

# Chapter 10

## Serving the Child’s “Best Interests” in Australia

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### I. Introduction

Medical advancements allow the treatment of many conditions that once ended in certain death. We also have the ability to maintain circulation and ventilation even after the heart has stopped beating or the brain has stopped functioning. There has been a consequent shift in how we view the concept of death, and how we view omissions or withdrawals of medical interventions that lead to a hastening of death or an allowance of nature to take its course.<sup>1</sup>

This shift is often most poignant in the plight of the newborn and young. There can be few clinical decisions that are more difficult than those that involve determining whether a medical treatment is futile with the consequent decision to withhold treatment when it involves the life of a baby or a young child. Conversely, it is distressing for clinicians to be involved in situations when parents oppose their advice for potentially life-saving treatment for a child. These are complex situations, the two cases experienced in the UK of Charlie Gard and Alfie Evans (henceforth referred to as Charlie and Alfie) being recent high profile examples that illustrate this clearly.<sup>2</sup>

In Australia, consensus with parents on treatment for babies and children is generally reached by establishing strong communication channels between the parents and the treating team. Decisions are ide-

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<sup>1</sup> C. Stewart, “Death Management in the Case of Baby D,” *ABC Religion and Ethics* (published on May 3, 2011), <https://www.abc.net.au/religion/death-management-and-the-case-of-baby-d/10101488> (accessed July 23, 2018).

<sup>2</sup> See the Introductory chapter of this book.

ally reached in a situation of support and trust, on the basis of information on prognosis and treatment options.

However, this approach is not always successful and in times of disagreement, other options are explored in an attempt to reach a resolution. These include: obtaining a second opinion; seeking third party mediation by involving ethics committees; and by providing counselling or pastoral care. When these efforts are not successful, other means include the arrangement of the transfer of care; treating according to the parents' wishes, at least for a period of time; treating according to the parents' wishes while legal proceedings are commenced; or treating according to the clinician's advice and leaving the responsibility of arranging legal proceedings to the parents.<sup>3</sup>

So, withholding treatment cases do present before the court on occasion. The legal background on which these cases are heard will be explained, and four cases will be initially outlined and then analysed with respect to anticipating Australia's response to the controversial UK cases of Charlie and Alfie.

## II. Legal foundations in Australia

The foundations upon which legal determinations are based in these cases are those of the "inherited" principles of law from England and Wales. Common law migrated with the convicts on settlement in 1788. With the Australia Courts Act 1828, the *parens patriae* jurisdiction of the English Court of Chancery became incorporated into Australian law.<sup>4</sup> This jurisdiction of the superior courts is Latin for "parent of the nation" and derives from the royal prerogative to protect the person and property of those subjects not legally competent to attend to their own

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<sup>3</sup> R. Drake et al, "Decision-Making at the End of Life in Infants, Children and Adolescents," *The Royal Australasian College of Physicians, Paediatrics & Child Health Division* 16 (2018).

<https://www.racp.edu.au/docs/default-source/advocacy-library/decision-making-at-the-end-of-life-in-infants-children-and-adolescents.pdf> (accessed November 17, 2018).

<sup>4</sup> P. L. G. Brereton, "The Origins and Evolution of The Parens Patriae Jurisdiction," The Honourable Justice Paul L. G. Brereton AM RFD Lecture on Legal History Sydney Law School, on Friday, May 5, 2017.

[http://www.supremecourt.justice.nsw.gov.au/Documents/Publications/Speeches/2017%20Speeches/Brereton\\_050517.pdf](http://www.supremecourt.justice.nsw.gov.au/Documents/Publications/Speeches/2017%20Speeches/Brereton_050517.pdf) (accessed November 14, 2018).

affairs.<sup>5</sup> The Supreme Court of each state and territory in Australia has the power of *parens patriae*. The overriding ethos of such legislation is to secure the welfare of children and to define the circumstances by which they are at risk of neglect or abuse.<sup>6</sup>

In the mid-1880s, there was also a growing attention to child protection within society, which led to the introduction of children's courts in the early 1900s, the intention being to advocate on the behalf of children and to ward against cruelty and child offence. By the 1970s, there was federal in addition to state and territory legislation, in which the reasoning of "the best interests of the child" was adopted.<sup>7</sup> The state, as *parens patriae*, and the family, intersect under this legislation in this arena of child protection. As will be explained, this legislation extends not only to situations of abuse or neglect, but also to the protection of the "person" in general terms, which naturally includes medical treatment.

In Australia, parents generally have the lawful authority to consent to medical treatment for infants and young persons.<sup>8</sup> This right is based on the parental role as guardian of the child until the child reaches the age of 18, at which time he or she can consent as an adult. However, this authority is only unfettered if the parents are acting in the "best interests" of the child, and any person who is concerned about the

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<sup>5</sup> C. Smith, "Parens Patriae Jurisdiction," presentation to Legal Aid Queensland on July 24, 2016, <https://elo.legalaidqld.gov.au/webdocs/internal/irregseries/cle/2018/parens.pdf> (accessed October 26, 2018).

<sup>6</sup> Australian Law Reform Commission, "Purposes of Laws Relevant to Family Violence, Child Protection Law," <https://www.alrc.gov.au/publications/4.PurposesofLawsRelevanttoFamilyViolence/child-protection-law> (accessed November 14, 2018).

<sup>7</sup> *Ibidem*.

