

**Paediatric Oncologist, Dr B**  
**Auckland District Health Board**

**A Report by the**  
**Health and Disability Commissioner**

**(Case 13HDC00475)**



Health and Disability Commissioner  
*Te Toihau Hauora, Hauātanga*



## **Table of Contents**

Executive summary.....	1
Complaint and investigation .....	2
Information gathered during investigation.....	2
Opinion: Introduction.....	9
Opinion: Adverse comment — Dr B .....	10
Opinion: Breach — ADHB.....	12
Recommendations.....	14
Follow-up actions.....	14
Appendix A — Independent advice from Dr Andrew Murray.....	15



## Executive summary

1. On 5 June 2008, when Mr A was 14 years old, he underwent a biopsy which indicated that he had Ewing sarcoma (cancer) of the pelvis. On 10 June 2008, Mr A was admitted to hospital for surgical treatment, to be followed by chemotherapy treatment.
2. Mr A's first chemotherapy treatment was scheduled for the afternoon of 12 June 2008. That morning, on-call paediatric oncologist Dr B met with Mr A and his parents to discuss the treatment. Dr B mentioned the potential impact of chemotherapy on fertility, but did not emphasise it. The discussion focussed mainly on the potential adverse effects of the drugs to be used during the treatment. Mr A and his parents were provided with written information about the chemotherapy drugs, but those information sheets did not refer to the potential impact of chemotherapy on fertility.
3. Auckland District Health Board (ADHB) advised that, at the time of these events, the normal process was for fertility to be discussed with the patient by the Adolescent Nurse Specialist as part of a checklist prior to chemotherapy starting. However, on 12 June 2008 the nurse specialist was on leave and there was no apparent system in place to ensure that the checklist was covered by someone else in the nurse specialist's absence.
4. Mr A underwent his first chemotherapy treatment on the afternoon of 12 June 2008. The next day, a nurse mentioned fertility to Mr A and his parents when completing a routine checklist. Mr A's mother was upset when advised of the risk of infertility. Dr B met with Mr A and his parents on 13 June 2008 to discuss fertility and the option of storing a sperm sample. Part of this discussion took place in private with Mr A, without his parents being present.

## Decision

5. Prior to consenting to chemotherapy treatment, Mr A and his parents, who were his legal guardians at the time, were entitled to the information that a reasonable consumer, in Mr A's circumstances, would expect to receive. In this case, that would include information about the risk of chemotherapy treatment in respect of fertility, and the option for banking sperm in light of that risk.
6. Adverse comment was made about Dr B's failure to provide that information to Mr A prior to his first chemotherapy treatment, and his decision to discuss the option of Mr A providing a sperm sample in the absence of Mr A's parents.
7. ADHB was found to have breached Right 6(1) of the Code of Health and Disability Services Consumers' Rights 1996 (the Code)<sup>1</sup> for failing to have adequate mechanisms in place in 2008 to ensure the provision of fertility information and treatment options to consumers prior to undertaking chemotherapy treatment.

---

<sup>1</sup> Right 6(1) of the Code states: "Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive."

8. The Commissioner noted the steps being taken by Dr B, ADHB, and nationally, to improve the provision of information about fertility to consumers in these circumstances.
- 

## Complaint and investigation

9. The Commissioner received a complaint from Mr A about the services provided by Dr B and ADHB. The following issues were identified for investigation:
- *Whether Dr B provided Mr A with an appropriate standard of care in 2008.*
  - *Whether the ADHB provided Mr A with an appropriate standard of care in 2008.*
10. An investigation was commenced on 5 March 2014. The parties directly involved in the investigation were:

Mr A	Consumer/complainant
Dr B	Provider, paediatric oncologist
ADHB	Provider

11. Information from the Accident Compensation Corporation (ACC) was also reviewed.
12. Independent expert advice was obtained from Dr Andrew Murray, an obstetrician and gynaecologist with expertise in reproductive endocrinology and infertility (Appendix A).<sup>2</sup>
- 

## Information gathered during investigation

### Diagnosis

13. On 5 June 2008, when he was 14 years old, Mr A underwent a biopsy after a scan had identified a left ischium<sup>3</sup> lesion. The biopsy indicated that Mr A had Ewing sarcoma (cancer) of the pelvis.
14. Mr A had a history of pain in his hip and leg and had been limping because of the pain since December 2007. At the time of his diagnosis, Mr A was in a significant amount of pain and was taking medication, including morphine, for the pain.

