SAVE THE CHILDREN?

Processes and principles to be applied when the Court is asked to override parents' refusal to consent to a child's life-saving medical treatment

In February 1999 New Zealand's attention was focused on a three-year-old boy and his family, hiding out far from home. They were hiding from the "uncompromising approach" of HealthCare Otago who had been administering the child's chemotherapy treatment. Soon they were also hiding from the court order that took custody away from the parents and made the young boy a ward of the state.

Liam Williams-Holloway was three years old when he was diagnosed in November 1998 with neuroblastoma, a life-threatening child cancer. Liam's oncologist prescribed the treatment "rapid cojec" comprising seven intensive chemotherapy sessions at ten day intervals followed by a stem cell transplant and a course of cis-retinoic acid. His parents, who were firm believers in natural therapies, wanted to try something less invasive. They had read about the quantum booster, an alternative cancer treatment, and decided to give it a go. When HealthCare Otago said any alternative therapy would have to go alongside chemotherapy and not in place of it, Liam and his parents disappeared.

In January 1999, after it became clear that the family would not return, HealthCare Otago made an ex parte application to the Dunedin Family Court, seeking an order placing Liam under the guardianship of the Court. The question that the Court had to answer was what was in the best interests of Liam: making a wardship order, or leaving Liam's parents' decision alone?

The order was granted and consent was given for the medical treatment. With the goal of aiding efforts to find Liam and his parents, the Family Court released details of the case to the media. The public's interest was aroused before a "media gag" was imposed just two weeks later. At the same time, unbeknownst to the media, the treatment order

was suspended and an order was made that Liam could not undergo chemotherapy without consent from the Court. The intention of these orders was to encourage Liam's parents to produce him just for assessment. However they refused to come out of hiding until all the orders were completely discharged.

Eventually it became clear that Liam's best interests were not being advanced by the continuing delay. Through their lawyer, the parents gave an undertaking that Liam would be returned for assessment if all orders were discharged. So, fifteen weeks after the initial application, the Family Court discharged all the orders. Liam and his family came out of hiding and were headline news in the media. Despite the parents' undertaking, doctors at HealthCare Otago did not see Liam again before his parents took him to Mexico for treatment, where he died in October 2000.

This case highlighted the difficulty faced by the Court when asked to make such decisions. The author suggests a process that should be followed by a Court asked to override parents' refusal to consent to medical treatment for their pre-school children, when that refusal will, in the medical opinion, result in the child's death.

Guardianship of the Court

Guardianship of the Court, also known as wardship, is governed by the Guardianship Act 1968. An application can be made to the Family Court or the High Court to place a child under the guardianship of the Court. Once made, an order removes the guardianship rights of the parents and no major decision involving the child can be made without the Court's consent.

However, the Guardianship Act does not give any guidance as to when a child may be placed under the guardianship of the Court, nor does it set out any rules or requirements

to be satisfied before wardship will be appropriate. Only section 23, requiring the Court to consider the welfare of the child as the paramount consideration, offers any guideline. It is this question: What is in this child's best interests? that the Courts struggle to answer.

There are several principles that emerge from past child medical consent cases. A proper decision can not be made by considering only one of these factors. The relevant principles are:

- preservation of life
- quality of life and pain and suffering
- cultural considerations
- likelihood of the treatments' success
- bodily integrity
- parental choice

The author applies these principles (excepting cultural considerations) to Liam's case and analyses whether the Family Court made the "right" decision.

Preservation of life

The New Zealand Bill of Rights Act 1990 guarantees that everyone has the right not to be deprived of life. The United Nations Convention on the Rights of the Child 1989 guarantees that every child has an inherent right to life and requires governments to ensure to the maximum extent possible the survival and development of the child.

In most cases in the past, the preservation of the child's life has been the dominant consideration for the Courts. The Courts have taken the view that a child's welfare is best served when life-saving treatments are ordered. In cases such as *Re Norma* [1992]

NZFLR 445, the Court has ordered that conventional treatment be carried out when the proposed alterative treatments offer no proven chance of success.

