of assisted dying, this implied meaning will inherently lead to abuse and murder of vulnerable persons such as the disabled with a lack of capacity.[92]

Opponents of legalising assisted dying argue the Groningen Protocol is a step towards the 'slippery slope'[93] they so desperately wish to avoid. The question is whether by legalising voluntary assisted dying and the Protocol, has society accepted the act of non-voluntary assisted dying as lawful with it? And more importantly, if it has done so in the Netherlands, would Australia also be so accepting if it had similar laws? The 'slippery slope' argument falls into two related arguments:[94] that by accepting voluntary assisted dying, acceptance of non-voluntary assisted dying is naturally a consequence over time,[95] and; that there will never be adequate safeguards in practice to prevent the slide.[96] Similarly, the Protocol has been likened to a 'Hitleresque types of eugenics programme'[97] for parents 'who don't want

[88] Ibid.
[89] Ibid.
[90] James E. Wilkinson, above n 77, 5.
[91] A.Klijn, F. Mortier, M. Trappenburg, M. Otlowski (editors), *Regulating Physician-Negotiated Death* (Elsevier, 2001) 4.
[92] John Keown, 'Euthanasia in the Netherlands: Sliding Down the Slippery Slope?' (1991) Vol 338, Issue 8773 *The Lancet*, 407, 407.
[93] Ibid.
[94] Ibid.
[95] Ibid.
[96] Yale Kamisar, 'Some Non-Religious Views against Proposed Mercy-Killing Leglisaltion' (1958) Vol 42:969, *Minnesota Law Review,* 969, 976.
[97] B A Manninen, above n 69.

to contend with raising a disabled child'[98] irrespective of whether they could have had a meaningful life.[99]

These propositions can be considered absurd in the context of Australia, as there is no evidence of the existence of the slippery-slope[100] in Australia's unregulated assisted dying practice.[101] The recent decision involving Doctor Philip Nitschke was hoped to shed light on consequences on physicians assisting non-terminally ill patients to die,[102] but instead has proved to cause further uncertainty. In July 2015 the Northern Territory Supreme Court overturned the suspension of Dr Nitschke's medical licence by the Medical Board of Australia over the death of Mr Nigel Brayley.[103] Mr Brayley approached Dr Nitschke at a workshop in February 2014 and spoke of wishing to have access to 'the means of a peaceful and reliable death'[104] and subsequently bought the lethal drug, Nembutal, illegally from China.[105] Mr Brayley also bought from Dr Nitschke's organisation, Exit International, an 'Exit Dilution Purity Test Kit'[106] which tests the purity of Nembutal.[107] Via email correspondence in April 2014 Mr Brayley alerted Dr Nitscke that he was not terminally ill but was suffering[108] to which the response was: 'Thank you very much for your information, and I will be

[98] Ibid, quoting Bar B. 'Euthanasia … or a 'Dutch Treat?' <http://www.washtimes.com/commentary/20041226-123251-5015r.htm>.
[99] Ibid.
[100] Victoria Hiley, *In Pursuit of a Good Death: Responding to Changing Sensibilities in the Context of the Right to Die Debate* (PhD Thesis, The University of Sydney, 2008) 229.
[101] Charles Douglas, 'The Intention to Hasten Death: A Survey of Attitudes and Practices of Surgeons in Australia' (2001) 175 (10) *Medical Journal of Australia* 511.
[102] Adeline Tran, above n 11, 28.
[103] Craig Butt, 'Court Finds Philip Nitschke's medical licence suspension unlawful', *The Sydney Morning Herald* (online) 6 July 2015 <http://www.smh.com.au/national/health/court-finds-philip-nitschkes-medical-licence-suspension-unlawful-20150706-gi6cdd.html>.
[104] *Nitschke v Medical Board of Australia* [2015] NTSC 39, 74 per Hiley J.
[105] Ibid.
[106] Ibid.
[107] Ibid.
[108] Ibid.

interested in your final statement.'[109] The Medical Board of Australia decided to suspend Dr Nitschke's medical license on the basis he '[f]ailed to respond in an appropriate manner'.[110] Justice Graham Hiley stated the Health Professional Review Tribunal, which upheld Dr Nitschke's suspension, had 'misconstrued'[111] the code of conduct in imposing an obligation on Dr Nitschke to 'assess, treat or refer Mr Brayley'[112] who was not a patient of his.[113] Due to an error in the law[114] the Northern Territory Supreme Court did not rule on the legality or ethical dilemmas of assisting non-terminally ill patients to die.[115]

Despite suffering being a subjective feeling each individual experiences uniquely in a manner which may not be experienced by anyone else, the Protocol uses this as the means test[116] for selecting patients eligible for assisted dying. Dr Verhagen and Dr Sauer, in writing the Protocol, accepted that competent adults can express their unbearable suffering[117] when children,[118] and perhaps disabled adults, cannot express their suffering in the same manner. They believe through the 'different types of crying, movements and reactions to feeding'[119] combined with vital signs of the patient,[120] the amount of suffering and pain can be ascertained. Realistically, this is not an appropriate method of understanding whether a patient is suffering unbearably or is in pain. Methods of gaining understanding of a patient's

[109] Ibid.
[110] Ibid, 13.
[111] Ibid, 141 per Hiley J.
[112] Ibid, 1.
[113] Craig Butt, above n 104.
[114] Helen Davidson, 'Philip Nitscke says NT medical body is 'insufferably arrogant and paternalistic', *The Guardian* (online) <http://www.theguardian.com/australia-news/2015/jul/23/philip-nitschke-says-nt-medical-body-is-insufferably-arrogant-and-paternalistic>. Note: It was held that it was not up to the court or the tribunal to determine whether Nitschke's conduct amounted to professional misconduct; rather they needed to determine whether the conduct alleged amounted to a breach of the code of conduct.
[115] *Nitschke v Medical Board of Australia* [2015] NTSC 39.
[116] Dr Verhagen and Dr Sauer, above n 59,Table 2.
[117] Ibid.
[118] Ibid.
[119] Ibid.
[120] Ibid.

