

JURISDICTION : FAMILY COURT OF WESTERN AUSTRALIA

ACT : FAMILY COURT ACT 1997

LOCATION : PERTH

CITATION : DIRECTOR CLINICAL SERVICES, CHILD &
ADOLESCENT HEALTH SERVICES and KISZKO & ANOR
[2016] FCWA 34

CORAM : THACKRAY CJ

HEARD : 16 MAY 2016

DELIVERED : 20 MAY 2016

FILE NO/S : PTW 1388 of 2016

BETWEEN : DIRECTOR CLINICAL SERVICES, CHILD &
ADOLESCENT HEALTH SERVICES
Applicant

AND

ANGELA JADE KISZKO
First Respondent

AND

ADRIAN COLIN STRACHAN
Second Respondent

Catchwords:

CHILDREN - Medical treatment - Doctors at children's hospital seek orders for 6 year old child to receive radiotherapy for a brain tumour in addition to the chemotherapy previously ordered on an interim basis - The parents originally opposed chemotherapy but now agree it should continue - The parents oppose radiotherapy being administered - Conflicting expert opinions on whether radiotherapy should be mandated - The Independent Children's Lawyer recommended that there be no order for radiotherapy - An independent expert considers only chemotherapy should be administered at present, especially given the strong objections of the parents - The dispute is a social, moral or ethical issue - There must be some clear justification for a court interfering with parental responsibility - In the absence of a consensus of medical opinion, the state should not intervene - No order for radiotherapy - Matter adjourned generally with liberty to the hospital to relist.

Legislation:

Family Court Act 1997 (WA), s 66C, s 69

Category: Reportable

Representation:

Counsel:

Applicant : Ms Conley
First Respondent : Mr Skerritt
Second Respondent : Mr Skerritt
Independent Children's Lawyer : Ms Cohen

Solicitors:

Applicant : State Solicitor's Office
First Respondent : Diana Velevski Solicitors
Second Respondent : Diana Velevski Solicitors
Independent Children's Lawyer : Legal Aid WA

Case(s) referred to in judgment(s):

CDJ v VAJ (1998) 197 CLR 172

Department of Health & Community Services v JWB and SMB (Marion's Case) (1992) 175 CLR 218

Director Clinical Services, Child & Adolescent Health Services and Kiszko & Anor [2016] FCWA 19

In Re B (A Minor) (Wardship Medical Treatment) [1981] WLR 1421

In re B (Children) (Care Proceedings Standard of Proof) [2008] 2 FLR 141

In re Marion (No 2) (1994) FLC 92-448

In re T (Wardship Medical Treatment) [1997] 1 WLR 242

Minister for Health v AS (2004) 29 WAR 517

Re JM (A Child) [2015] EWHC 2832 (Fam)

Re M [2014] NZFLR 381

Re Norma [1992] NZFLR 445

The NHS Trust v A (A Child) [2007] EWHC 1696 (Fam)

1 I am asked to decide whether a six-year-old boy should be required to undergo
radiotherapy to treat a brain tumour over the strong objection of his parents.

Background

2 Oshin Kiszko was a happy little boy who enjoyed good health until November
2015, when he began to experience headaches, vomiting and weight loss. Oshin
presented at Princess Margaret Hospital (“PMH”) on 1 December 2015, where testing
revealed that he had medulloblastoma, a type of brain tumour which occurs in
children.

3 On 3 December 2015, Oshin underwent surgery to remove the tumour.
The operation was performed with the consent of Oshin’s parents. Thereafter,
disagreements arose between the medical staff at PMH and the parents concerning
ongoing treatment. The treating doctors wanted to administer radiotherapy and then
chemotherapy, in accordance with an established protocol. The protocol indicated that
treatment should start within 28 to 36 days after the surgery.

4 Oshin’s parents opposed the proposed treatment. Although their views have
fluctuated, their primary preference was to pursue alternative therapies involving
herbs, iridology and massage (noting that the mother has a Diploma in Bodyworks and
an Advanced Diploma in Diet and Nutrition, and has studied naturopathy). The
parents’ stated views about the effectiveness of these therapies have also varied, but as
recently as 29 March 2016, they told a doctor at PMH that their therapies had a 90%
chance of curing Oshin.

5 The commencement of conventional treatment for Oshin was delayed as the
hospital attempted to reach an agreement with the parents. The PMH Ethics
Committee was convened on two occasions, but there were differences of opinion
amongst the committee members about the way forward, although they were
unanimous in rejecting the proposition that standard oncological therapy could be
replaced by alternative therapies. Some members of the committee were of the view
that a palliative approach could be supported “on the basis of a rational and careful
assessment of the burdens on Oshin”, but the committee members all accepted that “an
ethically supportable palliative process would involve active symptom management ...
and would likely include some conventional therapy”.

6 While discussions were ongoing, testing undertaken on 16 February 2016 and
17 March 2016 revealed that the disease was progressing, and that abnormal cells
consistent with medulloblastoma were present in Oshin’s cerebrospinal fluid.
Although this was a very worrying development, some solace was taken from the fact
that the disease was progressing in a “linear” rather than an “explosive” manner.
The doctors considered that the results of the testing were such that a palliative
approach could not be supported. They therefore decided to apply to this court for
authorisation to follow their preferred treatment program, since the alternative for
Oshin was certain death in a matter of months.

7 The doctors estimated at the time that the recommended treatment would give
Oshin a 50–60% prospect of being alive in five years. Lest there be any

misunderstanding, if Oshin were to be alive in five years' time, he would be regarded as having been "cured", and would then have a good chance of a long life.

8 These proceedings were commenced by PMH's representative on 18 March 2016. On 24 March 2016, over the parents' strong objections, I made interim orders authorising the commencement of treatment. I did so having been told by the doctors that the tumour was "on the cusp of a massive and irreversible progression, suggesting that it is critical that the boy commences treatment with curative intent urgently, and that each day which passes may make the difference between whether curative or palliative treatment is considered appropriate". My reasons for authorising commencement of treatment are contained in my judgment: *Director Clinical Services, Child & Adolescent Health Services and Kiszko & Anor* [2016] FCWA 19.

