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### **End-of-life in Florida**

The circumstances of Terri Schiavo were discussed in the first issue of the Journal (*J Bioethical Inquiry*. 2004; 1(1): 43-48). Ms Schiavo, who has been in a persistent vegetative state for over 15 years, had been at the centre of a dispute between her husband (who was her guardian and surrogate decision-maker) and her parents. The dispute centred on whether her artificial nutrition and hydration should be withdrawn or not. Following a great deal of controversy Terri Schiavo died on 31 March 2005, 13 days after the removal of her feeding tube.

Following the striking down of 'Terri's Law' (a special bill passed by the Florida legislature with the purpose of setting aside a decision of Circuit Court Judge George Greer) by the Florida Supreme Court an application was made to the United States Supreme Court arguing that the Florida Supreme Court misapplied the separation of powers principle. On 24 January 2005 the United States Supreme Court refused to grant review of the case. The decision set off a remarkable chain of events.

A series of applications to the Florida courts were made by the parents of Ms Schiavo and the Governor of Florida, Jeb Bush, as well as protest vigils organised outside of the hospice where Ms Schiavo was being cared for. Despite a series of applications to Judge Greer for reconsideration of his orders concerning the feeding tube he reaffirmed the original 2000 judgment (and subsequent 2003 decision) that the feeding tube could be removed. On 25 February

Judge Greer ordered that 'absent a stay from the appellate courts, the guardian, Michael Schiavo, shall cause the removal of nutrition and hydration from the ward, Theresa Schiavo, at 1 p.m. on Friday, March 18, 2005'.

There were numerous attempts by members of the Florida legislature to pass additional legislation to prevent the removal of the feeding tube, as well as an unsuccessful application to the appellate courts. The feeding tube was removed in mid-afternoon on Friday, 18 March (this was the third time that the tube had been removed during this saga). At the federal level, the United States Senate delayed its Easter recess and worked on Saturday to reach a compromise with the House of Representatives on a proposed bill, S.686, which was eventually passed on Palm Sunday. The House of Representatives returned for a special session and shortly after 12.30 a.m. on Monday, 21 March, voted to pass S.686. President Bush signed the bill into law at 1.11 a.m. (Public Law 109-3).

In accordance with this new Act, Federal District Court Judge James Whittemore heard an application by Ms Schiavo's parents that he order re-insertion of the feeding tube while a lawsuit based upon S.686 could be litigated. Judge Whittemore refused that application on 22 March and the parents appealed his decision to the United States Court of Appeals for the Eleventh Circuit. In a 2-1 vote the Court of Appeals rejected the appeal on 23 March. A further application to the Court of Appeal, acting *en banc* (as a whole), was made and rejected on the same day. A further

application was made to the United States Supreme Court but was refused on 24 March.

The parents made another application to the Federal District Court, which was refused and then appealed to the Court of Appeals for the Eleventh Circuit but their application was denied on 30 March. Finally, the United States Supreme Court declined to review the Eleventh Circuit Ruling. Terri Schiavo died at 9:05 a.m. on 31 March.

The events of this case raised remarkable public debate. Protesters and the news media gathered outside of the hospice that was caring for Ms Schiavo. There were news stories of death threats against Mr Schiavo and the judges who had upheld the view that the feeding tube should be removed to allow Ms Schiavo to die.

The final acts in this drama, again, are interesting in what could be seen as a continuing tension between the legislature and the courts – both state and federal. When Federal District Court Judge Whittemore heard the application for a preliminary injunction that would mean that the feeding tube would be reinserted, he accepted, for the sake of the interim application, that Public Law 109-3 was constitutional. The Court of Appeals took a similar approach. However, in a separate judgment, agreeing with the majority of the Court, Circuit Judge Birch was moved to write ‘In resolving the Schiavo controversy it is my judgment that, despite sincere and altruistic motivation, the legislative and executive branches of our government have acted in a manner demonstrably at odds with our Founding Fathers’ blueprint for the governance of a free people – our Constitution.’ And later, ‘[B]ut when the fervor of political passions moves the Executive and the Legislative branches to act in ways inimical to basic constitutional principles, it is the duty of the judiciary to intervene. *If sacrifices to the independence of the judiciary are permitted today, precedent is established for the constitutional transgressions of tomorrow*’ [emphasis in the original].