<sup>8</sup> Under the Family Law Act, Section 63E "(1) A person who is the guardian of a child under this Act has responsibility for the long-term welfare of the child and has, in relation to the child, all the powers, rights and duties that are, apart from this Act, vested by law or custom in the guardian of a child, other than: (a) the right to have the daily care and control of the child; and (b) the right and responsibility to make decisions concerning the daily care and control of the child. (2) A person who has or is granted custody of a child under this Act has: (a) the right to have the daily care and control of the child; and (b) the right and responsibility to make decisions concerning the daily care and control of the child."

child's welfare or treatment can challenge the decisions of the parents by applying to the court on the grounds that a parental decision is not in the child's best interests. This is on the basis of the aforementioned power of the court in being able to supervise parents and other guardians<sup>9</sup> in the court's role as the protector of the welfare of children in the interests of society.

The jurisdiction of *parens patriae* can be far reaching in the application of this purpose. Its power is more extensive than that of parents in that "it can be invoked in such matters as custody, protection of property, health problems, religious upbringing and protection against harmful associations."<sup>10</sup> Parents cannot consent to certain interventions for their children such as sterilisation, involuntary admission (for instance for conditions such as anorexia nervosa), the donation of a child's bone marrow, treatment for intersex, treatments for gender identity disorder, or indefinite protective detention.<sup>11</sup>

But there is also restraint in the application of *parens patriae*. This power is to be exercised only in exceptional cases and used with particular caution in those matters where there is "some clear justification for a court's intervention to set aside the primary parental responsibility for attending to the welfare of the child."

Exceptional cases can and do arise under the jurisdiction of *parens patriae* with respect to medical interventions for a child as a result of applications to the court from either the parents or from treating practitioners, regarding treatment that is to be withheld or withdrawn or to be administered against the wishes of the parents. The legal test for assessment of a child's "best interests" in these cases includes a consideration of the physical effects of the proposed treatment together with any psychological and social implications of this intervention.<sup>12</sup>

It is important to understand that these cases are considered in the broader contexts of both the Australian public health system and the common law legal framework. Australia has a federally funded universal health coverage system (Medicare) and maintains a strong public hospi-

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<sup>9</sup> P. L. G. Brereton, "The Origins," 11.

<sup>10</sup> Ibidem, 8.

<sup>11</sup> C. Stewart, "Death Management."

<sup>12</sup> S. Bird, "Mohammed's Case," *Australian Family Physician* 43:5 (2014): 332. <https://www.racgp.org.au/afp/2014/may/mohammeds-case/> (accessed November 14, 2018).

tal system that is state managed. Medical practitioners are registered under a national system that regulates qualifications and practice, and hospitals comply with state health legislation as well as ministerial health policies.

In addition to these levels of control, there are extensive common law provisions that are relevant to medical practitioners. Significantly, under these provisions, medical practitioners are not obliged to provide medical treatment that is deemed to be “futile.” The basis for the determination of futility is that the treatment is of no benefit to the patient; or that the burdens of treatment are out of all proportion to any potential benefit of that treatment for the patient. Such a medical assessment is, by preference, made in accordance with clinical guidelines and/or hospital policies.<sup>13</sup>

### III. Case law

There is a range of Australian case law that can be cited to illustrate these principles in action, both with respect to enforcing and withholding treatment in minors. These former cases often involve the administration of blood transfusions when there is a religious objection, most notably from Jehovah's Witnesses.

However, for these purposes, four cases will be outlined in detail:

- *Secretary, Department of Health and Community Services v JWB & SMB (Marion's case)*<sup>14</sup>
- *Baby D (No. 2)*<sup>15</sup>
- *TS & DS v Sydney Children's Hospital Network (Mohammed's case)*<sup>16</sup>
- *Director of Clinical Services, Child & Adolescent Services v Kizsko*<sup>17</sup>

These cases have been selected in order firstly to provide the foundation of these principles (especially “Marion's case”) and secondly to serve as a basis for comparison with the matters of Charlie Gard and Alfie Evans. What follows is a brief summary of the cases.

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<sup>13</sup> *Ibidem*.

<sup>14</sup> [1992] HCA 15; (1992) 175 CLR 218. *Re Marion (No 2)* [1992]17 Fam CA 87 (1 May 1992).

<sup>15</sup> [2011] FamCA 176 (16 March 2011).

<sup>16</sup> [2012] NSWSC 1609.

<sup>17</sup> [2016] FCWA 19, FCWA 34, FCWA 75.

*A. Secretary, Department of Health and Community Services v JWB & SMB (Marion's case) and Re Marion (No. 2)*

One often-quoted case is that of the so-called “Marion’s case” which commenced in 1990 before the Family Court of Northern Territory but continued on appeal before the High Court of Australia in 1991. This case dealt with issues involving the sterilisation of an intellectually disabled girl. Marion’s parents had asked the Court to either grant permission for the sterilisation or to deem it lawful for parents to consent to the procedure. The majority of the High Court found that common law does not extend rights for parents to consent for non-therapeutic medical procedures such as sterilisation which was, in this instance, indicated on social rather than medical grounds. Instead, the High Court determined that the Family Court of Australia had jurisdiction to authorise the procedure, which it subsequently did at the 1991 hearing.