9 The practical effect of my orders was that Oshin would commence only chemotherapy. I did not address the issue of whether he would have radiotherapy, as it was not practicable for that part of the treatment to commence due to the delay that had occurred to that point. The parents were given liberty to bring the matter back to court once they had obtained evidence they hoped to find to persuade me that the proposed treatment was not in Oshin's best interests. They have since obtained advice from an expert in the United Kingdom, but I have been informed it is no different to other opinion already in evidence.

10 The proceedings have now been relisted at the request of the Independent Children's Lawyer, Ms Robin Cohen, who I appointed at the last hearing. I am grateful that Legal Aid WA not only funded an ICL, but also provided further funding to obtain a report from an expert, Professor Stewart Kellie, who has not been involved in Oshin's treatment. I am also grateful to the ICL, who has spent time with the medical staff and with Oshin and his parents.

Oshin's response to the treatment already ordered

11 Oshin has now undergone two courses of chemotherapy. The effects were measured by a lumbar puncture and MRI conducted last Thursday, 12 May 2016. The results demonstrate that there has been "an unequivocal radiologic response", in that there has been a significant reduction in the size of cancerous nodules in Oshin's brain. However, there has only been a very minor response to the significant disease evident in the cerebellar folia (at the back of the brain, from where the disease originated). The results also reveal "degenerate small cells" in the cerebrospinal fluid which could be degenerate cancer cells.

12 Dr G, who is the head of the relevant department at PMH, is of the opinion that while the results of the chemotherapy are "pleasing", the level of response is such that further chemotherapy alone will not save Oshin's life, and that a high-level dose of radiotherapy (36 Gray, with a "boost" of around 54 Gray to the primary site), in conjunction with chemotherapy, is required if Oshin is to have a realistic chance of survival. Dr G is now of the opinion that Oshin's chances of survival for five years have reduced to around 30–40% if that treatment is undertaken. The probabilities for Oshin are difficult to gauge, since the delay in the commencement of treatment places him well outside the range of the sample groups used to make predictions. However,

what can be said is that the delay means his chances of survival are worse than for other children with a similar disease, and that he will be likely to die within months unless treated.

13 Oshin's parents continued to resist chemotherapy right up until the hearing on Monday of this week. Their opposition was so strong that they erected a "Forced Chemo" sign above Oshin's hospital bed during his first round of chemotherapy, and sometimes refused to assist nursing staff in caring for and comforting Oshin at that time. The sign was not erected again during the second round of treatment, and Oshin's parents have since been cooperative in assisting the staff and tending to Oshin's needs. They have also conscientiously complied with their obligations under the court order, notwithstanding the great burden it placed upon them.

14 Shortly prior to the hearing on Monday, a supplementary report from Professor Kellie became available, recommending additional chemotherapy, but opining that the parents' opposition to radiotherapy should be respected. Although the parents initially maintained during the hearing that their primary wish was for Oshin not to have either chemotherapy or radiotherapy, it was apparent from the submissions made on their behalf that they were attracted to the recommendation of the independent expert. Ultimately, the parents abandoned their primary position and said that they now wished Oshin to have the chemotherapy treatment recommended by Professor Kellie.

Professor Kellie's first report

15 Professor Kellie has been involved in the treatment of children with cancer since the early 1980s and has practised full-time in paediatric oncology and neuro-oncology for over 25 years. He was formerly the head of the Paediatric Oncology Unit at Westmead Hospital in Sydney, and is currently a paediatric oncologist and neuro-oncologist at the same hospital, as well as being a Clinical Professor in the Faculty of Medicine at the University of Sydney. He was, for three years, the Chairman of the Human Research Ethics Committee at the University of Sydney and the NHMRC Clinical Trials Centre. He is a highly qualified, much published, respected professional of national and international repute. Indeed, he headed up the trials that led to the protocol which is currently being used in Oshin's treatment.

16 Professor Kellie was asked by the ICL to review all of the material concerning Oshin and to provide a report concerning, inter alia, the treatment options focusing on the short, medium and long term. Professor Kellie's first report, which was provided before Oshin had his most recent MRI, contains a review of the material and an examination of the treatment options and the likely effects of those options.

17 Professor Kellie's report needs to be understood in the context that Oshin's cancer is classified as "high-risk" and "group 4", which indicates a higher probability of death from tumour progression or recurrent tumour despite radiation and chemotherapy, when compared with "average-risk" patients. Importantly, the higher level of risk means that the craniospinal (whole brain and whole spine) radiation dose proposed to be administered to Oshin is substantially higher than the dosage usually

administered to children of his age who have been diagnosed with an “average-risk” medulloblastoma.

18 In summary, Professor Kellie’s detailed and erudite report advises that:

- Radiation therapy followed by chemotherapy for 4–8 months is associated with the best chance of survival for children with medulloblastoma.
- The literature involving high-risk patients with medulloblastoma associated with metastatic disease (i.e. the circumstances facing Oshin) suggests that the probability of cure following treatment of the type recommended by PMH is somewhere between 30–50%, although one study suggests a survival rate of up to 67%.
- There is no internationally agreed consensus about a cut-off age for the use of radiation therapy in the treatment of medulloblastoma in young children, since there is no agreement about the age at which the tolerance of the developing central nervous system of children to radiation treatment reaches a safe threshold.
- Survival outcomes of patients with medulloblastoma are generally inferior in patients treated without radiation therapy, and if Oshin were to be treated with only chemotherapy, there would be only about a 30% or less chance of long-term survival, particularly as the presence of metastatic disease is a strong predictor of relapse.
- Quite apart from all the other scientific evidence, the MRI scans administered to Oshin provide clear evidence that massage, herbal remedies and dietary intervention have no effect in preventing tumour progression.