Clearly in Liam's case the Family Court felt that Liam's welfare depended upon the preservation of his life. The parents at no time disputed this, but argued that alternative treatment was the best way to save his life.

The Court heard evidence of the conservative medical opinion that with intense chemotherapy, Liam had a fifty percent chance of survival, and that without it, the cancer would "inevitably kill him" within a short period of time. Of that the paediatric oncologist was "absolutely certain." The chance of a cancerous tumour being cured without any treatment at all is next to none.

Liam's parents had not told the hospital what type of alternative therapy they were pursuing. It later emerged that Liam's treatment depended on many aspects, including a diet of organic food, supplements and mental visualisation. He was treated with twice daily sessions of the multi-frequency "quantum booster" that is said to vibrate the cancer cells at a specific frequency and shatter the cancer cells while enhancing the body's immune system.

There was no medical evidence offered to the Court to suggest that the quantum booster treatment would be successful. In fact, Liam's parents were aware that the healers they saw had never treated neuroblastoma. The alternative therapists that treated Liam did not claim that the booster can cure cancer, but that as part of a comprehensive holistic process, they can treat the "underlying condition" that has caused the cancer.

The Family Court paid particular regard to the Court of Appeal decision in *Re J (An Infant), B & B* v *D-GSW* [1996] NZFLR 337. The test in that case was that intervention was appropriate if the parents' refusal was "likely to place at risk the life, health or

welfare of their child." The Family Court found, on the evidence made available, that Liam's parents' refusal was likely to place Liam's life at risk. As the Court noted, the conventional medical opinion was "clear and abundant": without chemotherapy treatment Liam would die.

It is highly unlikely that the parents could have offered evidence that showed Liam's life could be saved with alternative treatment, as they themselves accepted that neuroblastoma had never been treated that way. Thus, even if the parents had been in Court, the evidence would have shown that Liam's life depended on chemotherapy.

Quality of life and pain and suffering

The United Nations Convention recognises that disabled children have a right to live a full and decent life with dignity. It leaves unanswered the question as to when a life may not be dignified.

In extreme cases where the child will have no chance to lead a 'normal' life, the quality of that life becomes highly relevant. In the English case *Re J (A Minor)(Wardship: Medical Treatment)* [1991] 2 WLR 140, the medical evidence was that the premature baby would not live beyond his teens, and would probably die much younger; he was quadriplegic, epileptic, blind, deaf, and would never speak. His only normal reaction was of pain. The Court of Appeal held that while there is a strong presumption in favour of prolonging life, it must be weighed alongside considerations of quality of life and pain and suffering. Quality of life considerations could override the presumption of preservation of life where the life that would be preserved would be "so cruel as to be intolerable" to that child, the test being whether that child, having known no other life, would find his life intolerable. The doctors were unanimous in their opinion that the

baby should not be resuscitated and the Court agreed, implicitly concluding that baby J's life was "intolerable".

Liam's parents were not happy with the side effects and pain that Liam was suffering with chemotherapy and felt alternative medicine would minimise Liam's pain. Liam was very unhappy and sick and told his parents he did not want the treatment. However, Liam suffered only minor side effects including diarrhoea, bed wetting, vomiting and blood loss.

These side effects, which may have continued during the three month course of treatment, could not mean that Liam's life during and after treatment would be completely intolerable, as it was in *Re J (A Minor)*

While Liam was clearly suffering from the chemotherapy, it is nonetheless a "tolerable" treatment. Liam could expect to live a normal, full life after treatment. As such, while considerations of quality of life and pain and suffering could have been considered, the level of suffering by Liam would not have been sufficient to override the importance of preservation of life.

Likelihood of the treatments' success

If a decision comes down to choosing between two treatments, the conventional and an alternative, statistical chances of success are clearly relevant when deciding which one is in the best interests of the child. Where the orthodox treatment clearly has a better chance of success, that treatment should be chosen over the alternative method.

In cases where the chance of success is extremely low there is more space to uphold parental views, and considerations of pain and suffering, culture and bodily integrity can be given more weight.