This case was significant in that it introduced the need for court authorisation for certain procedures or interventions for children. Further, Nicholson CJ at the subsequent Family Court hearing catalogued a number of factors that were important in any decisions concerning orders in relation to medical procedures. He listed these as follows, which is worth quoting in full in order to convey the relevant issues:

- (i) the particular condition of the child which requires the procedure or treatment;
- (ii) the nature of the procedure or treatment proposed;
- (iii) the reasons for which it is proposed that the procedure or treatment is to be carried out;
- (iv) the alternative courses of treatment that are available in relation to that condition;
- (v) the desirability and effect of authorising the procedure or treatment proposed rather than the available alternatives;
- (vi) the physical effects on the child and the psychological and social implications for the child of:
  - (a) authorising the proposed procedure or treatment
  - (b) not authorising the proposed procedure or treatment
- (vii) the nature and degree of any risk to the child of:
  - (a) authorising the proposed procedure or treatment

- (b) not authorising the proposed procedure or treatment
- (viii) the views (if any) expressed by:
  - (a) the guardian(s) of the child
  - (b) a person who is entitled to the custody of the child
  - (c) a person who is responsible for the daily care and control of the child
  - (d) the child to the proposed procedure or treatment and to any alternative procedure or treatment.<sup>18</sup>

### *B. Baby D (No 2)*

This catalogue was relevant to a case heard in Victoria in 2011 concerning “Baby D” who was born at 27 weeks gestation. This was a twin pregnancy and both neonates required resuscitation post-delivery. The twin of Baby D progressed well, but the course of Baby D was more complicated, with brain damage subsequent to extubation attempts. She was reintubated and fed via a nasogastric tube. The baby responded to touch, could feel pain and was often distressed. She still had brainstem function. At five months, it was considered that the ventilation tube should be removed but there was uncertainty about whether this should be replaced if there was deterioration in the child as a result.

The matter went before the hospital’s ethics committee. The consensus of the committee was to remove the tube, and should there be respiratory distress as a result, it would be appropriate for the tube not to be replaced but the baby to be given palliation to reduce pain and suffering. However, the committee was hesitant to recommend this course of action and advised that the advice of the Family Court be obtained.

The issues before the court were then:

- firstly, whether the parents would be able to authorise and consent to the extubation of the baby;
- secondly, whether they could authorise the palliation of the baby should there be consequent pain and/or respiratory distress following extubation. Such palliation would include the

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<sup>18</sup> *Department of Health & Community Services* (n 14), para. 5.

administration of sedation or other medication as deemed necessary by medical staff; and

- thirdly, should such consent be given, whether medical staff could withhold treatment that would artificially prolong the life of Baby D.

The judge hearing the case concluded that the parents were authorised to give consent to extubation and palliation and that the medical staff was permitted to withhold treatment. He found that the treatment decision reached by the parents in consultation with the doctors was appropriate and that no criminal sanctions would prevail should death result. The judge summarised the evidence as follows:

That eventual acceptance of her death is no doubt both difficult and distressing to parents and all professionals but at that stage the very best of effort and medical knowledge has been available to Baby D and there is a point in time where her best interests do require efforts to ease her distress with the knowledge and acceptance of her death.<sup>19</sup>

The consensus amongst all of the very experienced and qualified medical practitioners ... is that any future for Baby D must, with certainty, be seen to be one that is, at least, very burdensome and futile with no expectation of any enjoyment of life and without sight and any meaningful brain capacity.<sup>20</sup>

The judge also found that the doctors caring for Baby D may have been unable to relieve her pain and distress without the use of palliation, despite the risk of such medication further depressing the baby's breathing once the tube was removed. He concluded that the administration of palliative drugs was humane.

Significantly, the judgment was that it was in the baby's best interests to administer the medication even if it shortened her life, a reference to the ethical principle of the Catholic church of "the doctrine of double effect." This principle allows medications that are used primarily to relieve pain in a terminal situation, despite the unintended effect of the medications shortening life.

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<sup>19</sup> *Baby D* (No. 2) (n 15), para. 148.

<sup>20</sup> *Ibidem*, para. 149.

So this case illustrates the ideal of parents and doctors consulting in what is in the child's best interest. But it also demonstrates that even with parental, medical and ethics committee accord, there was still some uncertainty about the "lawfulness" of suppressing a drive to breathe should the baby develop distress from the proposed extubation.<sup>21</sup> The judge's determination allowed the parents to give consent to proceeding with a medical intervention that would likely lead to end-of-life care.

*C. TS & DS v Sydney Children's Hospital Network (Mohammed's case)*

A further case in 2012 was heard by the Supreme Court of New South Wales when the parents of a nine month old infant, who suffered from a mitochondrial disorder, made an application to the Supreme Court seeking an order to ensure that their child be kept alive by mechanical ventilation. Mohammed was deaf, blind, and unable to move. He suffered from seizures, needed to be artificially fed, and only responded to painful stimuli.

In response to the parents' application, an urgent sitting was convened at the hospital and evidence was heard from the parents, a treating paediatrician and two paediatric intensivists. The questions as defined by the judge were: was it in Mohammed's best interests to be mechanically ventilated, and if it was in Mohammed's best interests, should the Court order mechanical ventilation contrary to the treating doctors' recommendations?<sup>22</sup>

The judge in this matter agreed with the clinicians that it was not in Mohammed's best interests to sustain mechanical ventilation when his condition was incurable and when there was considerable pain and distress for the child associated with the proposed ventilation. He concluded:

Here I am well satisfied that the doctors' opinions as to Mohammed's best interests have been reached conscientiously.

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<sup>21</sup> *Ibidem*, para. 81.

<sup>22</sup> *TS & DS* (n 16), para. 88.

tiously and in the proper discharge of their professional obligations.<sup>23</sup>

*D. Director of Clinical Services, Child & Adolescent Services v Kizsko*

A more recent case, about which there were three hearings heard in 2016, is more complicated. This matter, at least initially, reflects the opposite situation of the court imposing a recommended treatment against the parents' consent. The Family Court of Western Australia made a series of determinations in regard to the treatment of a 6-year old boy subsequent to his diagnosis of a brain tumour – a medulloblastoma. The boy, Oshin Kizsko, underwent surgery, with the consent of his parents, in Perth, Western Australia, to resect the tumour at the end of 2015.