19 Oshin is now just over six years of age. In dealing with the cut-off age for use of radiation therapy in young children, Professor Kellie noted that clinical practice varies. There is an international consensus for avoiding such therapy entirely in patients aged less than three years. In clinical practice in various places in the world, there have been cut-off ages of anywhere between four and 10 years. There are currently clinical trials exploring higher cut-off ages than three years because of concerns about the “severity and impact of late effects, particularly neuro-cognitive, neuro-endocrine and late health status of survivors who received craniospinal radiation”. These effects are inversely related to age, and directly related to dose and the overall volume of tissue treated. A child such as Oshin, who has a high-risk medulloblastoma, requires about 150% or more of the standard dose.

20 Although three years is widely used as the cut-off age for the use of radiation therapy in treatment of medulloblastoma, a range of higher cut-off ages still exists. Professor Kellie advised that at Westmead Hospital, treating doctors would “routinely discuss the pros and cons of a curative treatment plan that includes or excludes radiation therapy in children up to 6 years at diagnosis and even older if there were strong parental views about therapy selection or life-long side effects”.

21 Professor Kellie’s findings correspond very closely to the evidence of the doctors at PMH. His findings strongly vindicate the doctors’ decision to reject the proposition that Oshin be given only palliative care. In Professor Kellie’s opinion, the parents’ approach was “unreasonable”, as it eliminated any opportunity for survival or

cure. The Professor also rejected the suggestion that alternative therapies would provide an adequate response to Oshin's initial presentation, since they "are not intended or able to cure malignant cancer and cannot be justified in a previously untreated post-operative patient with a cancer associated with a reasonable prospect of long term survival".

22 Professor Kellie went on to say (original emphasis):

Concerns about immediate side effects of chemotherapy, recovery from neurosurgery or Oshin's parents' uncertainty about their ability to care for him during chemotherapy ... are not reasons to deny any child with potentially curable cancer a chance of survival by denying access to post-operative therapy *with curative intent*. Modern healthcare interventions in general are characterised by short-term discomfort and treatment side effects in an effort to be restored to health and well-being.

23 Professor Kellie's report also discussed "quality of life" issues and the long-term effects of the treatment options. The focus of my consideration of this aspect of his report will be on the effects of radiotherapy, as the parents now agree that Oshin should continue to receive chemotherapy, and PMH is prepared to facilitate this option, even if I do not mandate radiotherapy as well.

24 Professor Kellie's starting point in dealing with the quality of life issues was to observe that cancer survivors "must be restored to health that lasts for decades and five-year survival is only the beginning, not the end of successful treatment". He was also of the opinion that "cognitive effects are significantly more limiting than physical effects in the integration of cancer survivors into mainstream society". In this context, Professor Kellie referred to a recent, comprehensive, single institution study of survivors, which found that (original emphasis):

the relative risk of severe neurocognitive impairment among survivors previously treated with craniospinal radiation *compared* to other long-term survivors of paediatric brain tumours treated without radiation show significant neurocognitive impairment in the domains of intelligence, academic achievement, attention (as a substrate for learning), memory, processing speed, and executive functioning.

25 It is important to observe that the comparison group in the study referred to was not a sample of the general population, but instead comprised patients with paediatric brain tumours who had been treated without radiation therapy. The study also revealed that:

- Unemployment was high across the entire study population, but was highest in patients treated with craniospinal radiation (48% v 56%).
- Only 18% of craniospinal radiation patients completed college education compared to 34% who did not receive radiation.
- 73% of patients who received radiation were not living independently, compared to 63% for the whole group and 48% for those treated without radiation.

- There was a much lower rate of marriage or cohabitation among survivors compared to siblings (22.2% v 73.4%).
- There was a significantly reduced likelihood of living independently (53% v 93.6%).
- There was a markedly reduced probability of pregnancy or partner pregnancy (11.6% v 61.8%).

26 Professor Kellie also recorded that the study concluded that “younger age was associated with severe neurocognitive impairment across all domains and craniospinal radiation conferred the greatest risk of severe neurocognitive impairment compared to patients who were not treated with craniospinal radiation”. He went on to observe, most importantly, that the observations from the study could not be applied directly to Oshin because he was three years younger at diagnosis than the median age in that study, and accordingly, the data in the study was likely to provide an underestimate of the long-term severe neurocognitive effects and difficulties with social attainment associated with radiotherapy.

27 In another study referred to by Professor Kellie, significant impairments were seen in 50% of survivors, including neuropsychological domains of attention, memory, visuo-spatial abilities, motor functioning, language and executive functioning. The study also found impairments in psychosocial domains, including employment, ability to drive, participation in normal education, independent living and dating history. Nevertheless, survivors and caretakers reported quality of life scores within the normal range.

28 Professor Kellie also reported that studies have demonstrated that:

- 36% of long-term survivors of medulloblastoma have significant hearing loss due to chemotherapy or radiation, and that this remains a significant and sometimes poorly recognised factor in impaired quality of life. A higher likelihood of hearing impairment, tinnitus and persistent dizziness were reported to be associated with doses of radiation of the type proposed for Oshin.
- Children receiving craniospinal radiation are at an increased risk of stroke. One report found that 13 out of 14 paediatric subjects with stroke had received cranial radiation, that the incidence of neurovascular events in this population is 100-fold higher than in the general paediatric population and that cranial radiation is an important risk factor.
- Patients treated with craniospinal radiation are at significant risk of long-term hormone deficiencies due to hypothalamic and pituitary dysfunction, particularly more than five years from diagnosis. The majority of younger children require injections of growth hormone until mid to late adolescence, but despite this, most young adult survivors are shorter than their peers. Most children receiving craniospinal radiation require life-long thyroid hormone supplementation because of the effects of radiation therapy on the thyroid gland. (Oshin would be at higher risk for endocrinopathies compared to standard-risk medulloblastoma patients because the proposed radiation dose required is higher.)

- Doses of radiation were significantly associated with the risk of developing cataracts, legal blindness, double vision and dry eyes, in a dose-dependent manner.
- The majority of survivors in a cohort of medulloblastoma patients receiving chemotherapy only for non-metastatic medulloblastoma were found in one study to have a mean intellectual functioning and quality of life within the normal range. In another study comparing children treated with or without cranial radiation therapy, mean scores for the children who had not been given radiation were generally within the average range in all cognitive areas except visual-spatial skills, which were significantly below aged-based normative means.

