**Medicine, ethics and the law**

**Emerging roles for law and human rights in ethical conflicts surrounding neuro critical care**

This paper argues that recourse to judicial resolution for protracted ethical disputes concerning end-of-life decision making may become a more necessary and common part of clinical practice in neuro critical care. It discusses the relevance of this in the context of legal and ethical standards in this area becoming significantly influenced by a political agenda with an absolutist rather than qualitative view of the value of life. It discusses the emerging importance of international human rights in this context.

The *Schiavo* dispute in the United States has recently heightened interest in the role of the judiciary and legislature in withdrawal and withholding of treatment decision-making in neuro critical care. It also raised questions about whether “substituted judgment” or “best interests” should be the determinant test for making end-of-life decisions in neuro critical care. In the United States, courts have been prepared to accept as decisive clear and convincing evidence of what the incompetent patient would have wanted.¹ In the United Kingdom, courts have looked to the more objective standard of determining what is in the patient’s best interests.² There, critical care clinicians more routinely seek judicial resolution of protracted ethical disputes with relatives about when to cease active treatment of patients.³

The Australian legal system has till recently had few precedents in these types of cases. In *Auckland Area Health Board v Attorney General (Re I)* [1993] 1 NZLR 235 Thomas J held that withdrawal of treatment could take place when it was no longer in the best interest of the patient as determined by “prevailing medical standards.” He encouraged referral to a clinical ethics committee in contentious cases.

In a series of cases, the Queensland Guardianship and Administrative Tribunal (GAAT) found a 39 year old man with severe brain and spinal injuries, competent to request the removal of artificial ventilation (*Re PVM* [2000] QGAAT 1), agreed to a no-CPR order, but refused to consent to the withdrawal of antibiotics on the application of the wife of a 73yo male with an acquired brain injury (*Re RWG* [2000] QGAAT 2) and granted permission to withdraw artificial feeding from an 80 year old woman in persistent vegetative state on the basis that it was not in her best interests (*Re MC* [2003] QGAAT 13). In these cases “best interests” was defined as involving an assessment of the patient’s reasonable prospects of return to what would be considered a meaningful quality of life. The role of the patients prior statements in helping define “meaningful quality of life” is one of the most problematic areas in this process.

In *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549 relatives of a patient who’d suffered brain damage after a drug overdose contested the decision of clinicians at the Royal Prince Alfred Hospital to withdraw artificial nutrition and hydration, as well as antibiotics, after five days in intensive care. A no-CPR order was entered on his chart, even though his GCS rating had risen to 9, and he was responding to voice. On the relatives application to the NSW Supreme Court, orders were made by a single judge to continue treatment and the court to be involved in future decisions about his treatment. Justice O’Keefe stated:

“There is undoubted jurisdiction in the Supreme Court of New South Wales to act to protect the right of an unconscious person to receive ordinary reasonable and appropriate (as opposed to extraordinary, excessively burdensome, intrusive or futile) medical treatment, sustenance and support.”

The judgment is a poor authority, however, as it contains no reference to prior judicial decisions in any jurisdiction and makes conceptual errors concerning the definition of futile treatment. It was also based on affidavit evidence rather than direct testimony from the health professionals involved.

In *Re BWV* [2003] VSC 173 – the Supreme Court of Victoria ordered a guardian to be a appointed to refuse artificial feeding for a 68 year-old woman with advanced Pick’s disease. The Supreme Court found that artificial feeding was medical treatment, not the reasonable provision of food and water, and so could be refused under the *Medical Treatment Act 1988* (Vic).

In the recent case of *Messiha (by his tutor) v South East Health* [2004] NSWSC 1061 however, a judge adopting the “best interests” of the patient test, common in United Kingdom jurisprudence authorised the withdrawal of futile treatment from a 71 year old COPD patient suffering hypoxic brain damage after an out of hospital asystolic cardiac arrest, over the objection of relatives. His Glasgow Coma Score ranged between 5 and 3 persistently and his EEG showed complete absence of cortical activity. The patient was off sedation and metabolically stable, being mechanically ventilated via an endotracheal tube and fed via a nasogastric tube. The patient had not met the criteria for brain death and

221
though in a deep coma, was not yet in a persistent vegetative state. The patient’s relatives believed, however, that the patient had spontaneously opened his eyes to voice and demanded everything possible be done. They arranged for an eminent independent neurologist to examine the patient on 27 October. The neurologist agreed with the clinician’s assessment of Mr Messiha’s condition, and with her proposal to withdraw active treatment.