The evidence was that with conventional medicine Liam had a fifty percent chance of survival and without it he would inevitably die. The chance of Liam dying from the adverse effects of the chemotherapy treatment was less than two percent. There was no evidence whatsoever that alternative therapy would have any success at all.

In Liam's case the Court had to rely on the evidence put before it and was compelled to accept that chemotherapy had a higher success rate than alternative medicine. It would have been inappropriate for the Court to give greater weight to the parents' choice than to preservation of life.

Bodily integrity

Every adult New Zealander has a right to bodily integrity, and unwanted touching can amount to an criminal assault or a tortious trespass. This right to refuse unwanted touching through medical treatment is affirmed in the Bill of Rights Act 1990.

Not all medical treatment without consent will be a tort, as there exists a common law defence of implied consent. When an unconscious patient is unable to consent to necessary treatment, the medical practitioner may treat the patient as impliedly consenting to the treatment and is thus justified in treating that patient to preserve his or her health, unless it is known the patient would refuse to consent if they were able to.

Applying this principle to child consent cases would lead to the Court asking: "Would this child consent to this treatment if he or she were competent to do so?" The fact that

there is a strong human instinct for survival would lead courts to assume that a child would consent to treatment that would save its life. However, in cases where a child's parents are refusing on religious grounds, the Court would have to consider the fact that the child would most likely grow up to have the same beliefs as its parents. This could lead to the conclusion that the child, if competent, would not consent, and so to preserve the child's bodily integrity, treatment should not be ordered. Of course, the assumption that a child will grow up to have the same religious beliefs as it parents is not absolute and it would be dangerous for the Court to refuse to intervene on that ground alone.

The Court should put itself in the position of the child and ask what the child would decide, based on the principles set out in this article. This test can not be the sole one but should be considered in light of all the other principles.

Liam understood that they had to get rid of the lump on his face and he repeatedly told his parents that he did not want the chemotherapy treatment. While the Court could have taken Liam's views into account, his view was coloured by the fact that he was only three years old. Understandably Liam did not like the treatment he was undergoing, but his objection was based solely on the physical pain he felt. At three years of age it is highly unlikely that he could have understood the consequences of choosing alternative treatment over chemotherapy. It is unlikely that his parents ever explained to him that there was a chance he could die, and even if they had, he could not have comprehended the meaning of his own death. Thus, while the Court could consider the fact that Liam did not like the chemotherapy treatment, it could not give great weight to it.

The Family Court could have asked itself what Liam would be likely to choose if he was competent to make an informed decision. The question is whether Liam would choose to undergo chemotherapy with all its side effects, or would choose alternative therapies with fewer side effects but a lower chance of success. This would depend on whether Liam held the same views towards alternative therapies as his parents. If he also

believed that the therapy would cure him, then clearly he would choose that. However, if he was aware of, and believed, the statistical evidence regarding the treatments, he would then have had to make his decision based on a consideration of the side effects. The human instinct to survive would indicate choosing the chemotherapy, especially as this is a young boy who has not yet had a chance to experience adulthood.

It is proper for the Court to step back from the parents' arguments and ask itself what the child would want. In cases where there is a lot of pain and suffering, and no good quality of life can be expected, it may be appropriate to conclude that the child would not want the orthodox treatment. However, in cases where the quality of life will be tolerable, it should be assumed that the child's instinct to preserve his life, so he will reach adulthood, would mean he would consent if he were competent, despite the fact that the treatment involves considerable pain and suffering. While Liam did not like the chemotherapy, it is unlikely that he would forfeit his chance to live a normal adult life for the sake of saving himself three months of painful treatment.

Parental choice

It is universally assumed that parents do have certain rights in respect of their children although it is less acceptable today to talk of 'owning' one's child (McDowell, 1998).

The long title of the Guardianship Act states that its purpose is to define and regulate the authority of parents as guardians of their children. The rights of guardianship of a child are defined in the Act as the right to custody (possession and care) of a child, and the right of control over the upbringing of a child. The question for the Court is whether these rights extend to refusing medical treatment.