29 In dealing with the longer-term effects of radiation therapy, Professor Kellie referred to the summary provided in the report of the first Ethics Committee meeting at PMH, which stated that “Radiation also leads to some depression of intellect with an expected measured IQ of 70–80. This is a level compatible with normal schooling function at the lower end of the standard class”. It was Professor Kellie’s opinion that this statement was in contrast to “the literature on neurocognitive and psychosocial functioning”, and understates “the potential for radiation treatment-related harm”.

30 I am unaware of the extent to which the full ramifications of the radiotherapy were discussed at the meeting of the Ethics Committee, since it could not be expected that the report would record everything that was said in what was a very lengthy meeting. Given the meticulous attention to detail that seems to have gone into the planning for Oshin’s treatment and care, it would be surprising if the parents were not fully informed of the risks (and in any event, they have obviously undertaken considerable reading on the topic themselves). Certainly, the affidavit evidence provided on behalf of PMH at the hearing on 24 March 2016 gave details of the side effects of radiation. While the inevitable depression in intellect of radiotherapy patients was noted, it was only one of six groups of side effects that were mentioned in paragraph 24 of the affidavit of Dr W. Furthermore, the affidavit attached a report dealing with “four possible ways forward” for Oshin, one of which was a chemotherapy-only option. The report set out the specific treatment requirements, likely prognosis and potential side effects of all of the options. A very large quantity of other information and research was also provided to the court at the same time. The evidence also indicates that a chemotherapy-only option was formally presented to Oshin’s parents on 21 March 2016 and discussed with them.

31 While Professor Kellie was unable to determine whether a chemotherapy-only option was discussed at either of the two meetings of the Ethics Committee, he feared that absence of such an option may have led to a “polarised discussion between a craniospinal radiation-containing treatment plan and palliative care”, without discussion of the “middle ground” represented by a chemotherapy-only option. Professor Kellie said that it was his practice to present both options (i.e. a combination of radiotherapy and chemotherapy with a higher survival chance of 40–50%, versus a chemotherapy-only option with a survival rate of 20–25% but with significantly lower long-term adverse consequences). In his experience, presented with these options, parents usually fell into one of two groups, namely those who “prioritise survival at any cost over quality of survival, and those who prioritise quality of survival over survival at any cost”.

32 Professor Kellie agreed with the doctors at PMH that the “vast majority of parents” would opt for a curative treatment of a child such as Oshin, but that when a chemotherapy-only option was discussed alongside a chemotherapy and radiotherapy option, it was his experience that “at least a substantial minority” of parents would opt for the chemotherapy-only approach. The Professor said that he would respect that decision, particularly in a patient aged between three and six years at diagnosis (noting that Oshin was five years old when diagnosed).

33 Professor Kellie completed his first report by recommending that the next therapeutic decision should pivot on the response to the chemotherapy as measured by the MRI scheduled for 12 May 2016. He said at paragraph 72 of his report that (original emphasis):

if there is *complete or very near complete clearance* of all previously demonstrated tumour, I would continue the current treatment program because the MRI scan provides evidence that Oshin’s tumour is sensitive to chemotherapy...

34 On the other hand, if there was a “lesser degree of response”, with no change in the MRI appearance or evidence of progression of the disease, Professor Kellie said he would recommend discussion of palliative options, since the absence of an unequivocal response to chemotherapy would mean that the opportunity for cure would have substantially lapsed.

Professor Kellie’s second report

35 Professor Kellie provided a second report dated 14 May 2016, following review of the MRI scans obtained on 12 May 2016. In providing this report, Professor Kellie noted that he had no information about some of the details concerning the two courses of chemotherapy that Oshin had received. It was not suggested at the hearing that the fact Professor Kellie did not have access to this information might have impacted on his further recommendations. Professor Kellie also wrote his second report on the basis of a preliminary verbal report from Sir Charles Gairdner Hospital, where the recent lumbar puncture results were analysed, but it must be noted that the subsequent written report provided to PMH differed subtly from the information conveyed verbally. The verbal report said there were no malignant cells seen, whereas the written report noted the presence of free cells that are degenerate (i.e. damaged). It was not possible to determine whether these may be cancer cells, or only lymphoid cells.

36 Professor Kellie noted that the MRI revealed that Oshin had experienced “an unequivocal radiologic response” to the chemotherapy, but that he had not achieved a “complete” response. Professor Kellie then examined the possible options for Oshin by reference to what would be recommended for a child younger and a child older than Oshin who had achieved only a partial response from two courses of post-operative chemotherapy. In his view, in the younger child, radiation therapy would definitely not be recommended, but radiation therapy for the older child could be used as a “final consolidation” to ongoing chemotherapy. However, in the case of a child of Oshin’s age, Professor Kellie’s recommendation would vary depending upon whether

the child's parents were "willing to seriously engage with experienced medical advice to arrive at a treatment plan that is in their child's best interest".

37 Professor Kellie noted that at the age of five or six years, there is scope for a range of options, based on parental preferences. In the case of parents who are willing to engage, he would recommend continuing with a chemotherapy-only approach and performing another scan after another two courses of chemotherapy. In the event the patient achieved a complete radiological response to the chemotherapy, he would then recommend radiotherapy, albeit at a dosage lower than that proposed by PMH. However, in Oshin's case, taking into account the strong parental opposition to radiation therapy, his recommendation would be for an additional two courses of chemotherapy to determine whether Oshin is able to achieve a complete radiologic response. If such a response was achieved, Professor Kellie said that he would then have a discussion with the parents about the possibility of using radiation therapy, but would be "prepared to accept a chemotherapy-only approach as would be standard practice [for] patients aged less than three to four years at diagnosis".

38 Professor Kellie said that in giving advice like this to parents, he "would take care to outline the risks and benefits of lower radiation doses or avoidance of radiation ... as the standard of care in patients with M2 disease [such as Oshin's] is to recommend high-dose radiation therapy at age six years". He went on to say that "many practitioners and parents are able to discuss and negotiate a reasonable alternative therapeutic plan based on informed consent and respect for parental values as parents seek to understand and achieve what is in their child's best interest".