One encouraging aspect of the Terri Schiavo controversy has been to raise the public profile of advance directives and the role of advance care planning.

– JM

### More Futility Cases in the United States

Schiavo’s case was not the only futility case to go before the courts in America in the last few weeks. An application was brought before the Texan courts by Wanda Hudson, to order doctors to continue to provide life-sustaining

treatment to her son, Sun. Sun was six months old and had been diagnosed with thanatophoric dysplasia. This disorder results in severe disabilities, including insufficiently developed lungs, and Sun had become ventilator dependant. His treating physicians had determined that he was not going to survive and they made a decision that continued ventilation was futile. The hospital bioethics committee reviewed and confirmed that decision. Under Texan law, the *Texas Health and Safety Code* s 166.046(a), once such a decision has been made and confirmed, the relatives of the patient have 10 days to find a replacement physician at another treatment facility, before the life-sustaining treatment can be withdrawn. Ms Hudson was unable to find another doctor and facility and time had run out.

Hudson applied for court intervention (on the advice of the hospital, which paid her legal fees), but the court denied her application. During the course of the hearing the trial judge made comments about Sun being in ‘significant pain’. These comments were seized upon by Hudson as being proof that the matter had been pre-judged and she asked the judge to recuse himself. He refused. Her appeal on that matter was upheld: *Hudson v Texas Children’s Hospital* 2005 Tex App LEXIS 1693. On rehearing, by a new judge, however, the application was again denied. Sun died on 15 March 2005.

The Texan law (commonly referred to as the *Advance Directives Act*) is interesting in that it provides a procedure for determining futile or ‘inappropriate’ medical treatment, rather than a legislative definition. Given that the term ‘futility’ has proven impossible to define, it represents quite a novel approach. Interestingly (and perhaps ironically), the law was made by George W Bush, during his term as Governor of Texas.

– CS

### Decision-making for Severely Disabled Newborns: *Winston-Jones, Wyatt and ‘Matthew’*

The problems of end of life care for disabled newborns have not been confined to the United States. Two cases have been widely publicised in the United Kingdom, and one has also been reported less widely in New South Wales.

The first of these decisions is that concerning Luke Winston-Jones: *Re L (A Minor)*[2004] EWHC 2713 (Fam). Luke, nearly nine months old at the time of judgment, was born with Edward’s Syndrome (Trisomy 18). As part of that syndrome, Luke suffered from multiple heart defects,

respiratory failure, reflux, severe developmental delay, epilepsy and hypertonia. He had lived all his life in hospital. He had suffered numerous cardiac and respiratory arrests, and there were problems with his naso-gastric feeding tube.

Disagreements occurred between the hospital and Luke's mother about appropriate care. The hospital believed that further mechanical ventilation and CPR should not be given to Luke when the need arose (although by trial they had not pursued the issue with regards to CPR).

Reviewing the issues, Butler-Sloss LJ decided that mechanical ventilation would not be in Luke's best interest because of the substantial risks it carried and because it would lessen the closeness of his relationship with his mother (in that she would be prevented from holding him). She asked both parties to forget their disagreements and encouraged the mother to listen to the advice of hospital staff.

Luke died on 12 November, after receiving over an hour of CPR. The family were reported to be angry about his death (*The Times*, 12 November 2004). A coronial inquest is set down for hearing on 18 April 2005.

The facts of Charlotte Wyatt's case are similar to Luke's. Charlotte was born extremely prematurely with severe brain damage, deafness, blindness, incapable of voluntary movement and with chronic kidney and respiratory problems. The hospital treating Charlotte believed it would not be in her interests to give her mechanical ventilation should she require it, but her parents disagreed.

Justice Hedley was asked to intervene: *Portsmouth NHS Trust v Wyatt* [2004] EWHC 2247 (Fam). His decision, like that of Butler-Sloss LJ above, was based on the best interests test. His Honour took an interesting approach and examined not only the objective medical issues, but also the issues concerning the child's feelings and sensations, her experience of pleasure, pain and love. His judgment seems to adopt a standpoint of substituted judgment whereby he asked himself what Charlotte would do if she were capable of exercising sound judgment (at [30]). This is a curious way to assess best interests in cases of newborns, and it has been criticised in other cases because of the practical impossibility of knowing what these children are experiencing. After considering these issues Hedley J felt that ventilation was not in Charlotte's best interests.