---

<sup>2</sup> There are only two child cancer units in New Zealand, and HDC was advised that the paediatric oncologists from those two sites work closely together. Accordingly, to maintain independence and impartiality, HDC obtained expert advice from a reproductive medicine expert in this case, rather than from a direct peer of Dr B (a paediatric oncologist), on the recommendation of HDC's expert paediatric oncologist advisor. However, in light of the fact that Dr Murray is not a peer of Dr B I recognise the limitations of this advice.

<sup>3</sup> The ischium forms the lower and back part of the hip bone/pelvis.

### Admission to hospital

15. On 10 June 2008, Mr A was admitted to hospital for surgical treatment, which was to be followed with chemotherapy treatment. Dr B was the on-call paediatric oncologist when Mr A was admitted.
16. Dr B advised HDC that he accepted the referral for Mr A's ongoing care, and coordinated the completion of Mr A's staging investigations<sup>4</sup> and baseline organ function testing prior to the commencement of his therapy. Dr B further noted that, as the on-call doctor that week, he was also responsible for directing Mr A's supportive care and medical requirements while he was in hospital.
17. Dr B noted Mr A's pain and that he was on analgesics, including morphine.

### Surgery

18. On 11 June 2008, Mr A underwent surgery in which a double lumen Hickman line<sup>5</sup> was inserted, and bone marrow aspirates and trephines were performed.<sup>6</sup> The child psychotherapist liaison consultant documented that prior to surgery Mr A was "... clearly feeling stressed and anxious. Not a good time to talk directly with [Mr A] while he waits for this procedure" and "[Mr A's mother] reports [Mr A] very distressed when possibility of chemotherapy discussed".
19. In contrast, Mr A told HDC that prior to chemotherapy commencing he was not stressed but rather he was quite excited about having time off school. Mr A said that at that time he was not fully aware of the implications and seriousness of having cancer.

### Chemotherapy — Pre-treatment discussions

20. Dr B advised that he prescribed Mr A's chemotherapy course according to standard protocol for Mr A's specific diagnosis and accepted best international practice.
21. Dr B stated that he had hoped to meet with Mr A's family following the surgery on 11 June to discuss the chemotherapy treatment. However, as Mr A's father was not available by 6pm on 11 June 2008, it was agreed that Dr B would meet with Mr A and his parents the following morning, prior to the administration of his first scheduled chemotherapy.
22. At 8.30am on 12 June 2008, Dr B met with Mr A and his parents, where they discussed Mr A's planned treatment according to the Children's Oncology Group<sup>7</sup> AEWS0031 protocol. Dr B stated that they "mainly discussed" the adverse effects of the drugs to be used in the first cycle of Mr A's chemotherapy treatment,<sup>8</sup> and that

<sup>4</sup> Investigations such as blood work and imaging done as part of the assessment of the cancer in order for the treatment to be tailored according to prognosis.

<sup>5</sup> A Hickman line is a line which is inserted into the major vein that goes into the heart. It is used for the administration of chemotherapy medications, as well as for the withdrawal of blood for analysis.

<sup>6</sup> Bone marrow aspiration is the removal of a small amount of tissue in liquid form for examination. Bone marrow trephines is the removal of a small amount of solid bone marrow for examination.

<sup>7</sup> The world's largest organisation devoted exclusively to paediatric cancer research.

<sup>8</sup> The drugs were: vincristine, cyclophosphamide and doxorubicin.

they went through the information sheets for those drugs. The information sheets were developed by ADHB to be made available for patients undergoing chemotherapy. The sheets included information about the drugs, but did not include any information about risks in relation to fertility.

23. Dr B stated that the possibility of infertility as a result of treatment was mentioned to Mr A and his parents, but not emphasised. Mr A told HDC that Dr B did not “emphasize and/or mention infertility”. Mr A’s mother told HDC that on the morning of 12 June 2008 Dr B discussed the treatment and the drugs that would be used, but made no mention of infertility. She said that, had he done so, she would have paid particular attention, because Mr A often referred to her being a “Nana” in the future.
24. ADHB submitted that, at the time, there was no specific written policy with regard to ensuring quality of care in relation to infertility as a side effect of chemotherapy treatment in relation to children and teenagers. It advised that the policy was limited to “an intention to discuss the issue with the young person and their parents at the time most appropriate in the clinical care by the person on the team with the greatest skill in the area”. It advised that this was a topic included on a checklist to be covered by the nurse specialist.
25. Dr B noted that the Adolescent Nurse Specialist, who typically conducts such discussions and liaises with fertility specialists, was on leave at the time and so, in this case, the “back-up” mechanism to ensure that good quality fertility information was given to families was not in place.
26. Dr B submitted:

“I do recall the specific and not unreasonable concern of [Mr A’s] mother regarding the potential cardiotoxic effects of the planned use of doxorubicin. We spent significantly more time than I had previously spent or subsequently spent with other newly diagnosed families, talking about this issue. I mention this as although the emphasis was not placed as much on the fertility aspects of [Mr A’s] treatment as I have repeatedly admitted I could have, the discussion was by no means a quick or superficial discussion. I was reactive to the concerns voiced by the family to what they were hearing and sought to explain the implications of what was planned for [Mr A’s] treatment.”

### **First chemotherapy treatment**

27. At midday on 12 June 2008, Mr A underwent his first chemotherapy treatment.

### **Chemotherapy — discussions following first treatment**

28. Mr A stated that the following morning, on 13 June 2008, a nurse completed a routine checklist with him, which included discussion in respect of fertility. Mr A’s mother said that this was the first time infertility had been mentioned, and she was upset when advised of the risk of infertility. Dr B was informed of this, and he scheduled a meeting for 2pm that afternoon to discuss the matter with Mr A and his family.



29. At 2pm on 13 June 2008, Dr B met with Mr A and his family. He said that he apologised for not emphasising the fertility aspects of the adverse effects of chemotherapy during his conversation with them on 12 June 2008. In contrast, Mr A's mother said that he apologised for not having mentioned infertility the previous day.
30. Dr B subsequently provided Mr A with information about the possibility of infertility, and Mr A was given the option to provide a sperm sample to store for future use. Mr A declined the option of providing a sperm sample. Mr A recalls that this discussion lasted about 10 minutes, that he was alone with Dr B (his parents having left the room at that time), and that during the conversation Dr B asked Mr A whether he masturbated and whether he had talked to his parents about masturbation. Mr A said he felt embarrassed to talk to a stranger about those matters and unable to fully discuss sensitive issues such as masturbation due to his age. Mr A also stated that he felt "pressured and unsure about what decision [he] should have made", unsupported, and that he was rushed to make a decision.
31. Mr A's mother said that she "thinks it was outrageous" to discuss such a sensitive matter with her son when he was alone, unsupported and feeling unwell. She said that she would have been able to discuss masturbation with her son, as they had a close relationship and were able to discuss matters openly. In her view, given Mr A's wish to have children in the future, he would have been willing to do what was required.
32. Dr B agrees that, after learning of the family's concern regarding possible infertility, he discussed the matter separately with Mr A. Dr B stated that he explained that, in some cases, it is possible to obtain a sperm sample to store sperm for future use. Dr B recalls that Mr A was "very clear in private conversation with him at that time, that he would not have wanted to produce a sperm sample".
33. In a retrospective note made by Dr B at 2pm on 13 June 2008, he stated:

"Met with both parents and [Mr A] [at] 0830hrs 12/06/08 on the ward. Went through chemotherapy parent information sheets for [chemotherapy drugs]. ... Fertility was not emphasised in discussion, and in fact our sheets do not even mention this.

...

I was informed on arrival on the ward today at 0830hrs that mother was distressed that [Mr A] may become infertile with the therapy. I met with both parents [and] maternal Grandparents [and] [Mr A] just now to go over this.

In private conversation with [Mr A], he is adamant that he would not want to produce a sperm sample."

34. Dr B further stated: "This attitude was reported also by his bedside nurse in a further conversation." A nursing note made on 13 June 2008 records:

"Topic of fertility not covered adequately before chemo started. Mum asked about sperm banking. [Discussed with] [Dr B] who had discussion with family. Once

Chemo has started it is not possible to sperm bank. [Dr B] [discussed with] Mr A who said he would not 'do it' anyway!"

35. Dr B also stated that, at the time, he sought advice from colleagues and a specialist at Fertility Associates, who stated that the likelihood of collecting viable sperm was very low given Mr A's pubertal status at the time (tanner stage III<sup>9</sup>),<sup>10</sup> even if it had been obtained prior to chemotherapy administration. Dr B further stated: "From a practical perspective obtaining a sperm sample in these circumstances, of being newly diagnosed with a life-threatening malignancy and particularly with the pelvic pain issues that [Mr A] was experiencing, is likely to be unsuccessful."