39 Professor Kellie concluded his second report by saying that in view of the results of the most recent MRI, the probability that Oshin will now be a long-term survivor, even if he had chemotherapy and radiotherapy, is less than the estimate of 40–50% he gave in his first report. He said that he would not compel radiation at the high dose proposed by PMH, "because, on the balance of probabilities, it is less than likely to save Oshin's life, but is virtually guaranteed to be associated with iatrogenic long term severe adverse health outcomes".

The PMH position

40 The position adopted by the PMH doctors emerges from their affidavit evidence and their oral testimony. At the hearing on Monday, I had the benefit of oral evidence from Dr G who has, since 2008, been the Head of Department and the Lead Paediatric Neuro-oncologist at PMH. Dr G is a highly qualified, widely published, expert of national and international repute. His expertise, communication skills and compassion impressed me greatly. He has been involved in the treatment of Oshin since he presented at PMH, and spoke of Oshin and his treatment for some hours in the witness box, during which he showed me the scans from the MRI and explained the findings to be drawn.

41 Dr G accepted that Professor Kellie is a renowned expert, indeed the most senior neuro-oncologist in Australia, and said that he valued his opinion. He said that while Professor Kellie was known to have a "particular viewpoint with regards to the dose of

radiation in young children”, he respected that opinion. Dr G did not seek in any way to shy away from what he accepted were the “horrible long-term side effects” of radiotherapy. He carefully described the side effects, although noting that some could be ameliorated, for example by providing hearing aids, performing cataract surgery, and offering growth hormone and thyroid support. However, Dr G recognised that it was not possible to ameliorate the neurocognitive impacts of radiotherapy, save by providing help in the classroom and extra time for exams.

42 Dr G also accepted that it is not possible to predict the extent of the side effects that any patient will suffer, but said that the general rule is that the higher the dose of radiation and the younger the child, the worse the side effects will be. Dr G observed that it was because of these side effects that a protocol called Head Start is used in some places for children up to six, who are administered chemotherapy only, and then beyond the age of six are administered chemotherapy and a reduced (24 Gray) dose of radiation. However, he said that even in children under six, if there was not a complete response to chemotherapy, radiotherapy would be recommended by the Head Start approach. Dr G described Head Start as being a “valid [and] noble approach” which was adopted by a number of physicians, albeit a minority.

43 In the event that Oshin had radiotherapy, Dr G said Oshin would be required to attend at Sir Charles Gairdner Hospital every weekday for six weeks in order to have small doses of radiation administered under a general anaesthetic. It would be expected that partway through this treatment he may require blood transfusions or some stimulant to increase the number of white blood cells to fight infection. He would also have some discomfort in his throat and oesophagus which may require painkillers, although the discomfort would be less than that experienced while having intensive chemotherapy. On occasion, Oshin may need to be hospitalised to get on top of some of the side effects of the radiation. He would have redness at the back of his head and his energy levels would be quite reduced. Following a period of recuperation, he would be given additional chemotherapy, but not as intensive as that he has had to date. He would nevertheless experience side effects with a possibility that he might again require hospitalisation for complications, such as an infection. This would probably go on for four to six cycles with adaptation, depending upon how he responded. The overall treatment would take a few months.

44 Dr G also gave evidence about the way in which Oshin would be likely to die in the event treatment was not successful, or if he was not given any further treatment. Importantly, in my view, Dr G anticipates that in the final stages of life, the hospital will be able to provide Oshin with relief from pain. Dr G is unable to predict what life Oshin has left. In the event that Oshin has palliative care which includes chemotherapy taken orally, the progression of the disease might slow down for a few months, but it is likely that he will pass away somewhere within six to 12 months, although more likely closer to six months.

The parents’ position

45 Oshin’s parents both filed affidavits recently, setting out their view of the impact of the treatment on their son. The mother said:

14. Since Oshin was ordered to undergo chemotherapy it has been extremely difficult for everyone. Oshin is traumatized, he won't bath or shower as he is scared to see the port on his stomach. We can only bed bath him. He's frightened of his own body, his blood. He has trouble telling when he needs to go to the toilet. What he is going through now is torture, he's not happy, constantly in pain, they have stripped away his insides and he has no immune system. Oshin is extremely traumatised and expressed fear and asked "what are they going to do to me now?".

...

16. Oshin is violently aggressive now, even towards us. We have to do clinical stuff and treat him at home and he now thinks of us as the 'baddies'. He has no other way to express it, because he has to submit. He advocates loudly that he doesn't want 'them' to do this and that, and they forcibly do it. He sometimes gets bruises. His only way is to get angry and frightened, even at the people he cares for most.

17. Oshin reacts very badly to general anaesthetic and the doctors want to do it most days. He screams every time he wakes from it and gets aggressive.

18. This treatment has taken away what could be quality, loving time with our son, instead of putting Oshin through this pain and suffering.

46 Oshin's father corroborated the evidence of Oshin's mother and concluded his affidavit by saying:

It has been so difficult to see a happy active boy turn into an angry, sick, traumatized boy, with stronger chemotherapy still ahead. This treatment should have never started. He should be given palliative care.

47 However, as noted earlier, since swearing their affidavits, the parents' position has changed in that they now propose to continue with the chemotherapy-only option mentioned by Professor Kellie.

The differences between the doctors

48 The decisions which must be taken in the treatment of life threatening illnesses will sometimes involve a consideration of the balance between maintenance of life and quality of life. The dilemma in striking the right balance is even more acute and agonising when the life in question is that of a child. That dilemma, and the deeply held conviction of Oshin's parents that the quality of life should be prioritised over its duration, is at the heart of this case.

49 Given the mutual respect and significant concurrence of medical opinion between the doctors, it seems that the real difference between them is that Professor

Kellie placed greater emphasis on the long-term quality of life of Oshin, whereas the PMH doctors placed greater emphasis on the maintenance of life itself. In doing so, the PMH doctors properly recognised that people with disabilities, even severe disabilities, can enjoy what they believe to be a good quality of life.