Consequently, his medical team advised a course of chemotherapy and radiotherapy to commence within 28 to 36 days following surgery to ensure his best chance of cure and survival. This treatment regime was acknowledged to be in accordance with accepted international practice. However, Oshin's parents objected to the proposed treatment regime on several grounds including a preference for natural therapies by the mother, an inability to care physically for Oshin due to a back condition from which the mother suffered, and the father's concern about taking further unpaid leave from work should Oshin be significantly impaired following the treatment.<sup>24</sup>

The ethics committee considered this matter on two occasions, and was divided in opinion. However, the committee concluded that it was "certain that Oshin's only chance of survival would be to embark on the standard treatment [...] and that the vast majority of parents faced with the same agonising choice would opt for a curative approach."<sup>25</sup> This was despite the expression by some on the committee that a more conservative approach involving palliative chemotherapy would be a valid and ethically sound alternative, suggesting that seeking orders to compel treatment against parental consent should be embarked upon

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<sup>23</sup> Ibidem, para. 94.

<sup>24</sup> *Director of Clinical Services, Child & Adolescent Services*, FCWA 19 (n 17), paragraphs 26–29.

<sup>25</sup> Ibidem, para. 19.

with caution.<sup>26</sup> The committee condemned the use of alternative approaches to care, though, concluding that it was “not considered a rational approach” and that it was “ethically indefensible to impose such irrational beliefs on the lives of others.”<sup>27</sup>

By mid-March 2016, investigations revealed that while Oshin’s disease was progressing, the progress was “linear” rather than “explosive” and the medical team considered that they could not recommend palliation over treatment. Oshin’s parents directly opposed the oncologist’s recommended treatment regime. Their stance provoked the hospital into approaching the Family Court for an urgent order to intervene and provide the child with the best chance of a cure, that of a combined radiotherapy and chemotherapy regime. It was predicted that the recommended treatment would afford Oshin a 50-60% chance of survival after 5 years, the period at which the disease could be considered to be “cured.”<sup>28</sup>

The Director, Clinical Services, Child and Adolescent Services of the Princess Margaret Hospital, brought this matter before the Family Law Court of Western Australia (WA). The Chief Justice, Thackray CJ, concluded that the evidence before him was that if Oshin received chemotherapy and radiotherapy, his chances of a long-term cure were good, despite the inevitable short to medium term negative impact of the treatment. This, together with his observation that most parents would choose intervention, led him to accede to chemotherapy commencing at the hospital. As Oshin’s booking to receive radiotherapy was no longer available, the judge reserved judgement on the issue of radiotherapy until such time as chemotherapy had been administered. The judge appointed an Independent Children’s Lawyer (ICL) to assist in the proceedings, funded by Legal Aid, WA.

The judge also noted that a holding order was in place prohibiting Oshin’s removal from Australia and enforcing the withholding of the parents’ passports.<sup>29</sup> This was on the background of a previous case before the Supreme Court of WA in which the parents were opposed to medical intervention and left the country with the child before the

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<sup>26</sup> *Ibidem*, paragraphs 31–32.

<sup>27</sup> *Ibidem*, para. 38.

<sup>28</sup> *Ibidem*, para. 48.

<sup>29</sup> *Ibidem*, paragraphs 5–6.

court decision. The child received alternative therapy overseas and subsequently died soon after.<sup>30</sup>

In May 2016, when the Oshin case was reconvened before Thackray CJ, the situation had become even more heated. Two courses of chemotherapy had been administered with difficulties for clinical staff. The parents had erected a sign above the child's bed that read "Forced Chemo" during the first course and there were reports that Oshin's parents had sometimes refused to assist nursing staff in caring for and comforting Oshin.<sup>31</sup> His mother reportedly instead took a video recording documenting Oshin's distress.<sup>32</sup> The parents concurrently conducted a highly public campaign against the proposed treatment regime.

By May 2016, there had already been a considerable time delay in receiving full treatment, the boy's prognosis was diminishing, and a clinical dispute developed with respect to the recommended high-dose radiotherapy. This challenge emanated from an expert from NSW who had been approached by the ICL to provide an opinion. This paediatric oncologist, Professor Kellie, while vindicating Oshin's doctors' decision to reject palliative care measures in preference to curative treatment, raised the issue of the risk of long-term neurocognitive effects as well as other side-effects associated with the proposed high dose of cranio-spinal radiotherapy.

This report raised the possibility of a chemotherapy-only option and prompted a change in the approach by the parents, who now agreed to chemotherapy but not radiotherapy. However, Professor Kellie's recommended regime was to review MRI findings to gauge the child's response to chemotherapy with then a further discussion with the parents with respect to radiotherapy, at a reduced dosage.

In his deliberation, Thackray CJ identified "two social, moral and ethical questions."<sup>33</sup> The first of these was "whether greater emphasis should be placed on life itself rather than quality of life," and the second was "whether the first question should be answered by ... the state or by the parents" who would otherwise make decisions in relation to the care of their child.<sup>34</sup> He thus raised the issue of the authority of the

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<sup>30</sup> *Ibidem*, para. 60.

<sup>31</sup> *Ibidem*, FCWA 34, para. 13.

<sup>32</sup> *Ibidem*, FCWA 75, para. 69.

<sup>33</sup> *Ibidem*, FCWA 34, para. 65.