It is at this point that many clinicians would consult a clinical ethics committee (and the wide range of professional and community views there represented) to reassure relatives that processes were transparent and in the patient’s best interests. Its effectiveness would depend on how familiar its senior members had previously become with the requirements of such situations and on its capacity to convene rapidly and offer appropriate expertise. For this to happen effectively a senior clinician should chair such committees. The St George Hospital has no clinical ethics committee.

The family challenged the clinician’s decision to withdraw treatment judicially. Justice Howie, on hearing the application to restrain withdrawal of treatment, stated that the guiding principle under the parens patriae jurisdiction is the best interests of the patient and that medical opinion about that issue would be of great weight:

“It seems to me that it would be an unusual case where the Court would act against what is unanimously held by medical experts as an appropriate treatment regime for the patient in order to preserve the life of a terminally ill patient in a deep coma where there is no real prospect of recovery to any significant degree.”

Subsequent to the judicial decision, requests by the family for a last electrocardiogram and to bring their own ventilator into the patient’s palliative care room were refused. Outside court, the patient’s son said “[I was told they] had to cancel two operations because of my dad. I heard [a staff member] say ... ‘What you’re doing to your father is cruel’. They play with you, they try to play with your mind psychologically and put you under a lot of stress in order to switch that life support off”. This type of public expression of distress can be extremely upsetting for the clinicians involved and other staff at the relevant hospital. The publicity aspect may have been one of the most significant reasons why judicial declarations have previously been rarely sought in this area. Yet it may be that such judicial decisions are emerging as a means of resolving these issues with considerable advantages to clinicians. One important lesson was that the NSW Coroner’s office recommended that where clinicians suspect that relatives may be challenging a patient’s death as unlawful, the death certificate should not be completed. This activates the jurisdiction of the coroner who will request an autopsy.

The Schiavo Case

On February 25, 1990, Terri Schiavo suffered hypoxic-ischaemic encephalopathy after a cardiac arrest caused by a hypokalaemia, precipitated by bulimia. Since that date she lived in nursing homes, and finally the Hospice of Florida Sun Coast, requiring constant care with defaecation, nutrition and hydration. She had severe contractures of her hands, elbows, knees and feet. Repeated subsequent neurological examinations revealed at best some persistence of sleep-wake cycles, reflex responses to light and noise and gag and swallowing reflexes. She made moaning sounds randomly, but displayed no signs of emotion, willful activity or cognition. CT-Scans revealed her frontal cortex had been substantially replaced by cerebro-spinal fluid. Her electroencephalograph (“EEG”) produced a flat trace. This left her in what was clinically diagnosed by her attending physicians and other expert witnesses as a persistent vegetative state.

Her husband, Michael, was appointed her legal guardian under a Florida statute. In 1993, he was awarded one million dollars in a malpractice lawsuit against physicians who failed to diagnose and appropriately treat his wife’s eating disorder. In 1998, Mr. Schiavo filed a petition with the court to discontinue his wife’s feeding tube, a request that her parents, Mr. and Mrs. Schindler, devout Catholics, opposed. These parties became involved in more than 25 court rulings and interventions over ten years, as a result of which Mrs Schiavo’s PEG feeding tube was twice removed and reinserted. Contentious issues concerned whether Terri made an informal advance directive and who had the ultimate authority to withdraw futile treatment from her.

In 2001 a guardianship court found that Theresa Schiavo was in a persistent vegetative state and, despite her having left no written advance directive, there was “clear and convincing evidence” that, if capable, she would elect to cease life-prolonging procedures. On October 15, 2003 the Second District Court of Florida, after a close review of all the evidence, issued its fourth opinion on the matter. It confirmed the order of the guardianship court and agreed that Mrs Schiavo’s nutrition and hydration tube could be removed. The court held:

“In the end, this case is not about the aspirations that loving parents have for their children. It is about Theresa Schiavo’s right to make her own decision, independent of her parents and independent of her husband.”
An executive order (Public Law 03-418) was now passed as the behest of the President’s brother Florida Governor Jeb Bush. This stayed the order of a Florida Second District Court that Mrs Schiavo’s nutrition and hydration tube be removed.