50 The other important apparent difference of opinion is that Professor Kellie (who was not cross-examined to clarify this) seems to hold out some hope that a continuation of the chemotherapy might, in itself, lead to a cure for Oshin. On the other hand, Dr G now holds virtually no hope that chemotherapy will ensure Oshin's survival. Dr G told me that, in his opinion, the chances of survival with chemotherapy-only treatment are "negligible", and that it was "inconceivable" that additional chemotherapy would lead to a "complete response or a very good complete response", which is what would be required, in his view, to contemplate refraining from administering radiotherapy.

51 Dr G said that the two extra cycles of chemotherapy proposed by Professor Kellie would be of the same type already administered, and thus involved a departure from Professor Kellie's study protocol. In Dr G's view, this suggests that the Professor recognised that continuing with the protocol would not achieve the outcome desired. In Dr G's opinion, continuing with chemotherapy-only would prolong Oshin's life, but would not result in a cure. In giving that opinion, he recognised that the data in the literature for the ongoing chemotherapy-only strategy was sparse. He also accepted that it is impossible to say with complete certainty that Oshin would not recover following a chemotherapy-only regime.

52 It should also be noted, as Dr G pointed out, that his gloomy prognosis seems to be consistent with what Professor Kellie originally said in paragraph 72 of his first report, to the effect that a chemotherapy-only option would be indicated only if there was a "complete or very near complete clearance of all previously demonstrated tumour". As Professor Kellie was not cross-examined on his reports, he did not have an opportunity to explain what otherwise might be thought to be some inconsistency between his reports. I can only speculate that his current opinion is based upon the significant impact of the chemotherapy as measured by the more recent MRI.

The law

53 In the ex tempore reasons I gave when the matter first came before me, I stated what I understood to be the applicable law and the power of this court to determine this dispute, recognising that this is the first occasion such an application has been made to this court. Counsel for the parents, who did not appear at the previous hearing, accepted that the law is as stated in those reasons, and that my power to make the orders sought by the hospital is undisputed. He accepted that the matter turns on the exercise of the court's discretion, bearing in mind that the best interests of Oshin are the paramount consideration.

54 Section 66C of the *Family Court Act 1997* (WA) ("the Act") prescribes a checklist of factors a court is obliged to consider when determining what is in a child's "best interests". However, most of those have no application in determining what is in Oshin's best interests. In my view, at least as presently advised, more

assistance is potentially to be gained from decisions made when a court is asked to authorise what are known as “special medical procedures” (albeit the treatment under consideration here does not fall within that category). In *In re Marion (No 2)* (1994) FLC 92-448 at 80,664, Nicholson CJ proposed a number of matters to be considered when dealing with such applications, namely:

- (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 be carried out;
- (iv) the alternative courses of treatment that are available in relation to that condition;
- (iv) the desirability of and effect of authorising the procedure for 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.

55 Counsel for PMH provided references to a number of cases decided in Australia and other common law countries around the world, dealing with treatment of children in circumstances where the parents were in conflict with the medical authorities. Most of these cases involved competent and loving parents who had a religious, cultural or philosophical objection to the treatment proposed, or preferred to put their faith in God

or alternative medicine. Counsel for PMH was unable to find any authority in which treatment had been ordered in a case where the position adopted by the parents was supported by the evidence of a reputable medical practitioner.¹ Nor could she locate any authority where radiotherapy had been ordered over the objection of the parents. In these circumstances, I am reminded of *Department of Health & Community Services v JWB and SMB (Marion's Case)* (1992) 175 CLR 218 in the High Court, where Brennan J said at 264:

The questions raised by this case starkly demonstrate the quandary of the law when it is invoked to settle an issue which is a subject of ethical controversy and there are no applicable or analogous cases of binding authority.

56 Nevertheless, I have found assistance in the seminal judgment of Holman J in *The NHS Trust v A (A Child)* [2007] EWHC 1696 (Fam), which was cited with approval in these terms by Mostyn J in *Re JM (A Child)* [2015] EWHC 2832 (Fam) (original emphasis):

14. How should the court exercise its powers when faced with an application to override the parental consent? The answer can be shortly stated. It is by reference to the principle that the welfare of the child is paramount, no more, no less. But that short answer deserves a fuller explication. To my mind it is never necessary to look further than the 10 propositions of Holman J in what is surely the seminal judgment in this field, namely *The NHS Trust v A (a child) & Ors* [2007] EWHC 1696 (Fam) ... At para 40 he set them out as follows:

- i. As a dispute has arisen between the treating doctors and the parents, and one ... [party has] asked the court to make a decision, it is the role and duty of the court to do so and to exercise its own independent and objective judgment.
- ii. The right and power of the court to do so only arises because the patient, in this case because [she] is a child, lacks the capacity to make a decision for [herself].
- iii. I am not deciding what decision I might make for myself if I was, hypothetically, in the situation of the patient; nor for a child of my own if in that situation; nor whether the respective decisions of the doctors on the one hand or the parents on the other are reasonable decisions.
- iv. The matter must be decided by the application of an objective approach or test.

¹ I was referred to the decision of the English Court of Appeal in *In Re B (A Minor) (Wardship: Medical Treatment)* [1981] WLR 1421, where medical treatment was authorised in a case where a surgeon had declined to perform surgery to remove a blockage in a baby girl with Down syndrome. The surgeon decided to respect the wishes of the girl's parents not to perform what was clearly lifesaving surgery after speaking to the parents on the telephone. Another surgeon was prepared to undertake the surgery and recommended it be carried out.