The matter returned to court in January: *Portsmouth NHS Trust v Wyatt* [2005] EWHC 117 (Fam). The family were arguing that Charlotte's condition had improved,

because she was now responding to loud noise and to light. Hedley J ordered that further investigations take place and that any evidence be brought back to him before Easter. Nevertheless, he declined to stay his orders in the meantime, as any current improvements did not change his assessment of Charlotte's best interests. The matter is still pending.

Finally, an emergency application was brought in New South Wales by the Director of Community Services to authorise medical treatment for a premature child, with brain damage, hydrocephalus and thrombocytopenia (lack of platelets): *Director of Community Services – re Matthew* [2005] NSWSC 132. The child was in urgent need of a blood transfusion, but the parents believed that the damage to the child's brain was too severe and that he should be allowed to die 'in peace'. Adams J made interim orders that the child be given the treatment on the basis that it would reduce the chance of further brain damage and he relisted the matter in February. No further judgment has yet been reported.

– CS

### **Advance Care Planning Developments in Australia**

On 3 March 2005 New South Wales Department of Health released new end-of-life care guidelines – 'Guidelines for End-of-Life Care and Decision-Making'. These guidelines are intended to replace the 1993 'Dying with Dignity: interim guidelines on management' which, as noted in the first issue of the Journal (*J Bioethical Inquiry*, 2004; 1(1): 43-48), were the subject of comment by O'Keefe J in *Northridge v Central Sydney Area Health Service* [2000] NSWSC 1241.

These end-of-life care guidelines complement the 'Using Advance Directives' guidelines that were released in June 2004. One feature of the new end-of-life guidelines is the focus on building consensus, in particular where patients do not have the capacity to decide on life-sustaining treatment for themselves. In arriving at such consensus decision-making the guidelines recognise eight principles:

- Respect for life and care in dying
- The right to know and to choose
- Appropriate withholding and withdrawal of life-sustaining treatment
- A collaborative approach to care
- Transparency and accountability
- Non-discriminatory care
- Rights and obligations of healthcare professionals
- Continuous improvement.

Consistent with the desire for consensus decision-making, Section 6 concerns the ways in which disagreements can be resolved. Recognising that disagreement can occur between the treating team, the patient or the family; the guidelines suggest that it can be prevented by 'early, sensitive and proactive communication that clarifies goals of treatment, possible outcomes and the patient's values and wishes'. Something that could not said to have occurred in the *Northridge* case.

In Queensland end-of-life decision-making is generally covered by the *Powers of Attorney Act* 1998 and the *Guardianship and Administration Act* 2000. These Acts were generally regarded as very progressive at the time of their enactment. Researchers at Queensland University of Technology (QUT) believe, however, that the aspects of the legislation that involve decisions to withhold or withdraw treatment are in need of review. A project – 'Rethinking Life-Sustaining Measures' – has been funded by the Faculty of Law at QUT.

The project, led by Associate Professor Lindy Willmott and Dr Ben White, has four stages:

- Formation of an Advisory Group;
- Production of an Issues Paper;
- Public Consultation; and
- Preparation of a Research Report.

An Issues Paper – 'Rethinking Life-Sustaining Measures: Questions for Queensland' – was launched by the Attorney-General of Queensland on 31 March 2005. Comments and submissions on the Issues Paper are welcomed by the investigators; the closing date for submissions is 30 May 2005.

The Rethinking Life-Sustaining Measure project has a web site where further information and a copy of the Issues Paper are available – <http://www.law.qut.edu.au/research/lifesustain> – JM

### **Jehovah's Witness Transfused by NSW Guardianship Tribunal**

While the development of advance care planning policies in NSW is encouraging, a recent decision of the NSW Guardianship Tribunal raises issues about the role of such Tribunals in cases where advance directives have been made by incapacitated patients. In *AB (Application for Consent to Medical Treatment)* (unreported, NSWGT, 2004/1867, 6 April 2004) consent was given by the Tribunal for blood transfusions for a man who had suffered a cerebellar

haemorrhage. The man had converted to the Jehovah's Witness faith around 1995-6 and had completed 'no transfusion' card every year since then up to 2003. The Tribunal was shown a card completed on 2001 and the Tribunal accepted that one had been signed in 2003. Nevertheless the Tribunal authorised a transfusion.