In *Re T (A minor)(Wardship: Medical Treatment)* [1997] 1 All ER 906 the English Court of Appeal confirmed that the welfare of the child is the paramount consideration but added that the parents' refusal to consent is important when considering the child's welfare. The English Court did not override the parent's refusal to consent to the necessary life saving treatment for their infant son, who suffered from a liver defect, on the basis that the child's best interests would not be upheld by forcing his parents to care for him against their wishes. The Court accepted that the child's post-operative care would be "injuriously affected" if his mother was forced to care for him. The best interests of the child, the Court said, required that his parents be given the autonomy to decide upon his treatment. However, saying, as the Court did, that the mother and child were "one" ignores the fact that the child was an individual in his own right. The Court failed to give regard to the rule that the child's welfare is paramount.

In the New Zealand case *D-GSW* v *L,* unreported, High Court Auckland, 5 November 1997, Salmon J, M708/97, the parents argued that the welfare of their child, a two year boy with cancer, would not be served by forcing his parents to care for him after treatment. The Court however ordered the treatment and noted that the parent-child relationship would be unlikely to change. Focusing on the parents' ability to provide post-operative care takes the focus away from the child's situation, and as such does not ensure the child's welfare is paramount. Preservation of the child's life cannot be overridden by the fact that the parents may find it difficult to provide after care. Where this is the case, alternative care arrangements may have to be made.

The desires of Liam's parents were clear by the time the guardianship application was made. The Court was aware of their beliefs regarding alternative therapies and that they did not want Liam to receive any chemotherapy treatment, although there was no indication as to what type of therapy they were seeking.

The Williams-Holloways, who prior to Liam's diagnosis had virtually no knowledge of cancer at all, had researched, analysed, weighed up the odds, and chosen what they believed was the best treatment for their child. They had evidence of serious side effects that can be caused by the rapid cojec treatment and the high recurrence rate of neuroblastoma. Liam's father claimed he was told by an oncologist that chemotherapy may be deemed "barbaric" in five years time. These factors were all part of the reason they had chosen non-invasive treatment.

However, Liam's parents were acting on out-of-date information. The parents had been told by an alternative therapist that chemotherapy would destroy Liam's immune system and damage any chance of recovery. This advice was based on outdated 1980s data and was not consistent with cancer success rates in New Zealand and overseas. The parents refused to accept credible scientific information, including results from the latest cancer research published internationally in October 1998, just one month before Liam was diagnosed.

In *Re T* the Court chose not to interfere where it believed there was "genuine scope" for the parents' decision. While Liam's parents had certainly given great consideration to their decision by researching cancer treatments and alternatives, they were relying on scientifically unproven or false information, and it could not be said that there was "genuine scope" for that decision.

The reasonability test has not traditionally been used in the guardianship context but is commonly used in judicial review proceedings. Tribunals, lower courts and public bodies, entrusted with making decisions in their area of expertise, may be subject to judicial review by a higher Court. The focus of judicial review is on the way in which the decision was reached, and not on the merits of the case itself. The reviewing Court is not entitled to substitute its own decision merely on the grounds that it does not like the decision that was made. The issue is whether the decision was so unreasonable that

no reasonable decision-maker could ever have made that decision. This test was first set out in the well-known case *Associated Provincial Picture Houses Ltd* v *Wednesbury Corporation* [1947] 2 KB 223.

Several similarities between judicial review and child consent cases can be seen. Both parents and tribunals are given decision making power by statute because they are assumed to have specialist knowledge. Giving parents the decision making power in relation to their children is efficient in terms of fewer Court hearings. When a Court is asked to override parents' refusal to consent, it is effectively being asked to review the parents' decision. However, in the past the Court has substituted its decision on the merits of the case. An analogous review process would mean the Court would ask itself whether the parents' decision was reasonable. If the reasons given for the decision made by the parents still leave a "gap of logic" to be leaped, then, if a reasonable parent could not have made that leap, the decision is unreasonable. Otherwise, if it is a decision that a reasonable parent could make, the Court may not interfere.