- v. That test is the best interests of the patient. Best interests are used in the widest sense and include every kind of consideration capable of impacting on the decision. These include, non-exhaustively, medical, emotional, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations.
- vi. It is impossible to weigh such considerations mathematically, but the court must do the best it can to balance all the conflicting considerations in a particular case and see where the final balance of the best interests lies.
- vii. Considerable weight (Lord Donaldson of Lynton MR referred to “a very strong presumption”) must be attached to the prolongation of life because the individual human instinct and desire to survive is strong and must be presumed to be strong in the patient. But it is not absolute, nor necessarily decisive; and may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering or other burdens of living are sufficiently great.
- viii. These considerations remain well expressed in the words as relatively long ago now as 1991 of Lord Donaldson of Lynton in *Re J (A minor) (wardship: medical treatment)* [1991] Fam 33 at page 46 where he said:

“There is without doubt a very strong presumption in favour of a course of action which will prolong life, but ... it is not irrebuttable ... Account has to be taken of the pain and suffering and quality of life which the child will experience if life is prolonged. Account has also to be taken of the pain and suffering involved in the proposed treatment... We know that the instinct and desire for survival is very strong. We all believe in and assert the sanctity of human life Even very severely handicapped people find a quality of life rewarding which to the unhandicapped may seem manifestly intolerable. People have an amazing adaptability. But in the end there will be cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause it increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's, and mankind's desire to survive.”

- ix. All these cases are very fact specific, i.e. they depend entirely on the facts of the individual case.
- x. The views and opinions of both the doctors and the parents must be carefully considered. Where, as in this case, the parents spend a great deal of time with their child, their views may have particular value because they know the patient and how he reacts so well; although the court needs to be mindful that the views of any parents may, very understandably, be coloured by their own emotion or sentiment. It is important to stress that the reference is to the views and opinions of the parents. Their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship.”

57 I would respectfully adopt those 10 considerations as being useful to bear in mind in exercising the discretion conferred on the court, although in reality the penultimate one can be seen as overarching all the others, since every case will be different, and must be decided on its own merits. I would add that I also respectfully agree with Tompkins J in *Re Norma* [1992] NZFLR 445, who said at 451:

But welfare is not to be regarded in only a physical or medical context, although undoubtedly those will be important. A child’s welfare is also bound up with his or her family. If a course of action is likely to cause serious distress and disruption within a family, that too is a factor that must bear on the welfare of the child and therefore weigh with the Court.

58 In my earlier reasons given in this matter, I said that I would be guided by the judgment in *Minister for Health v AS* (2004) 29 WAR 517, where Pullin J said at [21]:

Where faced with the stark reality that the child will die if lifesaving treatment is not performed which has a good prospect of a long-term cure, it is beyond doubt that it is in child’s best interests to receive that treatment...

59 However, his Honour also went on to say at [23]:

Obviously the court’s power in the inherent jurisdiction to countermand the wishes of a child patient or a parent, is to be exercised sparingly and with great caution.

60 It must be recorded, however, that Pullin J was concerned with a case involving blood transfusions. Issues of pain and suffering and long-term deleterious side effects therefore did not loom large in his Honour’s consideration, as they must in Oshin’s case. The prospects of the treatment being lifesaving in that case were also far higher than they now are for Oshin. Accordingly, Pullin J’s remarks must be understood in

their context and, in my view, tempered where there is an issue about pain and suffering and quality of life.

61 I also consider there is much to be said for the views expressed by Waite LJ in *In re T (Wardship: Medical Treatment)* [1997] 1 WLR 242 at 254:

All these cases depend on their own facts and render generalisations – tempting though they may be to the legal or social analyst – wholly out of place. It can only be said safely that there is a scale, at one end of which lies the clear case where parental opposition to medical intervention is prompted by scruple or dogma of a kind which is patently irreconcilable with principles of child health and welfare widely accepted by the generality of mankind; and that at the other end lie highly problematic cases where there is a genuine scope for a difference of view between parent and judge. In both situations it is the duty of the judge to allow the court’s own opinion to prevail in the perceived paramount interests of the child concerned, but in cases at the latter end of the scale, there must be a likelihood (though never of course a certainty) that the greater the scope for genuine debate between one view and another the stronger will be the inclination of the court to be influenced by a reflection that in the last analysis the best interests of every child include an expectation that difficult decisions affecting the length and quality of its life will be taken for it by the parent to whom its care has been entrusted by nature.

62 I therefore maintain the view I expressed in my earlier reasons that it is relevant for the court to consider whether the approach adopted by the parents is completely at odds with the approach which would be adopted by other parents faced with similar circumstances. As McHugh, Gummow and Callinan JJ said in *CDJ v VAJ* (1998) 197 CLR 172 at 219, “best interests are values not facts”. Accordingly, to use Waite LJ’s phrase, if a particular approach to a medical or ethical issue is “widely accepted by the generality of mankind”, taking that fact into account might be seen as one way of guarding against the decision being driven entirely by the idiosyncratic values of the presiding judicial officer. On the other hand, where there exists what Waite LJ described as “scope for genuine debate between one view and another”, it could not be appropriate to attempt to ascertain and then follow the majority view. In this regard, I respectfully agree with Baroness Hale who said in *In re B (Children) (Care Proceedings: Standard of Proof)* [2008] 2 FLR 141 at [20]:

Families in all their subversive variety are the breeding ground of diversity and individuality. In a free and democratic society we value diversity and individuality. Hence the family is given special protection in all the modern human rights instruments ... As Justice McReynolds famously said in *Pierce v Society of Sisters* 268 US 510, 535 “The child is not the mere creature of the State”.

63 My decision therefore is not to be made in a vacuum. It is to be made in the context of Oshin being a unique and important individual, but also in the context of him being a member of his own family and a member of the wider society. It is to be made also in light of the fact that by operation of s 69 of the Act, each of Oshin’s parents is invested with parental responsibility for him, which is defined as meaning

“all the duties, powers, responsibilities and authority which, by law, parents have in relation to children”. The state should not interfere in the performance of their parental obligations unless there is “some clear justification” for doing so: *Marion’s Case* per Brennan J at 280.

The court’s decision

64 My decision necessarily involves an assessment of the relative benefits and burdens of the proposed treatment alternatives for Oshin. In arriving at my decision, I have been greatly assisted by the evidence of Professor Kellie and that given by Dr G and the medical and nursing staff at PMH. However, unlike almost all other litigation that comes before this and other courts, I do not perceive that it is my function to determine which of the expert opinions should be accepted, to the extent that there are differences between them. As I perceive this dispute, given the common ground between the opinions of well-respected experts, the question is properly conceptualised not as a medical issue, but rather as a social, moral or ethical issue, in which the answer is “inevitably affected by personal perceptions of current social conditions, standards and demands”: Deane J in *Marion’s Case* at 304.