A. Effective immediately, continued withholding of nutrition and hydration from Theresa Schiavo is hereby stayed.

B. Effective immediately, all medical facilities and personnel providing medical care for Theresa Schiavo, and all those acting in concert or participation with them, are hereby directed to immediately provide nutrition and hydration to Theresa Schiavo by means of a gastronomy tube, or by any other method determined appropriate in the reasonable judgment of a licensed physician.

C. While this order is effective, no person shall interfere with the stay entered pursuant to this order.

D. This order shall be binding on all persons having notice of its provisions.

E. This order shall be effective until such time as the Governor revokes it.

F. The Florida Department of Law Enforcement shall serve a copy of this Executive Order upon the medical facility currently providing care for Theresa Schiavo.”

The Florida Supreme Court and Florida Circuit Court found this legislation unconstitutional, principally on the ground that it allowed the Florida Governor to nullify the orders of the judicial branch of government, making individual rights insecure and permitting rule by “whim, favoritism and unbridled discretion.”

Late in March 2005 her doctor Dr Stanton Tripodis, following the permit of a Florida Supreme Court judge, again removed the feeding tube that had been keeping Schiavo alive for 15 years. This was despite the extraordinary, last-minute efforts of Republican congressional leaders to extend her life by issuing a subpoena for her to give testimony before them. Catholic organisations, including the Vatican, supported the Schindlers.

At a midnight sitting in March 2005, the US Congress now voted to order a federal court to review the case. A bizarre aspect was medically qualified politicians claiming, after viewing a videotape of the patient appearing to turn toward her mother’s voice and smile, moaning and seeming to follow the progress of a brightly coloured Mickey Mouse balloon, that treatment was not technically “futile.”

The legislation gave Mrs Schiavo’s parents standing to challenge the withdrawal and withholding of treatment in the District Court for the Middle District of Florida. On Monday 21 March 2005, US President Bush issued the following public statement:

“Today, I signed into law a bill that will allow Federal courts to hear a claim by or on behalf of Terri Schiavo for violation of her rights relating to the withholding or withdrawal of food, fluids, or medical treatment necessary to sustain her life. In cases like this one, where there are serious questions and substantial doubts, our society, our laws, and our courts should have a presumption in favor of life. This presumption is especially critical for those like Terri Schiavo who live at the mercy of others. I appreciate the bipartisan action by the Members of Congress to pass this bill. I will continue to stand on the side of those defending life for all Americans, including those with disabilities.”

The resultant Act of Congress granted the US District Court for the Middle District of Florida, and ultimately the US Supreme Court, unique jurisdiction over any claim made by the parents of 41 year old Theresa Marie (“Terri”) Schiavo, concerning any violation of their daughter’s rights “relating to withholding or withdrawal of food, fluids or medical treatment necessary to sustain her life.” Both the Florida District Court and the US Supreme Court, however, declined to intervene. The patient died and a subsequent autopsy revealed she was blind and had severe, irreversible brain damage.

Schiavo and Emerging Roles for Law and Human Rights in Neuro Critical Care

The Schiavo Case represented an unprecedented legislative involvement in individual end-of-life clinical decision making. Clinicians around the world are entitled to ask what was so unique about this case as to require individually-tailored pieces of legislation from both the Florida legislature and US Congress. The resource allocation consequences of making such intervention routine would be considerable. Criticisms that the legislative action in this instance is the result of a broader agenda on the human right to life and the political role of its religious proponents must be taken seriously. The courts involved in the Schiavo Dispute, in the face of considerable political pressure, confirmed that end-of-life decision making in the US involves an assessment of the substituted judgment of the patient, what the patient would have wished.