threshold are only useful when the patient is able to communicate with the physician in some way.[121] The primary argument and ethical justification proponents for legalising assisted dying is the concept of autonomy of persons[122] to have the choice to end their life with dignity.[123] The Groningen Protocol, by way of existence, abrogates this right that has been declared to exist in Australian common law.[124] Despite this acceptance of autonomy and being able to communicate the pain and suffering from the patient in order for assisted dying to be an option, the courts have declared in instances this is not enough. Mr Nicklinson suffered a catastrophic stroke which left him completely paralysed with exception of his eyes and head. He could only communicate through blinking and spelling words out letter by letter. He communicated by these means for some time that he wanted to end his life, describing it as 'dull, miserable, demeaning, undignified and intolerable' despite having a supportive network around him. As a result of his disabilities the only legal option for Mr Nicklinson to attempt to end his own life was through starvation – a slow, painful and inhumane way to die. He wished for a lethal drug to be administered to him by a doctor or through a machine Exit International Founder, Dr Philip Nitschke, designed. This would mean Mr Nicklinson could digitally activate the administration of the barbiturate via an eye blink computer. The Court refused Mr Nicklinson an order for a physician to lawfully assist him in dying[125] and he died of pneumonia after starving himself in late 2012.[126] How

[121] Letter to the Editor from Willem H.J. Martens, M.D., Ph.D to Med Law Editor, 'Recommendation of the Groningen Protocol for Euthanasia of Newborns with Unbearable Suffering and Unacceptable Quality of Life', 2008 < http://heinonline.org.ezproxy.cdu.edu.au/HOL/Page?handle=hein.journals/mlv27&div=74&start_page=925&collection=journals&set_as_cursor=0&men_tab=srchresults>.

[122] A B Jotkowitz and S Glick ' The Groningen protocol: another perspective' (2206) 32(3) *J Med Ethics* 157-158.

[123] Oregon Public Health Division, above n 58.

[124] See, *Ms B v An NHS Hospital Trust* [2002] All ER 362.

[125] Matthias Mueller, *Supreme Court hands down judgement in R (Nicklinson) v Ministry of Justice [2014] UKSC 38* (25 June 2014) Jordan Publishing < http://www.jordanpublishing.co.uk/practice-areas/private-client/news_and_comment/supreme-court-hands-down-judgment-in-r-nicklinson-v-ministry-of-justice-2014-uksc-38-25062014-029#.VhHzVvmqpBc>.

was it that the Courts could allow a disabled 12 year old child the right to be assisted in dying through substitute consent when a competent disabled adult could not be granted the same right? The distinction may lie within the International Conventions which protect the right to life for all persons and for persons with disabilities.

4. International Conventions

I. CONVENTION FOR THE PROTECTION OF HUMAN RIGHTS AND FUNDAMENTAL FREEDOMS

The Convention for the Protection of Human Rights and Fundamental Freedoms was declared in 1948 as a response to World War II by the United Nations.[127] Its aim is to achieve a unified international recognition of equal rights for all persons.[128] The Convention has been considered in many cases such as Pretty and Nicklinson to consider whether the basic human right to life encompasses the right to die,[129] and more importantly, whether it encompasses the right to assisted dying.[130]

In the matter of Diane Pretty v United Kingdom the European Court of Human Rights stated:

> 'In an era of growing medical sophistication combined with longer life expectancies, many more people are concerned that they should not be forced to linger on in old age or in states of advanced physical or mental decrepitude which conflict with strongly held ideas of self and personal identity.'[131]

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[126] *R (Nicklinson) v Ministry of Justice* [2014] UKSC 38, 6.
[127] Aisha Gani, 'What is the European convention on human rights?', *The Guardian* (Online), 4 October 2014, <http://www.theguardian.com/law/2014/oct/03/what-is-european-convention-on-human-rights-echr>.
[128] Ibid.
[129] *R (Nicklinson) v Ministry of Justice* [2014] UKSC 38, 29.
[130] *Diane Pretty v United Kingdom* (2002) III Reports of Judgements and Decisions.
[131] *Diane Pretty v United Kingdom* (2002) III Reports of Judgements and Decisions, 36.

Diane Pretty suffered from motor neurone disease which left her debilitated and unable to end her life on her own[132] due to being paralysed from the neck down.[133] Pretty sought from the European Court of Human Rights the ability to have her husband lawfully assist her with suicide without the fear of him being prosecuted.[134] She argued that Article 8 of the Convention (the right to respect for private and family life)[135] provided a right to self-determination which was being violated by domestic law, namely the Suicide Act 1961 (UK), preventing her from assisted dying.[136] Lord Hope stated:

> 'Respect for a person's 'private life', which is only part of Article 8 which is in play here, relates to the way a person lives. The way she chooses to pass the closing moments of her life is part of the act of living, and she has a right to ask that this too must be respected. In that respect Mrs Pretty has the right of self-determination. In that sense, her private life is engaged even where in the face of terminal illness she seeks to choose death rather than life. But it is an entirely different thing to imply into these words a positive obligation to give effect to wish to end her own life by means of assisted suicide. I think that to do so would be to stretch the meaning of the words too far.'[137]

Mrs Pretty's case was deemed inadmissible. Similarly, Mr Nicklinson's case was also deemed inadmissible by the European Court of Human Rights declaring Article 8 of the Convention does not impose obligations on domestic courts to examine merits of a challenge brought in

[132] Ludwig A. Minelli, 'The European Convention on Human Right Protects the Right to Suicide' in Dieter Birnbacher and Edgar Dahl (eds), *Giving Death a Helping Hand*: *Physician-Assisted Suicide and Public Policy. An International Perspective* (Springer, Volume 38, 2008) 149.
[133] *Diane Pretty v United Kingdom* (2002) III Reports of Judgements and Decisions, 8.
[134] Ludwig A. Minelli, above n 133.
[135] *Convention for the Protections of Human Rights and Fundamental Freedoms*, opened for signature 4 November 1950, CETS No. 005 (entered into force 3 September 1953) art 8.
[136] *Diane Pretty v United Kingdom* (2002) III Reports of Judgements and Decisions, 58.
[137] *Diane Pretty v United Kingdom* (2002) III Reports of Judgements and Decisions, 15 (emphasis added).

respect of primary legislation.[138] It was argued that the prevention of assisted dying was inconsistent with the Convention, in particular Article 3: the right to life. The matter of *Re B (Consent to Treatment – Capacity)* was highlighted and demonstrates the perplex decision physicians and court's having in determining who has the capacity to consent to assisted dying. The applicant, B, was a tetraplegic who was completely dependent on life support machine's and wished to have the treatment withdrawn. [139] It should be reiterated that the ability to have treatment withdrawn or withheld is considered lawful[140] – it is the positive action by giving a lethal drug that is illegal. B's doctors refused to withdraw the treatment and subsequently she made an application to the court for an order to turn the machines off. Dame Elizabeth Bulter-Sloss P held that as long as the patient was in a fit mental state at the time of making the decision, then the decision was 'purely a matter for the [patient]'.[141] This matter demonstrates the complexity of assessing the fluid nature of capacity to consent to medical treatment. It can also be distinguished from that of *Pretty* and *Nicklinson* as, despite all applicants being paralysed, the latter two were *not* on life support; they each needed positive assistance to die, whereas B was on life support and merely needed the support withdrawn. This distinction has been noted as being discriminatory for those physically disabled yet mentally competent.[142] Yet where does the law stand for those that are both physically disabled and mentally incompetent?

II. THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (UNCRPD)

[138] *R (Nicklinson) v Ministry of Justice* [2014] UKSC 38, 164 per Lord Mance.
[139] Ibid, 301-305 per Lady Hale.
[140] *Airedale NHS Trust v Bland* [1993] 2 WLR 316 per Lords Keith, Goff, Browne-Wilkinson and Mustill.
[141] *R (Nicklinson) v Ministry of Justice* [2014] UKSC 38, 26.
[142] *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229 (Unreported, Martin CJ, 14 August 2009).

The United Nations Convention on the Rights of Persons with Disabilities aims to: '…promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.'[143]

The United Nations General Assembly saw in in 2001 that negotiations for a Convention on the rights of persons with disabilities was needed to ensure that respect and basic human rights are given to persons with disabilities internationally. The Convention was agreed to by the Committee in August 2006 with intention of the Convention coming into force on the thirteenth day after twenty member states ratified it.[144] Along with its Optional Protocol, the Convention was ratified by Australia on 17 July 2008.[145] The Convention aims to express the existing rights which should be applied to persons with disabilities in line with those afforded to all other human beings under the Universal Declaration of Human Rights. Despite this Declaration some 10% of the world's population is living with disabilities and being discriminated against into having lesser rights than non-disabled persons. Article 1 of the UNCRPD outlines the purpose of the Convention being to promote, protect and ensure that all human rights and fundamental freedoms are being afforded to all persons with disabilities. It further goes on to define a disabled person as being an evolving concept which deals with 'long-term physical, mental, intellectual or sensory impairment' and how this effects the person's interactions with various elements around them.[146]

[143] *United Nations Convention on the Rights of Disabled Persons*, opened for signature 30 March 2007, 2515 UNTS 3, art 1.
[144] Ibid, art 45 (1).
[145] People with Disability, *Key Pieces of Legislation* <http://www.pwd.org.au/student-section/key-pieces-of-legislation.html>.
[146] *United Nations Convention on the Rights of Disabled Persons*, opened for signature 30 March 2007, 2515 UNTS 3, art 1.

The affirmation that every human being, irrespective of whether they have a disability, has the inherent right to life is found within Article 10.[147] It states that all State Parties 'shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.'[148] This inherently is a continuation of Article 2 of the Convention on Human Rights and Fundamental Freedoms.

Article 12 of the Convention requires that persons with disabilities are recognised equally before the law[149] including having 'legal capacity on an equal basis with others in all aspects of life.'[150] The Article recognises that in some instances this may require support and provides that the required support in allowing persons with disabilities should be given to all persons requiring the services.[151] In order to prevent abuse of disabled persons acting with their legal capacity, it further provides that adequate and proportionate safeguards should be in place with 'review by a competent, independent and impartial authority or judicial body.'[152] In *Shtukaturov v Russia* the applicant had a history of mental illness and in 2003 was declared disabled. The applicant's mother was appointed as his guardian in 2004 when the applicant was declared legally incompetent to having capacity. Subsequently, the following year he was admitted to a psychiatric hospital where he argued he had unknowingly been deprived of his legal capacity and received medical treatment without consent.[153] This amounted to a violation of Article 8 of the Convention for the Protection of Human Rights and Fundamental Freedoms. Unlike in Australia however, the Russian

[147] Ibid, art 10.
[148] Ibid.
[149] Ibid, art 12(1).
[150] Ibid, art 12(2).
[151] Ibid, art 12(3).
[152] Ibid, art 12(4).
[153] European Court of Human Rights, 'Persons with disabilities and the European Convention on Human Rights' (Factsheet – Persons with disabilities and the ECHR, September 2015) 14.

legislation only recognised a dichotomy of full capacity and full incapacity of disabled persons and not the fluid nature of capacity. In order to comply with Article 12 of the UNCRPD, guardianship and administrative laws have been implemented in all States and Territories. These laws aim at balancing the right for disabled persons with impaired capacity to make their own decisions in accordance with their autonomy with the disabled person's right to having adequate support in the decision making process.[154]

5. AUSTRALIAN LAWS

In order to comply with the provisions of the numerous international conventions regarding human rights, and in particular, the rights of disabled persons, a system of guardianship and administration laws ('the Framework') has been enacted within Australia.[155] This Framework of legislation contains numerous safeguards which enable the prevention of abuse and exploitation of vulnerable persons.[156] The Framework starts with the common law presumption that all persons have capacity until found in the contrary; albeit some legislative instruments provide this in more simple terms than others.[157] The difficult task the Framework attempts to assist with is assessing when the capacity of a disabled person is impaired enough to either reduce the patient's capacity to make decisions either temporarily or permanently. This Framework is not a national system and as such each State

[154] Law Council Australia, *Australia's Initial Report under the Convention on the Rights of Persons with Disabilities* (May 2010) Law Council Australia <http://www.lawcouncil.asn.au/lawcouncil/images/LCA-PDF/corporate/Australia'sInitialReportundertheConventionontheRightsofPersonswithDisabilities.pdf>,18.
[155] Patricia Staunton and Mary Chiarella, *Law for Nurses and Midwives* (7 Ed, Churchill Livingstone 2013, 154.
[156] Law Council Australia, above n 155, 17.
[157] See, *Guardianship and Administration Act 2000* (Qld) sch 1, pt 1; G*uardianship and Administration Act 1990* (WA) s 4(2)(b).