The reasons provided by the Tribunal are, with respect, rather strange. One factor considered by the Tribunal was evidence that AB had drunk to excess on occasion, and for that reason there was 'not the degree of close linkage with the Church and its teachings over a long period of time ...'. Similarly strange was the acceptance of evidence that AB had not objected to his grandchildren being baptised as Catholics.

It is true that AB's family all wanted him to have a blood transfusion, but that is hardly surprising given he was a Jehovah's Witness and they were not. Finally, the Tribunal took into account that the patient had already been given blood products by the treating doctor prior to the doctor being informed that AB was a Jehovah's Witness. The Tribunal accepted that AB's fellow church members viewed further transfusions as a continued violation of his rights, but the Tribunal also accepted the strength of the family's position in favour of transfusion.

Importantly, the patient had given some conflicting evidence as to whether he was consenting to blood transfusions by nodding. This is clearly important information in the assessment of whether the patient was now consenting to the treatment, and disavowing the directive. However the Tribunal appeared to accept that AB was not competent at the time he nodded, so it is difficult to understand how this evidence was weighed against the existence of a valid advance directive.

Throughout the decision the Tribunal made reference to how difficult the decision was and how difficult it was for the Tribunal to take matters into account. It was stated that 'The Tribunal does not go into all the details but simply indicates in a broad brush way the nature of the evidence ...'. With respect, this is completely unacceptable. If the Tribunal is unsure or unable to assess facts in a matter of substantial human rights, it should have immediately referred the decision to the Supreme Court, which has the resources and experience to deal with evidential concerns.

One of the most disturbing features of the case is how the Tribunal completely failed to treat the validity of the advance directive as a threshold issue relating to its

jurisdiction. Arguably the Tribunal had no jurisdiction to deal with the matter at all because Part 5 of the Guardianship Act applies only to patients who cannot consent to treatment. Mr AB had clearly refused treatment when competent on several occasions, as evidenced in his 'no transfusions' cards. To that extent it could be argued that a decision had been made by a competent patient, leaving no room for the Guardianship Tribunal to step in. Unfortunately, instead of examining the validity of the advance directive, the entire matter was dealt with on the best interests model, which is a model employed in the absence of a competent decision.

We should not be too critical of judgments to treat in circumstances where the patient's religious beliefs may have changed and where there are real questions about whether an advance directive was meant to apply. For example, in *HE v A Hospital NHS Trust* [2003] EWHC 1017 (Fam), the English High Court authorised a transfusion when there was evidence that a Jehovah's Witness had renounced her beliefs with an intention to convert to Islam. Nevertheless, in *AB (Application for Consent to Medical Treatment)* questions must be raised about whether the NSW Guardianship Tribunal considered the issues in an appropriate fashion. Additionally, the judgment raises serious issues about the implementation of NSW Health's recent guidelines on *Using Advance Care Directives* (mentioned above). That policy came out two months after the decision, and was written with the help of members of the Guardianship Tribunal. Perhaps future decisions of the Guardianship Tribunal will look more closely at advance directives now that the policy has entered the public domain. The best approach would be for the Tribunal to examine the validity and applicability of advance directives as one of jurisdiction. If the directive is valid and applicable then the Tribunal should not consider itself empowered to overturn the patient's competent decision. Moreover, the assessment of these issues needs to be done carefully and without regard to spurious issues. If the Tribunal is unable to deal with this issues in this way it should refer the matter to the Supreme Court rather than consent to the transfusions.

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### **Adolescents and Refusal of Blood**

Similar problems with religious refusal of blood products were raised in the Western Australian case of *Minister for Health v AS* [2004] WASC 286. This case concerned a 15-

year-old Jehovah's Witness (called 'L'), who was refusing transfusions which would have become necessary after proposed chemotherapy. The parents were also Jehovah's Witnesses and agreed with the boy's decision. The Minister for Health sought an order from the court to authorise transfusions.