<sup>34</sup> *Ibidem*.

family in these decisions and commented that the court's power to countermand this authority should be used cautiously and sparingly. He concluded that:

In the absence of a consensus of qualified medical opinion, there is, in my view, no role for the state in directing the parents to act in accordance with one entirely valid opinion in preference to another.<sup>35</sup>

He also raised other considerations in his determination, namely that there would now be a "substantial minority of parents" who would oppose radiotherapy at the doses proposed, and that:

If Oshin were to have "forced" radiotherapy, ... he would again be exposed to his parents' hostility and bitterness, potentially causing him even more psychological trauma.<sup>36</sup>

Thus, Thackray CJ concluded that enforced radiotherapy would not be in Oshin's best interests. However, in his judgment he acknowledged the time, effort, and energy of the treating doctors from Princess Margaret Hospital in attending court in order to preserve a "unique and valuable human life."<sup>37</sup> He added, "[i]t is therefore outrageous that they have apparently been denounced in social media for performing the very task that our society expects them to perform."<sup>38</sup>

The judge adjourned the hospital's application in regard to radiotherapy in light of this response from the parents to continue with further chemotherapy and ordered that they remain in Australia and receive treatment at the Princess Margaret Hospital for Children.

Oshin was reassessed by MRI scanning on July 7, 2016, following a further cycle of chemotherapy. There had been a significant improvement, again raising two difficult treatment options, both of which included chemotherapy and radiotherapy. When treatment was due to recommence at the end of July, Oshin's parents refused all treatment options other than palliation.

A further application to the Family Court was lodged to institute welfare orders in order to commence three cycles of consolidation

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<sup>35</sup> *Ibidem*, para. 68.

<sup>36</sup> *Ibidem*, para. 71.

<sup>37</sup> *Ibidem*, para. 67.

<sup>38</sup> *Ibidem*.

chemotherapy, stem cell rescue and craniospinal radiation, or at least, consolidation chemotherapy with stem cell rescue. The hospital also sought injunctions against the parents allowing photographs or interviews, including any form of denigration of the staff caring for Oshin.

The hearing was conducted in August 2016 before O'Brien J, but by this time Oshin's chances of survival and cure had dropped considerably due to, in the words of the paediatric oncologist from Sydney, "the delays in delivering effective chemotherapy [that] have been unreasonable, avoidable and that have weakened or even negated any benefit that may have been achieved."<sup>39</sup> The counsel appearing for Oshin's parents conceded at the hearing that there was "an acknowledgement that the delays in treatment occurred because of decisions taken by the parents."<sup>40</sup>

The judge made many statements in his summation, including that:

Considerable weight must be attached to the prolongation of life, but it is not absolute, nor necessarily decisive. Consideration must also be given to quality of life.<sup>41</sup>

The multitude of elements which together comprise the best interests of the child are wide-ranging and multifaceted, and susceptible to a legitimate diversity of views. Best interests are values not fact.<sup>42</sup>

The court's decision cannot be made in a vacuum. While the child whose best interests are being considered must be respected as a unique individual, each child lives in a family, and his welfare and best interests are inextricably interwoven with that family.<sup>43</sup>

The court may legitimately be informed in its deliberations not only by the clinical opinions of the medical experts, but by their opinions as to the ethical issues. These opinions are born of specialist expertise, and experience in the value judgments inherent in the treatment of life-threatening ill-

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<sup>39</sup> Ibidem, FCWA 75, para. 57.

<sup>40</sup> Ibidem, para. 68.

<sup>41</sup> Ibidem, para. 72.

<sup>42</sup> Ibidem.

<sup>43</sup> Ibidem.

ness. By having regard to the views born of that expertise and experience the court does not abrogate its decision-making responsibility; rather it better inform the independent exercise of its decision.<sup>44</sup>

He also made it clear what the case was not about, namely: “parental rights, ... the perceived power of the medical profession, ... quality of life [being] more important than duration of life, (or) ... the relative merits of traditional medicine and alternative or complementary therapies.”<sup>45</sup>

Instead, he stated that he considered what was in Oshin’s best interests at that point in time.<sup>46</sup> He held that Oshin was to undergo palliative care and any medical investigations and treatment that were necessary for this to take place as directed by the child’s oncology team.<sup>47</sup> There were also instructions that the parents be restrained from denigrating on social network or speaking negatively about any hospital staff or their treatment plans to the media.<sup>48</sup> He ordered that Oshin was not to be interviewed, and for there to be no photographs or footage by any media outlet of Oshin in the vicinity of any hospital at which he attended.<sup>49</sup>

Oshin died in December 2016.

#### **IV. Discussion**

When one considers how Australia may have responded to the cases of Charlie and Alfie, it is clear that we have some not dissimilar case law involving the withdrawal or withholding of treatment upon which to base inferences.

Baby D, while representing a situation where there was accord between all parties, nevertheless was brought before the courts in part at least because there was uncertainty with respect to criminal charges that could be laid against clinical staff. The palliation that the baby may require would suppress brainstem function and hasten death, and nei-

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<sup>44</sup> *Ibidem*, para. 73.

<sup>45</sup> *Ibidem*, para. 90.

<sup>46</sup> *Ibidem*, para. 91.

<sup>47</sup> *Ibidem*, para. 102.

<sup>48</sup> *Ibidem*.

<sup>49</sup> *Ibidem*.

ther the clinicians nor the ethics committee was prepared to proceed without legal sanction.

In Charlie's case, criminality was an issue as well in that the parents' lawyers threatened criminal proceedings against the hospital and its staff.<sup>50</sup> This brings into high relief that the process of end-of-life care is a difficult decision that inevitably, in both countries, necessitates, at times, a legal decision to protect clinical staff from criminal prosecution.