and Territory features different mechanisms within its provisions.[158] A consequence of the non-uniform legislation is the differing methods and outcomes that naturally result from the various mechanisms provided, creating a somewhat non-cohesive area of law.[159] The differences lie within the circumstances in which guardianship (or administration) is required and what factors need to be taken into consideration when determining issues facing the patient.[160] Table A found in Annexure 2, breaks down the relevant sections of the Acts in the Northern Territory, New South Wales and the Australian Capital Territory for consideration.[161]

Current laws within Australia provide uncertainty to the withdrawal of life-sustaining treatment of intellectually disabled persons[162] without beginning to consider the difficulties of consenting to assisted dying. Some jurisdictions expressly provide provisions for the substitute consent to withhold or withdraw treatment[163] whilst others draw on the common law principles.[164] *Re BAH* involved a 56 year old woman with a mild intellectual disability combined with a terminal illness[165] whose doctors wished to include a non-resuscitation order in her end-of-life care regime.[166] It was held that in certain situations, the limiting of

[158] Office of the Public Advocate, 'Autonomy and decision-making support in Australia' (A targeted overview of guardianship legislation) Queensland Government, February 2014, 1.
[159] People with Disability Inc and Blake Dawson Waldron Lawyers, Submission Number 201089039_1 to Attorney-General's Department of NSW, *Are the rights of people whose capacity is in question being adequately protected?*, 7.
[160] Office of the Public Advocate, above n 159, 2.
[161] *Guardianship and Management of Property Act 1991* (ACT); *Guardianship Act 1987* (NSW)*; New South Wales Trustee Guardianship Act 2009* (NSW); *Adult Guardianship Act 1988* (NT); *Guardianship and Administration Act 2000* (Qld)*; Powers of Attorney Act 1998* (Qld)*; Guardianship and Administration Act 1993* (SA); *Guardianship and Administration Act 1995* (Tas); *Guardianship and Administration Act 1986* (Vic); *Guardianship and Administration Act 1990* (WA).

[162] Staunton and Chiarella, above n 156, 158.
[163] *Guardianship and Administration Act 2000* (Qld), s 63A. See also, *Natural Death Act 1988* (NT); *Medical Treatment (Health Directives) Act 2006* (ACT).
[164] Parliamentary Library Research Service, above n 48, 4.
[165] *Re BAH* [207] NSWGT 1.
[166] Ibid.

treatment, particularly palliative treatment, may be in the best interests of the patient.[167] Justice Morris supported this view in *Public Advocate v RCS (Guardianship)* at 74-75:

> 'The contrary argument is predicated upon the proposition that it is always in a person's best interests to live. I cannot accept this. Death is an inevitable consequence of life on this earth. When death stares one in the face or when treatment is futile, the person concerned or the trusted agent or guardian may conclude that it is in the best interests of the person to refuse medical treatment and to allow the person to pass away.'[168]

Issues within the current system stem from unsatisfactory recognition of levels of capacity and the non-uniformity of the legislation.[169] Although it seems settled in Australia that withholding or withdrawing treatment of an intellectually disabled person on life support is, in certain circumstances, in the best interest of the patient; can the same be said for actively ending their life? Jointly the People with Disability Australia and Blake Dawson Waldron Lawyers responded to the NSW's department of Attorney-General in stating issues surrounding the protection of the rights of persons with a need to have capacity assessed are two-fold.[170] Firstly, there is a need to have a consistent and unified approach in the assessment of legal capacity to ensure the correct information is being given to patients and their families and to enable a system of precedents with foreseeable consequences of decisions relating to assisted dying available for persons with no capacity.[171] Secondly, a

[167] Stauton and Chiarella, above n 156, 159.
[168] *Public Advocate v RCS (Guardianship)* [2004] VCAT 1880, 74-75 per Morris J.
[169] People with Disability Inc and Blake Dawson Waldron Lawyers, above n 160, 10.
[170] Ibid, 4-5.
[171] Ibid, 10.

method of assessing capacity should be established to provide a system of consistency across all jurisdictions in Australia.[172]

I. WHAT IS CAPACITY?

'The law does not prescribe any fixed standard of sanity as requisite for the validity of transactions. It requires, in relation to each particular matter or piece of business transacted, that each party shall have such soundness of mind as to be capable of understanding the general nature of what he is doing by his participation.'[173] – *Gibbons v Wright*

Firstly, in order to understand the complex legal system regarding guardianship in Australia the concept of legal capacity must be understood. The Macquarie Dictionary defines *capacity* as meaning: 'power, ability or possibility of doing something.'[174] Inconsistency within the legislative Framework in Australia show that the word is not defined in each jurisdiction.[175] The Northern Territory Act does not provide for any definition of 'capacity'[176] but does provide a definition for 'disability' to mean 'intellectual disability'.[177] The Australian Capital Territory legislation brings in the meaning of 'decision-making capacity' from the *Powers of Attorney Act 2006* (ACT)[178] as meaning: 'a person has ***decision-making capacity*** if the person can make decisions in relation to the person's affairs and understands the nature and effect of the decisions.'[179] It further goes on to define that a 'person has ***impaired decision-making capacity*** if the person cannot make decisions in relation to the person's affairs or does not understand the nature of effect of the decisions

[172] Ibid, 23.
[173] *Gibbons v Wright* [1954] HCA 17, 437.
[174] *The Budget Macquarie Dictionary* (The Macquarie Library Pty Ltd, 6th Ed 1 October 2013) 65.
[175] See, *Guardianship and Management of Property Act 1991* (ACT); *Guardianship Act 1987* (NSW)*; New South Wales Trustee Guardianship Act 2009* (NSW); *Adult Guardianship Act 1988* (NT).
[176] *Adult Guardianship Act 1988* (NT), s 3.
[177] Ibid.
[178] *Guardianship and Management of Property Act 1991* (ACT), s 2.
[179] Ibid, s 9(1) (emphasis added).

the persons makes in relation to the person's affairs.'[180] It is important to note that simply because a person has an intellectual disability it does not mean they no longer have capacity and are not able to give consent.[181] Guardianship laws are used when a person lacks the capacity to make decisions for themselves and requires assistance to do so;[182] it is somewhat concerning that there is no clear consensus as to term's use in guardianship laws.