Such a process would still require the child's interests to be paramount. A reasonable parent is assumed to have their child's best interests at heart, and a decision that is not in the best interests of the child would be deemed unreasonable. Taking such an approach would change the focus of the Court. Rather than approaching the case as if it were the primary decision maker, the Court would start with the assumption that the parents' decision is the right one. The Court would not be able to overturn the parents' decision on the merits of the case but would have to find that the decision was so unreasonable that no reasonable parent could have made it. If the parents have considered all the principles set out in this article, and reached a decision that upholds the child's best interests, then that decision is reasonable and should not be interfered with.

If a reasonability approach had been taken in Liam's case, the Court would have started on the premise that Liam's parents were the preferred decision makers. The Court

would then have looked at the decision and asked whether Liam's parents' decision was so unreasonable that no reasonable parent could have made it.

The parents were clearly loving, devoted and genuine in their belief. They argued that alternative medicine involved less pain, resulted in a better quality of life and had a higher chance of success. However, there was a "leap of logic" made. Liam's parents felt that he was suffering from chemotherapy, and that alternative medicine would cure him. There was a leap of logic: their assumption that alternative medicine would cure Liam was not proven by any reliable means.

The Court must then decide whether a reasonable parent would have made this leap of logic. No reasonable parent would base a decision concerning the life of their child on unfounded data. As such, any decision that is based on unreliable data must be unreasonable and the Court should interfere.

The reasonability approach is the most appropriate test for the Court to use, as it allows for genuine differences of opinion, but still keeps the welfare of the child paramount, and requires the Court to justify its intervention. The use of the reasonability test in Liam's case would likely have led the Court to decide that the reliance by the parents on unproven evidence, in the face of substantial evidence to the contrary, was unreasonable.

Conclusion

Preservation of life will always be the primary principle in these decisions. Looking at the success rates of the treatments proposed will indicate to the Court which treatment would be most likely to save the child's life. Where the chance of survival with either treatment is extremely low, the parents' decision should not be interfered with. Otherwise, treatment should be ordered in all cases except those where the quality of

life after treatment would be such that the child's life would be intolerable. In all but these extreme situations, quality of life considerations alone should not be decisive. When a child's whole life is before it, it is not appropriate to deny that life because treatment will be temporarily painful.

The Court should ask itself what this child would be likely to choose, if it were competent. In doing so, the Court must keep in mind the human instinct to survive, and, where quality of life is at issue, the fact that a young child will have known no other life.

Any argument about parental "rights" can not succeed. However, the Court should look at the parents' decision and ask whether it is a decision that a reasonable parent could make. The conclusion is reached by looking at all the principles discussed and asking whether a reasonable parent, who had considered all of these principles, would make the decision to refuse consent. If there is a "leap of logic" that no reasonable parent could make, then the Court can overturn the decision.

The reasonable-parent approach is the most appropriate test to use, as it involves considering each of the principles discussed. The test starts with the presumption that parents are the preferred decision makers, because they have the specialist knowledge of their child.

As in judicial review cases, the Court should not reconsider the case on its merits, but should determine whether the parents' decision is one that reasonable parents could make. This upholds the parents' statutory right to make decisions regarding their child. If the parents have considered preservation of life, quality of life, pain and suffering, cultural issues, the chances of success of the treatments and bodily integrity and reached a decision that, with regard to those principles upholds the child's best interests, then that decision should not be interfered with. The reasonability of the decision will depend on an analysis of the principles discussed here.

In Liam's case, the correct decision was made by the Family Court. Liam's parents were not making a reasonable decision. Liam was suffering from the chemotherapy, but it was only temporary, and there was a good chance that he could look forward to a full and normal life after treatment. His parents were relying on unproven and unreliable evidence that the quantum booster would save Liam's life. Even if their true goal was to allow Liam to die quietly, they were unreasonable to deny him a full adult life on the basis that there would be three months of distressful chemotherapy.

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