The case of Mohammed has distinct parallels, even down to the sharing of a mitochondrial disorder with Charlie. As with Charlie and Alfie, the judge, Garling P, hearing Mohammed's case, agreed with the opinion of medical staff, and mechanical ventilation was not provided for the child. Medical staff were not obliged to provide futile treatment, and due attention was focused on the pain and suffering of the child in an effort to determine the child's best interests.

It is difficult to assess the parents' reaction to this decision. As names were not released, there was no intense media attention directed to the family. The case has attracted notice within both medical and legal circles, however, due to its contribution to the principles at common law, especially with respect to professional obligations in futility of care matters.

Oshin's case on first view does not appear to be similar to either Charlie or Alfie given firstly that this case was brought because the parents refused treatment and secondly the ultimate decision by the judge to palliate as per the parents' wishes. It does nevertheless have some overarching issues that can be highlighted. The first issue is the additional problems associated with delays in conducting recommended clinical management during the period of protracted legal disputes. This time lag shifts the burdens and benefits equation. Oshin's prognosis declined over the series of hearings such that palliation ultimately became a less contentious option. Charlie's period of ventilation was lengthened during the period of disputation. The harm of extending intensive care had then already occurred, so the question arose whether the additional period of intensive care for a limited trial of treatment

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<sup>50</sup> *Great Ormond Street Hospital v Yates, Gard & Gard* [2017] EWHC 1909, para. 2.

did in fact signify an unwarranted extension of further pain and suffering.<sup>51</sup>

Also an important element in common between the matters is that the cases necessitated a decision when there was some level of disagreement between the medical evidence. As previously cited, Thackray CJ presiding over the second Oshin hearing stated, "in the absence of a consensus of qualified medical opinion, there is ... no role for the state in directing the parents to act in accordance with one entirely valid opinion in preference to another."<sup>52</sup>

While this seems to imply that Australia may have allowed the transfer of a child to the US for experimental treatment had this been the set of circumstances before the court, there are two considerations that indicate that this may not have occurred. The first is the order of Thackray CJ to uphold the previous orders of the magistrate to prohibit Oshin from being removed from Australia.<sup>53</sup> Oshin should, in his opinion, remain in Australia to receive evidence-based care, an opinion mirrored by O'Brien J presiding over the third hearing. He directed Oshin's parents to "meaningfully engage with the oncology team at Princess Margaret Hospital and with any other health professionals as recommended by the treating oncologist."<sup>54</sup> The parents were thus directed to remain with the same clinical team so that the child could be monitored and palliated under specialist attention.

The second consideration in comparing the outcome of the Oshin matter with that of Charlie or Alfie is that the degree and type of medical inconsistency is not necessarily equivalent. In Alfie's case, there was overwhelming medical opinion on the degree of brain deterioration. Progressive MRI scanning demonstrated relentless neurodegeneration. With respect to the issue of Alfie's cognition of pain, the specialist paediatricians considered that while it was unlikely, it could not be determined conclusively that he was not aware of pain and discomfort. And

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<sup>51</sup> D. Wilkinson, J. Savulescu, "Hard Lessons: Learning from Charlie Gard Case," *Practical Ethics: Ethics in the News* (blog published by the University of Oxford, July 24, 2017). <http://blog.practicaethics.ox.ac.uk/2017/07/hard-lessons-learning-from-the-charlie-gard-case/> (accessed November 17, 2018).

<sup>52</sup> *Director of Clinical Services, Child & Adolescent Services*, FCWA 34 (n 17), para. 68.

<sup>53</sup> *Ibidem*, FCWA 19, para. 83.

<sup>54</sup> *Ibidem*, FCWA 75, para. 102.

Dr R, consultant in paediatric neurology, added a disquieting comment. He explained that also at issue was the possibility that the child may feel pain without any benefit of a sensation of comfort from the voice or touch of his parents.<sup>55</sup> There was also agreement with respect to life-support measures being able to sustain Alfie, but medical disagreement with respect to withdrawal of therapy and whether, should the child be transferred to either Italy or Germany, this signified continued suffering, or, worse, increased suffering.

Similarly, medical ethicist Dominic Wilkinson quotes the barrister for Great Ormond Street Hospital (GOSH) as saying that the hospital had been unable to identify a single UK intensive care unit that was prepared to sustain treatment for Charlie.<sup>56</sup> And Mr Justice Francis in his judgement makes reference to the expert independently instructed by Charlie's parents, who agreed with the experts from GOSH.<sup>57</sup> The implication of this is that the vast consensus amongst qualified UK medical specialists concurred with ending life-support despite the offer of the controversial experimental treatment, nucleoside bypass therapy, for Charlie's very rare form of mitochondrial disease at his stage of brain damage.

In contrast, in Oshin's case, the independent oncologist, while cautious about radiotherapy, still wanted to proceed with more intensive chemotherapy, especially given the boy's encouraging response on serial MRI scanning. Ultimately the delays in providing comprehensive possibly curative treatment meant that the goalposts shifted, altering prognosis in the process. The judge, while ultimately agreeing with palliative measures, made a point of saying that he was aware that both the staff caring for Oshin and the independent oncologist recommended curative treatment and that neither had ever before ceased the treatment of

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<sup>55</sup> See *Alder Hey Children's NHS Foundation Trust v Evans, James & Evans* [2018] EWHC 308.

<sup>56</sup> D. Wilkinson, "The Sad Case of Charlie Gard and the Rights \*and Wrongs\* of Experimental Treatment," *Practical Ethics: Ethics in the News* (blog published by the University of Oxford, July 24, 2017).

<http://blog.practicaethics.ox.ac.uk/2017/07/the-sad-case-of-charlie-gard-and-the-rights-and-wrongs-of-experimental-treatment/> (accessed November 17, 2018).