The concept of capacity is commonly linked to the notion of autonomy[183] and to intellectual ability.[184] As discussed above, autonomy of the person is the cornerstone of the assisted dying debate and has been defined by the House of Lords as 'the ability to choose and the freedom to choose between competing conceptions of how to live.'[185] Proponents and opponents of legalising assisted dying alike are not opposed to the concept of patient autonomy being of importance. Victorian physician, Dr Rodney Syme believes that all patients who wish to end their life due to 'great suffering'[186] have a 'moral right'[187] to do so. Proponents argue the decision to end their own life to escape a terminal illness does not harm others.[188] Conversely, opponents view the act of asking another human being to assist with the death can have profound effects on the 'morality, public order and general welfare' of society.[189] The effects of legalising assisted dying on persons with disabilities who cannot

[180] Ibid, s 9(2) (emphasis added).
[181] *Secretary, Department of Health and Community Services v JWB and SMB (Marion's Case)* [1992] 175 CLR 218, 24.
[182] Victorian Law Reform Commission, *Guardianship,* Final Report 24 (2012) 98.
[183] Ibid, 99.
[184] Ibid.
[185] Parliamentary Library Research Service, above n 45,14.
[186] Ibid.
[187] Ibid.
[188] Ibid, citing P Singer, *Rethinking Life and Death: The Collapse of Our Traditional Ethics* (1994, Melbourne Text Publishing) 197, 15.
[189] Australian Christian Lobby, *Submission to the Senate Legal and Constitutional Committee's Inquiry into the Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008*, (2008) ACL, 7.

consent for themselves needs to be considered more.[190] Chief Justice Martin in *Brightwater Care Group (Inc) v Rossiter* considered having capacity encompasses more than merely being able to make a decision.[191] The ability to understand the various options available to the patient and being able to weigh the options with their consequences is paramount.[192] The Queensland Law Reform Commission stated there are three common criteria used to assess capacity: functionality, status and outcome[193] although this is not a requirement. Legislation and adequate safeguards need to be in place to ensure vulnerable persons do not have a sense of 'worthlessness and isolation'[194] and feel pressured into choosing assisted dying.[195]

For Australia's legislative instruments to work as intended, a relevant standard of capacity and a unified regime of assessing capacity should be implemented.[196] Guardianship precedents within the common law attempt to shed insight into the possible consequences of assisted dying legislation for persons with disabilities who lack capacity to consent. Furthermore, it illustrates the complexity of the task and issues which have already arisen in medical treatment matters for disabled persons without capacity in recent years.

II. MARION'S CASE

The High Court of Australia was required to hand down a judgment on the matter known as *Marion's Case* in early 1992. Chief Justice Nicholson stated in an interview the matter was

[190] Craig Wallace, 'Euthanasia: let's look at the bigger picture', *ABC* (online) 21 January 2013 <http://www.abc.net.au/rampup/articles/2013/01/21/3673497.htm>.
[191] *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229 (Unreported, Martin CJ, 14 August 2009) 16.
[192] Gemma Ellis, 'The Right of Self-Determination: Brightwater Care Group Inc v Rossiter' (2010) 12 *The University of Notre Dame Law Review,* 215.
[193] Queensland Law Reform Commission, *Shaping Queensland's Guardianship Legislation: Principles and Capacity*, Working Paper No 64(2008) , 118-122.
[194] Parliamentary Library Research Service, above n 45, 19.
[195] Ibid.
[196] Australian Law Reform Commission, above n 9, 36.

heard before the Full Court of the Family Court due to a 'diversion of opinion'[197] not just between jurisdictions but within the bench itself.[198] This matter involved a 14 year old child with intellectual disabilities known by the pseudonym Marion.[199] The appellant brought forward the argument that guardians of disabled persons did not have the power to authorise the medical treatment in question and that an application for court authorisation was required.[200] The respondents, being Marion's parents and joint guardians, opposed this view by stating the decision does not differ from other parental/guardian type decisions which need to be made and as such they should be able to.[201] They further argued that the Family Court of Australia becoming involved is optional due to its 'supervisory nature'[202] due to the procedure being in the best interests of the child.[203] Pursuant to s 11(1)(b) of the *Human Rights and Equal Opportunity Commission Act 1986* (Cth) the Human Rights and Equal Opportunity Commission ('the Commission') intervened as the proceeding involved human rights.[204] The Commission's argument was that invasive surgery resulting in the removal of healthy organs from a patient who is unable to give consent due to intellectual disability cannot be carried out lawfully without the authority of the appropriate judicial authority.[205] The Commission argued this fell under the Family Court of Australia's *parens patriae* jurisdiction.[206]

[197] Interview with Chief Justice Alastair Nicholson (Four Corners Brisbane, 12 May 2003).
[198] Ibid.
[199] *Secretary, Department of Health and Community Services v JWB and SMB (Marion's Case)* [1992] 175 CLR 218.
[200] Ibid, 5.
[201] Ibid, 5.
[202] Ibid.
[203] Ibid.
[204] Ibid, 6.
[205] Ibid.
[206] Ibid.

Their Honours had the task of answering a twofold question: 1) whether a child can consent to medical treatment irrespective of having a disability; 2) if the child cannot consent, can the parents or guardians of the child consent on their behalf? In deciding the answers to the questions posed, the Court looked towards the common law and legislation surrounding assault, consent and medical treatment.[207] Their Honours started with the principle that adults with full mental capacity could consent to medical treatment[208] and that the specific medical procedure in question was lawful.[209] Upon legalisation of assisted dying in Australia the same position would be in place with adults with full mental capacity, who meet the legislative requirements, can consent to assisted dying. Chief Justice Mason, along with Dawson, Toohey and Gaudron JJ went on to state that parental rights have never been treated as 'sovereign or beyond review and control'[210] in order to protect minors.[211] If it is clear, as with *Marion's case*, in which the patient is incapable of giving valid, informed consent to the medical treatment, then the second question posed by their Honours must be asked.