Perhaps one hitherto under-emphasised reason for this conceptual position may be that in the US the entire doctor patient relationship is regarded as fiduciary in nature. This creates, in effect, an equitable legal
obligation on a treating doctor to champion the interest of his or her particular patient against all others. In Australia, on the other hand, the doctor-patient relationship is merely regarded as having fiduciary aspects (that is, equitable legal duties of utmost loyalty against sexual or financial abuse).12

The more objective “best interests” test, has dominated the limited Australian jurisprudence in the contentious area of defining “futile” treatment.13 One important issue in this respect, discussed by Justice Howie in the Messitha Case was whether resource restriction (pressure for beds) should ever be mentioned to relatives in discussions of end of life treatment. Clinical experience shows that to do so risks relatives considering that the relevant doctors involved are not truly attempting to evaluate what is in the patient’s best interests. Yet, macro-level rationing of government health expenditure inevitably filters down to intensivists for whom it often reluctantly becomes a matter of trading lives in pressured clinical deliberations.14 It would be a logical next step in the current political debate for right to life organizations to encourage their members en masse to complete advance directives requiring everything be done. The consequences of such a step for medical professionalism and social justice distribution of scarce healthcare resources, are significant.

Disagreements also still arise as to what level of probability of a treatment producing return to a meaningful quality of life clinicians should choose before one says a treatment is not in the patient’s best interests. Making these types of judgments is regarded by most clinicians as a professional skill. Ethically clinicians are mandated to make a close assessment of the unique features of each patient’s “Best interests.” The NHMRC Guidelines on Providing Information to Patients, for example, require competent clinicians to seek to understand the patient’s “temperament, attitude and level of understanding,” as well as “circumstances, personality, expectations, fears, beliefs, values and cultural background”.15

Many would thus consider that developments such as that in the United Kingdom Mental Capacity Bill 2004 merely codify what is already good clinical practise. Clause 4 of that Bill gives specific guidance as to what should be considered in any evaluation of what is in an incompetent patient’s “best interests.” Factors include likelihood that the patient will undergo a return to capacity and encouragement to do so, the patient’s past and present wishes and feelings, the beliefs and values that would be likely to alter the patient’s decision if she or he had capacity, the other factors this particular patient would consider and the views of nominated guardians or carers. The Bill provides that if a clinician who attempts to comply with the above decision making process believes their determination is in the patient’s “best interests” then no liability attaches.

Some changes to advance directive legislation that might improve the process of “best interest” determinations for clinicians include: hospital admission staff being required to encourage patient completion of such a direction, a form encouraging specification not only of what treatments should be withheld, but what level of functioning the patient considered provided a minimum acceptable level of quality of life. Informal oral and written advance directive should be available for clinician and judicial consideration, provided they reach the level of “clear and convincing” evidence.

Another emerging development clinicians should be aware of could be the creation of a legal fiduciary duty to promptly disclose to a patient or his or her guardian the occurrence of a adverse event. Such a duty flows naturally from the vulnerability of the patient and is important given that tort law reform has restricted the time limits for patients to bring actions for compensation.16

Importance of International Human Rights In Neurocritical Care

The Florida Supreme Court in the Schiavo Case considered whether or not withdrawing and withholding treatment in that instance might breach legislation prohibiting discrimination against disabled persons. Such arguments could become more important in other jurisdictions not only because of similar legislation but due to moves towards a United Nations Disability Convention. The court held it did not, as the guardian who was making the decision was not exercising State power and the hospice’s decision to do so arose only from its need to comply with a court order. The Florida Supreme Court considered the constitutional prohibition (via the 8th and 14th amendments) on cruel and unusual punishment, but held it only applied after a lawful conviction. They evaluated the 14th amendment right to life (no deprivation without due process of law) but held it created no obligation on the State to protect citizens from private actors.17

Judges and clinicians in other jurisdictions, however, are paying greater attention to international human rights in this context. There are a variety of reasons for this. First, almost every country in the world has ratified the International Covenant on Civil and Political Rights (“ICCPR”). This contains a right to life (article 6) and a prohibition on cruel, inhuman or degrading treatment (article 7) which are much broader in scope than the rights enunciated in the US constitution.18 Patient advocacy groups, arguably, are increasingly appealing to the ICCPR rather than to medical ethics, which they see as too oriented to professional interests.19
Second, much influential UK jurisprudence has been increasingly influenced by human rights concepts since the Human Rights Act 1998 (UK) required the judiciary to take into account norms flowing from the European Convention on Human Rights which are similar in this area to those in the ICCPR.