The Supreme Court of Western Australia exercised its *parens patriae* jurisdiction to authorise treatment (literally meaning 'father of the people'). This jurisdiction is an ancient jurisdiction (beginning sometime around the 11th century) given to superior courts for the purpose of caring for children and disabled adults. Under this jurisdiction the court can order treatment when it is in the child or adult's best interests. That the order was given in this case is not surprising in itself, given that superior courts in most common law countries will order treatment of children in their best interests, even when the parents refuse to consent. Such orders effectively allow the court to take over the parental role.

What is interesting about this case is the express statement by the court that it could exercise *parens patriae* powers in cases where the child was competent. Pullin J stated quite clearly that 'the fact that the child refusing consent to treatment may be of sufficient maturity and intelligence to understand the nature and implications of the proposed treatment, so as to be "Gillick competent", while relevant and important does not prevent the court from authorising medical treatment where the best interest (sic) of the child require' (at [20]). This follows the English approach outlined in the judgments of Lord Donaldson. Lord Donaldson frequently stated that the court can force competent minors to undergo unwanted medical treatment, if is in their best interests: *Re R (a minor)(wardship: treatment)* [1991] 3 WLR 593.

It is trite to say that the forcible treatment of competent human beings raises serious ethical issues. The position in Australia is also controversial legally. At least two other Australian courts have found that a court can override a competent refusal by a child: *DOCS v Y* [1999] NSWSC 644; *H and W* (1995) FLC 92-598. However, in the High Court case of *Secretary of the Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218, McHugh J stated that parental authority 'ends when the child gains sufficient intellectual and emotional maturity to make an informed decision on the matter in question' (at 316-7). One could argue that this means all parental

authority, even the court's. The uncertainty about the use of *parens patriae* on competent, mature minors will continue until determination by a higher court.

The judge also commented on s 21 of the *Human Tissue and Transplant Act* 1982 (WA), which gives medical professionals the power to transfuse children without parental consent, in cases where they would be 'likely to die'. Pullin J stated that 'likely' meant a real and not remote chance, rather than a greater than 50% chance. Consequently, Pullin J found that L could have been transfused under that section without the necessity for a court order.

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### ***Messiha (by his tutor) v South East Health* [2004] NSWSC 1061**

This case also highlights the problems of futility disputes at the end of life. It concerns 75-year-old Isaac Messiha, who had a history of cardiac problems and who, on 17 October 2004, suffered an asystolic cardiac arrest leaving him with severe hypoxic brain damage and in a coma. The treating physician, Dr Theresa Jacques, made an assessment on admission that the prognosis for Mr Messiha was very poor. By 19 October Mr Messiha's condition had not improved and she suggested to the family that comfort care was an option. On 20 October, Mr Messiha's condition began to deteriorate and comfort care was again raised. Additionally, Dr Jacques mentioned the availability of beds in the intensive care unit as an issue.

An independent neurologist examined Mr Messiha in the following days and concluded that Dr Jacques's assessment of prognosis was correct and agreed with the provision of comfort care. Throughout the period Mr

Messiha's rating on the Glasgow Coma Score was between 3 and 6, suggesting limited brain activity. A determination was eventually made to withdraw ventilation and other supports, and provide comfort care.

In contrast, the family believed that they saw responses in Mr Messiha's eye movements, and on that basis they argued that treatment should be continued. They sought an injunction from the Supreme Court to continue treatment.

Howie J found that the treatment was futile and upheld the decision of the Hospital and Dr Jacques. Exercising the *parens patriae* jurisdiction, Howie J stated that the best interests of Mr Messiha did not mandate continued ventilation. Howie J accepted the unanimous medical opinion about Mr Messiha's condition and he also considered the burdensome nature of continued ventilation, which may have necessitated a tracheostomy, with risks of kidney failure, ulcers, pressure sores and infection. His Honour stated that medical opinion was not determinative of best interests but he said it would be an 'unusual case where the Court would act against what is unanimously held by medical experts as an appropriate treatment regime ...' (at [25]).

The case is the first in NSW to follow on from the decision in *Northridge*. The case is not remarkable as it accepts and adopts the tests of best interests that have been employed elsewhere, such as in New Zealand and the United Kingdom. What was remarkable was the level of media criticism and outright attack on Dr Jacques. The leader of the NSW Opposition, John Brogden was reported as saying 'If the family are hoping for a miracle ... I think the court should respect the family on this occasion.' The criticisms aired in the press were on the whole unbalanced.

– CS