Consideration as to what is the relevant standard of capacity needs to be made.[212] Currently the Framework provides the guidance as to what standards of capacity are in Australia to an unsatisfactory view. In *Marion's Case* their Honours held that there is a potential for assessments of capacity to be wrong due to the misconceptions commonly held regarding

[207] Ibid.
[208] *Secretary, Department of Health and Community Services v JWB and SMB (Marion's Case)* [1992] 175 CLR 218, 12.
[209] Ibid, 13.
[210] Ibid, 19 citing *Gillick v West Norfolk AHA* [1985] UKHL 7, 183-184 per Lord Scarman.
[211] *Secretary, Department of Health and Community Services v JWB and SMB (Marion's Case)* [1992] 175 CLR 218, 19.
[212] Australian Law Reform Commission, above n 9.

persons with disabilities and the degree of their ability.[213] The complexity of holding a standard of capacity needed is in the nature of capacity itself and how a seemingly capable person may be incapable of making a decision. The law recognises that persons have the right to make irrational decisions as long as they understand the nature and consequences of the decision.[214]

Guardianship laws stipulate there are a range of medical procedures in which parents and guardians can substitute consent for disabled patients.[215] At present the existing law specifies euthanasia as being prohibited;[216] upon the legalisation of assisted dying however, it may fall under the special medical category with the legislation.[217] However, there is a chance the courts will decide, as was in the case of sterilisation,[218] that it should fall within a category of its own.

III. COURTS OR LOVED ONES?

In *Marion's Case* the High Court of Australia was required to determine whether joint guardians of a disabled person had the authority to order a specialised medical treatment without a court order.[219] In doing so they were required to ascertain whether the High Court of Australia had the jurisdiction to authorise such treatment or whether they could enlarge the powers of the guardians to do so themselves.[220] This decision, in theory, should simplify the precedents on determining who bears the burden of making the decision of

[213] *Secretary, Department of Health and Community Services v JWB and SMB (Marion's Case)* [1992] 175 CLR 218, 250.
[214] *Hunter and New England Area Health Service v A* [2009] NSWSC 761 (Unreported, McDougall J, 6 August 2009) 15.
[215] Staunton and Chiarella, above n 156.
[216] See, *Criminal Code* (NT), s 156.
[217] See, *Guardianship Act 1987* (NSW), ss 36, 45A.
[218] *Secretary, Department of Health and Community Services v JWB and SMB (Marion's Case)* [1992] 175 CLR 218.
[219] Ibid.
[220] Ibid, 11.

whether specialised medical treatment for disabled persons should be laid on the judiciary or guardians/loved ones. Furthermore, answering the question of how far should medical professionals be included in the process, if at all? Due to the illegality of assisted dying in Australia,[221] the specialised medical treatment was of sterilisation;[222] however the definition of such treatment may be broad enough to encompass assisted dying upon legalisation.[223] Alternatively, the courts or legislature may conclude that assisted dying should be in a separate legal regulation regime of its own, similarly to their conclusion on sterilisation.[224]

Should assisted dying of disabled persons be prima facie unlawful and upon determination of the court be held to be lawful? This would depart from the administrative side of the Groningen Protocol which sets out that medical practitioners and the family of disabled persons determine, by following the guidelines, whether assisted dying is the best option.[225] Once the termination of the life is done then authorities are called and the coroner looks into the legality of the death.[226] The National Council on Intellectual Disability argues that major non-therapeutic medical treatment should be considered an issue of public policy rather than a private family matter.[227] Remembering Mrs Pretty from above, the court held that the right found within Article 8 of the Convention on Human Rights and Fundamental Freedoms: the right to respect for private and family life, although provides a right to self-

[221] See, *Criminal Code* (NT), s156.
[222] *Secretary, Department of Health and Community Services v JWB and SMB (Marion's Case)* [1992] 175 CLR 218, 13.
[223] Interview with Chief Justice Alastair Nicholson (Four Corners Brisbane, 12 May 2003).
[224] The Family Law Council, Report to the Attorney-General', *Sterilisation and Other Medical Procedures on Children*, November 1994, 7.
[225] Dr Verhagen and Dr Sauer, above n 59.
[226] Ibid.
[227] Ibid, page 10.

determination, does not extend to implying a positive obligation on another person to assist with dying.[228]

Due to the unavailability of assisted dying cases in Australia, relevant cases regarding the sterilisation of disabled persons can be analysed to ascertain the position Australia is likely to take. Before Marion's Case, the Family Court considered if the courts or loved ones should make the decision for the medical treatment in *Re a Teenager*,[229] *Re Jane*,[230] *Re Elizabeth*[231] and *In re S.*[232] The precedents from these matters highlight the complex considerations which must be weighted in every matter where ethics plays a role. Authorities are divided as to whether courts should be involved with the process of giving consent for persons who need substitute consent.[233] *Re a Teenager* and *In re S* their Honours held that court authorisation was not needed as parental or guardian consent was sufficient.[234] *Re Jane* and *Re Elizabeth* held the opposite by stating that court authorisation is mandatory as Nicholson CJ stated it to be 'too great a risk without the safeguard of the court's participation.'[235] The matter of *Marion's Case* was an avenue for the High Court of Australia to create a clear precedent on the matter. Their Honours held that due to the 'invasive, irreversible and major surgery'[236] being performed combined with the 'significant risk of making the wrong decision'[237] the involvement of the court is required. Due to the inherent nature and irreversibility of assisted dying procedures, it is highly likely that

[228] *Diane Pretty v United Kingdom* (2002) III Reports of Judgements and Decisions, 15.
[229] *Re a Teenager* (1988) 94 FLR 181.
[230] *Re Jane* (1988) 94 FLR 1.
[231] *Re Elizabeth* (1989) 13 Fam LR 47.
[232] *Attorney-General (Qld) v Parents* (1989) 98 FLR 41.
[233] *Secretary, Department of Health and Community Services v JWB and SMB (Marion's Case)* [1992] 175 CLR 218, 29.
[234] Ibid.
[235] Ibid, 32.
[236] *Secretary, Department of Health and Community Services v JWB and SMB (Marion's Case)* [1992] 175 CLR 218, 49 per Mason CJ, Dawson, Toohey and Gaudron JJ.
[237] Ibid.