Third, Australian judges are beginning to pay more attention to international human rights, using them to fill in lacunae under the so-called Bangalore Principles, or, if they sit in the Australian Capital Territory, because of the Human Rights Act 2004 (ACT). The ACT Human Rights Act is essentially declaratory in form rather than being a statement of enforceable rights in the model of the US Constitution. In this it resembles the United Kingdom Human Rights legislation and that of New Zealand. The crucial section is section 30 (1). This provides that “in working out the meaning of a Territory law, an interpretation that is consistent with human rights is as far as possible to be preferred. Section 30 (2) provides that this is subject preference be given to that interpretation which best achieves the purpose of a law. ACT judges faced with a legislative ambiguity or obscurity (for example, in advance directives legislation) or otherwise seeking to discover the meaning of such a law or avoid its absurd or unreasonable application, will thus be involved in a process of balancing statutory purpose against consistency with human rights.

The right to life is one international human right set to loom large in end-of-life decision making. Article 2 of the European Convention on Human Rights (“ECHR”) provides

“Everyone’s right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.”

The case-law of the European Court of Human Rights accords pre-eminence to Article 2 as one of the most fundamental provisions of the Convention. The European Court of Human Rights has held that Article 2 enjoins the State not only to refrain from the intentional and unlawful taking of life, but also to take appropriate steps to safeguard the lives of those within its jurisdiction. US judicial authorities appear not to have gone so far with the right to life in the US Constitution.

This obligation may also imply in certain well-defined circumstances a positive obligation on the authorities to take preventive operational measures to protect an individual whose life is at risk from the criminal acts of another individual. In Dianne Pretty’s case, the Court was not persuaded that “the right to life” guaranteed in Article 2 can be interpreted as involving a negative aspect. They held it was unconnected with issues to do with the quality of living or what a person chooses to do with his or her life. Article 2 could not, without a distortion of language, be interpreted as conferring the diametrically opposite right, namely a right to die; nor can it create a right to self-determination in the sense of conferring on an individual the entitlement to choose death rather than life. Both UK courts and that at Strasbourg have confirmed that the withdrawal of artificial nutrition and hydration from a patient in a persistent vegetative state does not constitute a breach of the international human right to life as its positive obligation only arises where such treatment is in the patients best interests.

Article 3 of the European Convention on Human Rights, reads similarly to article 7 of the ICCPR. It provides:

“No one shall be subjected to torture or to inhuman or degrading treatment or punishment.”

This creates an absolute obligation, no exceptions or derogations have been permitted by the European Court of Human Rights. It may be described in general terms as imposing a primarily negative obligation on States to refrain from inflicting serious harm on persons within their jurisdiction and to take measures designed to ensure that individuals within their jurisdiction are not subjected to torture or inhuman and degrading treatment or punishment, including such treatment administered by private individuals. Where treatment humiliates or debases an individual, showing a lack of respect for, or diminishing, his or her human dignity, or arouses feelings of fear, anguish or inferiority capable of breaking an individual's moral and physical resistance, it may be characterised as degrading and also fall within the prohibition of Article 3.

In Dianne Pretty’s Case the European Court of Human Rights held that it is by Article 8 of the ECHR (“Everyone has the right to respect for his private and family life”) that “notions of the quality of life take on significance. In an era of growing medical sophistication combined with longer life expectancies, many 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.” The Court found, in agreement with the House of Lords and the majority of the Canadian Supreme Court in Rodriguez v. the Attorney General of Canada ([1994] 2 Law Reports of Canada 136), that States are entitled to regulate through the operation of the general criminal law activities which are detrimental to the life and safety of other individuals.

In Burke’s Case it was held that “if Article 3 [of the ECHR] embraces...the right to die with dignity and the right to be protected from treatment, or from lack of treatment, which will result in one dying in unavoidably distressing circumstances, then the personal autonomy
protected by article 8 means that in principle it is for the 
competent patient, and not his doctor, to decide what 
treatment should or should not be given in order to 
achieve what the patient believes conduces to his [or 
her] dignity and in order to avoid what the patient 
would find distressing. In effect this decision is 
stating that the international human rights prohibiting 
degrading treatment (article 3 ECHR) and protecting 
private life (article 8 ECHR), in certain limited 
circumstances, create a capacity in incompetent patients 
(who leave clear advance directives to that effect) to 
require everything to be done, that treatment never be 
withdrawn or withheld from them at any point.