<sup>57</sup> *Great Ormond Street Hospital* (n 50), para. 3.

a child who was responding positively.<sup>58</sup> His judgement is consistent with the observations made by academic Joanna Manning who, on researching like decisions in New Zealand, commented that:

there are no decisions authorising treatment overriding parental refusals where the prognosis is less than a 50 per cent chance of survival, or where the condition is merely treatable as opposed to curable, and the court is asked to balance quantity against quality of life.<sup>59</sup>

The judges then over these three matters confronted different degrees of medical divergence, especially in regard to prognosis and the benefit of any proposed intervention. What is significant, however, is their consistency in assessing this divergence in court, calling and testing all medical evidence.

But possibly the most striking similarity is the part that media outlets and social networking have played in this Australian case and the UK cases. Oshin's plight, like that of Charlie and Alfie, was a very public event, with the series of hearings using his name and location openly throughout.<sup>60</sup>

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<sup>58</sup> *Director of Clinical Services, Child & Adolescent Services*, FCWA 75 (n 17), para. 94.

<sup>59</sup> J. Manning, "Parental Refusal of Life-prolonging Medical Treatment for Children: A Report from New Zealand," *Journal of Law and Medicine* 8.1 (February 2001): 275.

<sup>60</sup> The many cases that have been heard previously across Australia in which the best interests of the child have been in dispute are, as a general rule, heard in a closed court. The court takes great pains to protect the anonymity of all concerned, withholding the names and location of the parents, and at times even the names of the representing counsels and solicitors, and the hospitals and treating clinicians. See C. Smith, "Parens Patriae Jurisdiction." In a case heard before the Supreme Court, Brisbane in 2015, the press accessed the file due to the inadvertent filing of documents without due attention to the legislative non-publication provision. See, *The Hospital v T and Anor* [2015] QSCA 185. As commented by Douglas J, this led to "distressing invasions of the privacy both of the respondents and the doctors...treating the child" at para. 9. The judge, too, in Oshin's case, attempted to staunch the media attention and public denigration of staff by issuing orders to this effect, a step that is in keeping with previous efforts to manage these matters with sensitivity. See *Director of Clinical Services, Child & Adolescent Services* FCWA 75 (n 17), para. 6.

All three sets of parents have in effect encouraged public participation in their cases, such that the public has often opted for the parents' side of the story with protests against clinical staff. The parents have taken measures that have included online campaigns, crowdfunding, public relations consultation, and petitions to other bodies, which range from governments through to religious leaders.

And the public has responded avidly to the widely reported campaigns, despite, by and large, having a limited grasp of the clinical and ethical issues confronting both the medical and legal teams in protecting the best interests of the child. This crowd obviously can be twisted into either wanting treatment or withdrawing treatment over the very same issues of prognostic chances and degrees of suffering. And ideological movements that range from pro-life groups to anti-medical campaigners grasp the opportunity to promote their causes in the media.<sup>61</sup>

One can only feel profound sympathy for the predicament of these parents, and trust that they believe that they were pursuing the correct course for their children. But one must also feel sympathy for the clinical staff who have been harangued and vilified with little opportunity to countermand the hostile allegations while they try to offer these very unwell children and their emotionally traumatised parents as much comfort and clinical care as they can.

Australian QC Ian Freckleton asks whether there should then be some primacy given to the views of the parents.<sup>62</sup> He comments that Oshin's case has produced a most unfortunate precedent in that it gives a signal to others that the manipulation of "the crowd" through the media ensures the outcome that the parents are demanding. Oshin, he argues, was essentially used as a weapon, and he cautions that, as a result, Oshin's voice was not heard.

While there is some validity to this observation, the courts, both in Australia and the UK, took pains to provide an independent "voice"

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<sup>61</sup> G. Hinsliff, "Alfie Evans' Parents Needed Help. The Vultures Came Instead," *The Guardian* (published on April 27, 2018). <https://www.theguardian.com/commentisfree/2018/apr/26/alfie-evans-parents-activists> (accessed July 23, 2018).

<sup>62</sup> I. Freckleton, "Parents' Opposition to Potentially Life-saving Treatment for Minors: Learning from the Oshin Kiszko Litigation," *Journal of Law and Medicine* 24:1 (2016).

for the child. Thackray CJ appointed an Independent Children's Lawyer (ICL) to represent the best interests of Oshin, and it was the ICL who approached Professor Kellie to provide an independent medical opinion. Baby D similarly had an ICL appointed through Legal Aid. The aim of the ICL is to "remain independent, objective and focused upon promoting the child's best interests in all dealings throughout the proceedings."<sup>63</sup> And, consistently, Charlie and Alfie had Guardians appointed to independently represent the children's interests throughout the legal process in the UK.

This observation naturally leads to the final point of resemblance, which is the process of both medical and legal assessments used in these matters, and the uniformity of the principles that have been adopted. Australia and the UK share a strong public health system wherein clinicians certainly do not set out to withdraw life-sustaining treatment, but nor do they advise on pursuing treatment options that are ultimately futile and painful.

It is apparent that in both jurisdictions, treatment plans are developed with parental consultation over lengthy periods of discussion. During disputes, additional measures are used such as ethics committees and mediations in an effort to reach a consensus about care. Medical decisions are made with caution when there is either dispute, such as with the matters of Oshin, Charlie and Alfie, or when the proposed procedure or treatment regime ventures towards areas that may surpass the zones of parental consent. "Marion" and the request of her parents for sterilisation, and Baby D with the likelihood of suppressing brainstem function are examples of the latter.