Australia will take the same approach in determining if courts should be involved with decisions of terminating disabled persons lives. In doing so it is abundantly clear that the best interests of the patient will be considered paramount.[238] Their Honours, in *Marion's Case,* agreed with Nicholson CJ that the likelihood of abuse or misuse, either deliberately or not, is less with the involvement of the court.[239] A problem with mandatory court proceedings to get authority is the costly time and monetary inconveniences which may be elevated through reform.[240]

IV. NATIONAL CONSISTENCY

The Australian Law Reform Commission (ALRC) looked into the equality, capacity and disability in Australia's federal laws in November 2013[241] and submitted a discussion paper on the topic in May 2014 to review the inequality for persons with disabilities in regards to their legal capacity and recognition before the law.[242] In this discussion paper, the ALRC recommends the implementation of a uniform approach to assessing and defining capacity in Australia.[243] The implementation of a nationally consistent approach can occur through a variety of regulatory options:

- Adoption of mirrored legislation throughout all jurisdictions;
- A system of applied law;
- National enactment of Commonwealth legislation; or
- Adoption of principles, guidelines and protocols.

[238] Ibid, 73.
[239] Ibid, 54.
[240] Ibid.
[241] Australian Law Reform Commission, above n 9.
[242] Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws,* Discussion Paper 81, (May 2014) 21.
[243] Australian Law Reform Commission, above n 9, 38.

For the purposes of this paper only the option of adopting principles, guidelines and protocols will be discussed in detail.

i. PRINCIPLES, GUIDELINES AND PROTOCOLS

The last option is the adoption of principles, guidelines and protocols. Prosecutorial guidelines that specifically deal with the procedures in which assisted dying should be conducted to ensure not only persons assisting will not be prosecuted,[244] but to ensure an accepted process is available to follow can be developed.[245] All Australian Jurisdictions have, with the exception of Tasmania, pursuant to the statutory authority creating the Director of Public Prosecutions, authorisation to produce guidelines.[246] This option is available regarding the discretion the Director of Public Prosecutions has in deciding if they will prosecute a matter[247] of assisted dying. The Northern Territory Director of Public Prosecutions currently have numerous guidelines on matters ranging from Witness Assistance Services[248] to Domestic Violence[249] and have the ability to change with the altering views of the public to which they apply.[250] Guidelines, such as the Groningen Protocol in the Netherlands, act as a tool for participants of assisted dying to follow to

[244] Ben White and Lindy Willmott, 'How Should Australia regulate voluntary euthanasia and assisted suicide?' (2012) 2092) *Journal of Law and Medicine* , 28.
[245] Dr Verhagen and Dr Sauer, above n 59.
[246] *Director of Public Prosecutions Act 1990* (ACT) s 12; *Director of Public Prosecutions Act 1986 (*NSW) ss 13–15; *Director of Public Prosecutions Act 1990* (NT) s 25; *Director of Public Prosecutions Act 1984* (Qld) s 11; *Director of Public Prosecutions Act 1991* (SA) s 11; *Public Prosecutions Act 199*4 (Vic) s 26; *Director of Public Prosecutions Act 1991* (WA) s 24.
[247] Director of Public Prosecutions Northern Territory, *Guidelines and Legislation*, Northern Territory Government <http://www.dpp.nt.gov.au/legal-resources/Pages/guidelines-and-legislation.aspx >.
[248] Ibid, see, Guideline 11.
[249] Ibid, see, Guideline 21.
[250] Ibid.

ensure prosecutors are able to provide 'consistency and efficiency, effectiveness and transparency in the administration of justice.'[251]

The United Kingdom has adopted offence specific guidelines regarding assisted dying after the House of Lords decision in *Purdy*.[252] In July 2009 the House of Lords delivered its final decision on the matter concerning Ms Purdy, a sufferer of multiple sclerosis, who wanted to travel to Switzerland to end her life.[253] Ms Purdy sought information from the Director of Public Prosecutions as to whether her husband, who would be assisting her, would be prosecuted.[254] Upon the Director of Public Prosecutions declining to provide information regarding the considerations they would take into account when deciding to use their discretion to prosecute, it was held that a breach of Article 8(1) of the *Convention for the Protection of Human Rights and Fundamental Freedoms* was made.[255] Their Honours concluded that not providing a policy guideline outlining the specific factors that would be considered for the offence was unlawful.[256] As such an interim policy[257] followed by a final policy in 2010 were published.[258]

Broadly speaking in the Australian jurisdictions, guidelines for prosecution currently in place express that the Director of Public Prosecutions will prosecute if there is enough evidence to secure a conviction and if it is in the public interest.[259] After the decision in *Marion's Case* a

[251] Ibid.
[252] *R(Purdy) v DPP* [2010] 1 AC 345.
[253] Ibid.
[254] Ben White and Jocelyn Downie, 'Prosecutorial Guidelines for Voluntary Euthanasia and Assisted Suicide: Autonomy, Public Confidence and High Quality Decision-Making' (2012) 36 (656) *Melbourne University Law Review* 656, 663.
[255] Ibid.
[256] Ibid.
[257] Crown Prosecution Services (England and Wales) , Interim Policy for Prosecutors in respect of Cases of Assisted Suicide (September 2009).
[258] Crown Prosecution Service (England and Wales), Policy for Prosecutors in respect of Cases of Encouraging or Assisting Suicide: Issued by the Director of Public Prosecutions (February 2010).
[259] White and Downie , above n 255, 662.

system of principles and guidelines were adopted in Australia to 'minimise the risk of unauthorised sterilisations occurring.'[260] It seems that in the circumstances that guidelines and principles are in place in lieu of legislative provisions.[261] Not only has Australia been accused of being blatantly disrespectful[262] to disabled persons[263] for not enacting legislation to prevent abuse and underground medical procedures on sterilisation, they have continued to not comply with any recommendations to do so.[264] It bears the question of whether adopting a protocol similar to the Groningen Protocol is something Australia should consider. With the existing reluctance to prosecute[265] or give a substantial imprisonment sentence[266] for assisted dying in Australia it seems that producing a protocol similar to the Groningen Protocol would be ineffective at most. It is clearly evident in the area of assisted dying the Australian legal system already is in an area where the judicial response to the offence is inconsistent with the legislative intentions.[267]

CONCLUSION

Australia's attitude towards persons with disabilities has arguably[268] increasingly improved upon ratification of international Conventions regarding disabled persons rights and recognising their abilities. With increasingly heated debates regarding legalising assisted

[260] Women with Disabilities Australia, Submission No 49 to Senate, *Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia*, ,March 2013,21.
[261] Ibid, 25.
[262] Ibid, 26.
[263] In particular women.
[264] Ibid.
[265] White and Downie , above n 255, 662.
[266] See *R v Hood* [2002] VSC 123; *R v Godfrey* (Unreported, Supreme Court of Tasmania, Underwood J, 26 May 2004).
[267] Victoria Hiley, *In Pursuit of a Good Death: Responding to Changing Sensibilities in the Context of the Right t Die Debate* (PhD Thesis, The University of Sydney, 2008) 7.
[268] Women with Disabilities Australia, above n 26, 26.

dying in Australia, it is evident that a focal point must be on not only the fundamental human rights of terminally ill patients, but also the fundamental human rights of disabled persons[269] to ensure there are adequate safeguards in place to protect vulnerable disabled persons.