65 It seems to me that there are two social, moral or ethical questions involved. The first is whether greater emphasis should be placed on life itself or on the quality of the life. The second question is whether the first question should be answered by me as the representative of the state or by the parents, who in every other respect are permitted to make decisions on behalf of their child who is too young to make decisions for himself.

66 I am not permitted to approach these questions on the basis of what I would do if I were faced with the dilemma with which Oshin’s parents have been presented. I know what I would do, but my decision would be informed by my own opinion of the value of life, and by my own view of the richness and diversity that every living being brings to our world. Instead, my decision must be informed by an independent and dispassionate view of all the circumstances, knowing that my decision will not only have a profound impact on Oshin, but also on his family in dealing with the consequences of a decision forced upon them.

67 I have already observed that there appears to be no other case where a medical intervention has been imposed on parents in circumstances where there is a reputable, independent expert who considered that the views of the parents were supportable based on an assessment of the relative benefits and burdens of the proposed treatment. In saying this, I wish to make it plain that I admire and respect the viewpoint of the PMH doctors who have an entirely valid alternate view of life and morality. They have expended enormous time, intellectual effort and no doubt emotional energy in coming to court to obtain direction about the preservation of a unique and valuable human life. It is therefore outrageous that they have apparently been denounced in social media for performing the very task that our society expects them to perform – that is, doing their best for a young and vulnerable child entrusted by his parents to their care in December 2015.

68 Decisions must now be made for Oshin against the background of conflicting opinions from eminently qualified medical specialists. Both opinions are carefully considered, and neither can be said to be wrong. The medical specialists have respect for the opinion of the other, but they disagree as to the central issue of whether radiotherapy treatment, with all that entails, both positive and negative, is the best option for Oshin. 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. My view is reinforced by the fact that at least in Professor Kellie’s clinical experience, although it is not the experience of the doctors at PMH, a substantial minority of parents would follow the course adopted by Oshin’s parents.

69 It must be remembered that there were also differences of opinion amongst the members of the Ethics Committee on this topic. It is also important that I record that Dr G accepted that the question of whether or not to undertake radiotherapy involved a “value judgment of quality of life versus life per se”; that his recommendation reflected his “own personal value judgment”; that he was not saying that anybody else’s judgment was “wrong or right”; and that therefore Professor Kellie’s opinion was “not erroneous”.

70 In arriving at my decision, I have placed particular weight on the fact that, due to the unfortunate circumstances I have described, Oshin’s chances of survival have now been reduced significantly from what they might have been. As Dr G said, “the odds are stacked against Oshin”. My decision would have been even harder to make if the chances of survival were greater than they now are. I have also placed weight on the parents’ evidence concerning Oshin’s reaction to the treatment received to date. In saying this, I have little doubt that that his reaction would have been different had his parents been supportive of the treatment.

71 In arriving at my decision, I have also taken into account the conduct of the parents, and their passionate and highly public objection to Oshin undergoing radiotherapy. Their behaviour gives cause for concern about their ability to control their emotions around this topic in the presence of Oshin. If Oshin were to have “forced” radiotherapy, I fear he would again be exposed to his parents’ hostility and bitterness, potentially causing him even more psychological trauma. The impact on the parents of such forced treatment is therefore itself relevant in the determination of Oshin’s best interests in circumstances where his treatment regime and after-treatment care will require the intimate involvement and support of the family: see *Re M* [2014] NZFLR 381 at [23].

72 The ICL submitted that orders should be made in accordance with the recommendation of Professor Kellie, and that I should not require Oshin to undergo radiotherapy. She accepted that it would be an appropriate exercise of the court’s discretion either to dismiss the application of the hospital altogether (i.e. order no treatment) or to adjourn the application pending possible further developments.

73 The doctors at PMH are prepared to work with the parents in carrying out the parents’ decision to take up the chemotherapy-only treatment discussed by Professor Kellie. Dr G accepted that if there is a glimmer of hope that the extra chemotherapy might help, then he would like “to give Oshin the chance of that life”. Given the

agreement now existing between the parents and the hospital, I see no need for me to mandate the chemotherapy treatment, especially given Dr G's evidence about the poor prognosis and the impact on Oshin. The parents will therefore embark upon the agreed continuation of the chemotherapy-only option having been fully advised that it provides a significantly reduced prospect of survival for Oshin. They will also proceed in the knowledge of Dr G's advice that the level of discomfort Oshin will experience during the proposed additional chemotherapy will be greater than what he has experienced to date, and will involve two periods of hospitalisation of perhaps three to four weeks each.

74 I have decided that rather than dismissing the hospital's application, I should adjourn it without fixing a further date for hearing. This will provide opportunity for the hospital to bring the matter back before the court in the event that they consider any other intervention is required in Oshin's best interests. In the meantime, subject to hearing from counsel, I propose to discharge the earlier interim orders, save for the order preventing Oshin being removed from Australia. Oshin should, in my view, remain in Australia so that he receives, at the very least, the proper level of conventional palliative care that PMH hospital can provide.

75 I conclude by thanking the lawyers for their assistance in this difficult matter. I also acknowledge the efforts of the PMH doctors and staff who have so strenuously and professionally sought to achieve the one outcome everyone would have desired. Finally, I acknowledge Oshin's parents, who have done what they thought was right. Although it was they who chose to expose themselves to the glare of an, at times, unforgiving public, there is no reason to consider that they were ever motivated by anything other than genuinely held beliefs and love for their son. I wish them well in their journey with Oshin in the difficult days and months ahead.

Orders

- 76 Subject to hearing from counsel, I propose to make the following orders:
- 1 The orders contained in the Minute of Proposed Orders attached to the orders made on 24 March 2016 be discharged.
 - 2 The proceedings be adjourned generally with liberty to the parties to seek a relisting on very short notice on written application being made.

I certify that the preceding [76] paragraphs are a true copy of the reasons for judgment delivered by this Honourable Court

Associate
20 May 2016