The International Right to Health (article 12 of the 
International Covenant on Economic, Social and 
Cultural Rights) of which Australia is a signatory, 
requiring a regular report on compliance to the relevant 
United Nations committee, may be relevant in these 
circumstances in terms of ensuring that health care 
systems continue to provide a minimum level of 
universal access to healthcare services (particularly 
those of an emergency nature). At its justiciable core, 
the international right to health was previously generally 
regarded as involving a state’s obligation to fulfil public 
health duties providing the preconditions for health, 
such as provision of food, water, sanitation, shelter and 
protection of the environment, but also access to health 
care. Progressive realisation of such a right requires 
effective use of available resources. The minimum 
content of this core, which cannot be set aside on 
grounds of progressive realisation, may be conceptu-
alised as a responsibility to reduce serious threats to 
the health of individuals, or the state’s population, 
according to international standards. It is uncertain 
whether the human right to health has horizontal 
application within the doctor-patient relationship.

The international right to health includes a 
component assuring universal access to affordable, 
esential medicines. This could be challenged by 
provisions in Annex 2C of the Australia-United States 
Free Trade Agreement. These facilitate multinational 
pharmaceutical companies lobbying the Pharmaceutical 
Benefits Advisory Committee to break comparator 
classes and offer price premiums (on top of increasingly 
“evergreened” patent royalties) for innovation without, 
as is required by Annex 2C, having to also justify that in 
terms of benefits to overall public health. The result 
could be to reduce the fiscal price control mechanism 
provided by scientific cost-effectiveness pricing. The 
flow-on effect could be higher medicines expenditures 
for ICU’s and hospitals.

Conclusion

The Schiavo Case emphasises the important 
protective role that applying for a judicial declaration 
may have for clinicians involved with relatives in a 
dispute over end-of-life decision making about a patient. 
In Burke’s Case an English judge went further and held 
that in certain circumstances judicial authorization was 
now required as a matter of law before medical 
treatment could be withdrawn. These circumstances, 
each with salutary lessons for clinicians, are:

1. where there is any doubt or disagreement as to the 
capacity (competence) of the patient
2. where there is a lack of unanimity amongst the 
medical professionals as to whether (i) if the patient’s 
condition or prognosis or (ii) the patient’s best 
interests or (iii) the likely outcome of ANH being 
either withheld or withdrawn or (iv) otherwise as to 
whether or not ANH should be withheld or withdrawn
3. where there is evidence that the patient when 
competent would have wanted ANH to continue in 
the relevant circumstances
4. where there is evidence that the patient (even if a 
child or incompetent) resists or disputes the 
proposed withdrawal of ANH; or
5. where persons having a reasonable claim to have 
their own views or evidence taken into account 
(such as parents, close relatives, partners, close 
friends, long-term carers) assert that withdrawal of 
ANH is contrary to the patient’s wishes or not in the 
patient’s best interests.

Finally, in a political climate where end-of-life 
decisions may become a public spectacle, the capacity of 
clinicians to argue their case in terms of international 
human rights may hold distinct advantages, not the less 
than because this may increasingly be the normative 
system their disputers will appeal to. The prospect of 
increasing numbers of advance directives requiring 
everything be done, regardless of clinical judgment or 
resource implications is a real one. It may create one of 
the most significant emerging problems for law and human 
rights in ethical conflicts surrounding neuro critical care.

T. FAUNCE

Medical School and Law Faculty, Australian National 
University, Canberra, ACT

REFERENCES

3. Oates L. The courts’ role in decisions about medical 
life support after court bid fails” Sydney Morning Herald 
5. The Multi-Society Task Force on PVS. Medical aspects of 

T. FAUNCE

Critical Care and Resuscitation 2005; 7: 221-227
7. In re Guardianship of Schiavo, 851 So 2d, 183 (Fla. 2d DCA 2003).
11. Connell v Medical and Surgical Clinic 315 NE 2d 278 (1974).
33. "It seems that the international right to health is not particularly suited for doctor-patient relationships. The obligations...are generally directed towards the state..." Brigit Toebes, The Right to Health as a Human Right in International Law (1999) 270.