Realistically, a protocol similar to the Groningen Protocol would not operate well as a part of the Australian legal system. The Groningen Protocol somewhat contradicts current laws and precedents as it emphasises the pain and suffering of patients rather than what is in their best interest.[270] Although there is a lack of authoritative case law on assisted dying and disabled persons, *Marion's Case* demonstrates the attitude likely to be adopted in Australia.[271] As a result of this is seems that Australia is likely to adopt an approach where court involvement to ensure consistency, transparency and adequate protection of disabled persons is preferred in the process of assessing capacity.[272] When Australia is ready to enact legislation to make assisted dying lawful, careful consideration needs to be made to ensure it does not become the quick fix way to manage health problems in disabled persons who lack capacity.[273] It is evident through the convoluted and confusing Framework of Guardianship laws that a consistent and unified legislative approach to the assessment of legal capacity is desperately needed irrespective of assisted dying legislation. [274] It is

[269] Ibid.
[270] Dr Verhagen and Dr Sauer, above n 59.
[271] *Secretary, Department of Health and Community Services v JWB and SMB (Marion's Case)* [1992] 175 CLR 218.
[272] Director of Public Prosecutions Northern Territory, above n 248.
[273] Ian Kerridge, Michael Lowe and John McPhee, *Ethics and Law for the Health Professions* (Social Science Press, 1998) 472-473.
[274] People with Disability Inc and Blake Dawson Waldron Lawyers, above n 160.

essential that discussions to improve the lives of disabled persons occur before all persons can truly have the opportunity to die with dignity.[275]

Unlike the act of voluntary assisted dying, non-voluntary assisted dying impacts the life of a disabled person who is deemed to lack the capacity to make the decision to terminate their own life. It is within the public's interest to ensure that members of society are not misusing and abusing a system intended for humane relief of unreliable pain, suffering and terminal illnesses. Currently, the law offers no comfort to disabled persons nationwide who are afraid of being labelled as a sub-par class of society if the Commonwealth manages to pass legislation on assisted dying.

[275] Stella Young, 'Disability – a fate far worse than death?', *The Guardian* (online) 18 October 2013 <http://www.theguardian.com/commentisfree/2013/oct/18/disability-euthanasia-assisted-dying>.

Annexure 1 – The Groningen Protocol

Table 2. The Groningen Protocol for Euthanasia in Newborns.

Requirements that must be fulfilled

The diagnosis and prognosis must be certain

Hopeless and unbearable suffering must be present

The diagnosis, prognosis, and unbearable suffering must be confirmed by at least one independent doctor

Both parents must give informed consent

The procedure must be performed in accordance with the accepted medical standard

Information needed to support and clarify the decision about euthanasia

Diagnosis and prognosis
- Describe all relevant medical data and the results of diagnostic investigations used to establish the diagnosis
- List all the participants in the decision-making process, all opinions expressed, and the final consensus
- Describe how the prognosis regarding long-term health was assessed
- Describe how the degree of suffering and life expectancy were assessed
- Describe the availability of alternative treatments, alternative means of alleviating suffering, or both
- Describe treatments and the results of treatment preceding the decision about euthanasia

Euthanasia decision
- Describe who initiated the discussion about possible euthanasia and at what moment
- List the considerations that prompted the decision
- List all the participants in the decision-making process, all opinions expressed, and the final consensus
- Describe the way in which the parents were informed and their opinions

Consultation
- Describe the physician or physicians who gave a second opinion (name and qualifications)
- List the results of the examinations and the recommendations made by the consulting physician or physicians

Implementation
- Describe the actual euthanasia procedure (time, place, participants, and administration of drugs)
- Describe the reasons for the chosen method of euthanasia

Steps taken after death
- Describe the findings of the coroner
- Describe how the euthanasia was reported to the prosecuting authority
- Describe how the parents are being supported and counseled
- Describe planned follow-up, including case review, postmortem examination, and genetic counseling

Annexure 2 – Table A

Table A – The Guardianship Framework in Australia

Jurisdiction	Australian Capital Territory	New South Wales	Northern Territory
Legislation	*Guardianship and Management of Property Act 1991*	*Guardianship Act 1987* and *New South Wales Trustee* *Guardianship Act 2009*	*Adult Guardianship Act 1988*
Threshold for Appointing Guardianship	-The patient must have 'impaired decision-making ability in relation to a matter relating to the person's health or welfare' – **s 7** - cannot give substitute consent to a prescribed medical procedure – **s7B** -The ACAT may consent to prescribed medical procedures if lawful, in the best interests of the patient and the patient is represented at hearing – s 70	-If the patient is deemed in need of a guardian because of a disability – **s 14** -Tribunal must make orders in relation to special treatment as defined in **s 33**	-The extent of the intellectual disability and the nature and extent of the support systems available -effects of the proposed order on the patient and their family must be considered – **s 9(3)** -An adult guardian does not have the authority to give consent to a major medical procedure – **s 21** -a major medical procedure is defined in **s 21(4)** as being a 'procedure that does not remove an immediate threat to the person's health and which is generally accepted …as…major'.
Considerations	-The best interests* of the patient, insofar as they can be worked out - **s4(2)(a)** - this must be done in a way that does not adversely affect the patient – s **4(2)(b)** - with minimal interference to the patient's life – s **4(2)(d)** - the decision maker must consult with each carer of the patient – **s 4(3)** *Interests are defined in **s 5A.**	- The welfare and interests of the patient should be given paramount consideration – **s 4(a)** -Freedom of the patient should be restricted as little as possible – **s 4(b)** -The patient should be protected from abuse, neglect and exploitation – **s 4(g)**	-the best interests of the patient are considered, in a means which are least restrictive of the patient's freedoms – **s 4(1)**

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