When the situation becomes irreconcilable, the judiciary, under the jurisdiction of *parens patriae*, becomes the final arbiter. The judges in their determinations have applied the test of whether continued treatment or withdrawal of treatment is in the best interests of the child. As Thackray CJ, as previously quoted, observes, the judge in these circumstances is confronted with two essential moral and ethical questions of "whether greater emphasis should be placed on life itself rather than

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<sup>63</sup> Guidelines for Independent Children's Lawyers (2013), para. 6.4. [https://www.legalaid.nsw.gov.au/\\_\\_data/assets/pdf\\_file/0012/20046/ICL-Guidelines.pdf](https://www.legalaid.nsw.gov.au/__data/assets/pdf_file/0012/20046/ICL-Guidelines.pdf) (accessed November 20, 2018).

quality of life” and whether this question needs to be answered by the state or the parents.<sup>64</sup>

Given the extreme media attention that has initiated a wide commentary on the case of Charlie in particular, this issue of quality of life versus life itself has generated alternate medical ethical opinions. Peter Singer and Julian Savulescu, both Australian ethicists, have written in support of Charlie receiving experimental treatment on the grounds of a “life worth living.”<sup>65</sup> But this therapy was advocated despite having not been previously tried for this rare mutation, not even on mice, prior to a clinical assessment being conducted by Professor Hirano from the US,<sup>66</sup> and in the presence of irreversible brain damage.<sup>67</sup> As commented by Alistair Stewart in response to the contributions to the debate offered by Savulescu and Singer, it is “the space between probability and absolute certainty into which traders of hope can insert themselves.”<sup>68</sup>

Wilkinson (another Australian ethicist) observes on this issue that decisions with respect to experimental treatment involve a number of steps that include seeking experts with relevant expertise, obtaining additional opinions, and then approaching an impartial arbiter.<sup>69</sup> He argues that these are steps taken by Mr Justice Francis in the Family Division of the High Court and that his decisions were upheld in the Appeals Court, the Supreme Court and in the European Court of Human Rights.

There has certainly been a general observance of this process by the recognised impartial arbiters, the judges in both jurisdictions, when testing medical evidence throughout this case law. The judges have

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<sup>64</sup> *Director of Clinical Services, Child & Adolescent Services*, FCWA 34 (n 17), para. 65.

<sup>65</sup> J. Savulescu, P. Singer, “Unpicking What We Mean by Best Interests in Light of Charlie Gard,” *The BMJ Opinion* (blog uploaded August 2, 2017). <https://blogs.bmj.com/bmj/2017/08/02/unpicking-what-we-mean-by-best-interests-in-light-of-charlie-gard/> (accessed November 24, 2018).

<sup>66</sup> *Great Ormond Street Hospital* (n 50), para. 9.

<sup>67</sup> *Ibidem*, para. 15.

<sup>68</sup> A. Stewart’s blog comment on “Unpicking What We Mean by Best Interests in Light of Charlie Gard,” *The BMJ Opinion* (blog uploaded August 2, 2017). <https://blogs.bmj.com/bmj/2017/08/02/unpicking-what-we-mean-by-best-interests-in-light-of-charlie-gard/> (accessed November 24, 2018).

<sup>69</sup> D. Wilkinson, “The Sad Case.”

sought expert advice on futility of care, likely prognostic outcomes and most importantly, levels of cognition and suffering. But too, they have listened with sensitivity to parental concerns and opinions and, Oshin being a ready example, have taken into consideration the family and social network of the child.

On the second issue of state versus parental determination, both Australia and the UK come back to the fundamental issue of protecting the child and see this as a function of the judiciary. Public commentary, particularly in response to Charlie and Alfie, has been plentiful on this aspect, but, as commented by UK criminal barrister Matthew Scott, “well-intentioned calls to give parents more legal rights over these terrible end of life decisions are fundamentally mistaken.”<sup>70</sup> He applauds the UK’s “courageous and independent family court judges who follow clear and long-established principles of law.”<sup>71</sup>

These “principles of law” use past case law as guidance in both Australia and the UK, but the overwhelming ethos is that each case needs to be considered in the interests of the individual child in the context of a legal responsibility to society to protect the life and wellbeing of the young and vulnerable. It is significant that these cases are heard not from the perspective of wasting public money on futile care, or the inappropriate use of limited resources, but on the consistent fundamental concern of what is in the best interests of this particular child at this time.

## **V. Conclusion**

Would Australia have responded differently to Charlie and Alfie? An overview of these four Australian cases has illustrated a consistency of both medical approaches and legal principles with those of the UK cases of Charlie and Alfie. In particular, it is significant that these cases adopt a comparative process of assuring that the child is represented separately from other parties; of seeking medical opinion and testing the opinion with independent advice; addressing the particularities of the medical and social situation of each child that comes before the

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<sup>70</sup> M. Scott, “The Tragic Case of Alfie Evans,” *Quillette* (published on April 28, 2018), <https://quillette.com/2018/04/28/tragic-case-alfie-evans/> (accessed November 20, 2018).

<sup>71</sup> *Ibidem*.

court; and giving the parents a voice. Given this degree of consistency, it is quite possible that the outcomes would have been the same.

Further, from this comparison, it is clear that Australia is grappling with the parallel issues and difficulties associated with these complicated and highly emotional end-of-life choices in the face of new factors. These include the increasing participation of the public with crowd-funding and social media interests; the “expert” parent who accesses the internet for possible treatments and cures; the increasing role of medical ethics in resolving these matters; and the continued advances in medicine and life support that pose further challenges to the already complex and multifaceted decisions around medical intervention and the withholding of treatment.