### **Complaint and subsequent actions**

36. Mr A completed the cancer treatment and is now 20 years old. Mr A has since been diagnosed as being infertile.
37. Mr A complained to HDC that Dr B failed to explain adequately, prior to chemotherapy starting, that infertility was a commonly expected outcome of chemotherapy treatment and, as a result, treatment commenced without a sperm sample being collected from him.
38. In his response to HDC, Dr B stated: "I again apologise to [Mr A] for the poor quality of the initial discussion of adverse effects in relation to fertility ... I maintain that fertility was mentioned but agree with [Mr A's] ... statement that it was not emphasised enough, and for that I am truly sorry." Dr B did, however, submit that his approach in this case, while one he regrets, "was not inconsistent with the actions of [his] peers" in 2008.
39. With regard to his discussion with Mr A on 13 June 2008, Dr B stated:

"I am sorry that [Mr A] felt he was rushed, pressured and unsupported. I felt I had given [Mr A] as much time as he wanted and it is not my nature or practice to put pressure on anyone to make decisions when they are uncertain. It is standard practice for young people such as [Mr A] to be seen alone by their doctor, in addition to with their parent(s) or family. This is a fundamental aspect of practising medicine in the adolescent and young adult setting and allows for the disclosure of information to a health care professional that the individual may not feel comfortable discussing in front of family members."

40. ADHB submitted:

"The urgency of treating a difficult cancer, the emotional stress of a new diagnosis with a poor prognosis, and the large amounts of information to be conveyed and understood prior to starting treatment were all barriers to this discussion being given high prominence in [Mr A's] care."

---

<sup>9</sup> The Tanner scale is a scale of physical development in children, adolescents and adults. Tanner stage III generally refers to someone in between the age of approximately 10 and 15 years.

<sup>10</sup> This matter is also recorded in Dr B's retrospective note documented at 2pm on 13 June 2008 (Ibid).

41. ADHB further submitted that it “believes that this situation would be the same in other centres providing care for young people with cancer at that time” and that “[t]his has been an area of gradually increasing awareness and practice change”. It stated:

“[C]linical practice in the field of fertility preservation in cancer patients has continued to develop in the intervening [five] years and there are now improved documentation and processes in place to prevent similar experiences from occurring to other people ... these are addressing the gaps which [Mr A’s] complaint highlights.”

42. Dr B advised HDC that he is now “much more aware of the importance of detailed and well emphasised discussion around fertility as a result of [his] interactions with [Mr A]”, and that this has “impacted on how and when [he] conduct[s] [his] discussions about chemotherapy adverse effects with any new child or young person and their family”. He said that he “prefers to have staged discussions (multiple sessions) if the clinical situation allows so that all details including fertility aspects can be fully explored as much as possible within the constraints imposed by the need for prompt treatment” and that he also considers starting discussions regarding fertility even before a diagnosis is confirmed, “to allow the family more time to consider what if any options they might have”.
43. Dr B submitted that he does not consider that the likelihood of obtaining viable sperm from Mr A prior to chemotherapy treatment was high, particularly given the physical, psychological, environmental and developmental factors in play at the time. He further noted: “It is impossible to quantify the effect on prognosis by delaying [Mr A’s] therapy for 24 or 48 hours or for a longer period had this been taken to explore fertility preservation options further.”
44. In relation to whether sperm could be retrieved using needle aspiration,<sup>11</sup> Dr B stated that that technique was not routine at the time of Mr A’s admission, and neither is it routine today. He noted:

“The retrieval of sperm by testicular aspiration or wedge biopsy<sup>12</sup> is not routine practice, even today, in our unit. We have undertaken four of these procedures over the past five years, and my understanding is that only two have been successful, although the yield was still low, and they occurred in older and more sexually mature males. Another anaesthetic is involved and the procedure is not without its own risks of infection and haemorrhage. The early pubertal status of [Mr A] I believe means that even testicular aspiration or wedge resection, were it offered, would have been unlikely to be successful.”

### **Changes made at ADHB since 2008**

45. ADHB and Dr B advised that the following changes have been implemented at hospital and ADHB since 2008:

<sup>11</sup> Where a needle is used to extract the sperm directly from the testis.

<sup>12</sup> A biopsy of a small wedge of testicular tissue.

- Patient information sheets for chemotherapy drugs are no longer routinely used. Rather, the Children’s Oncology Group Adverse Effects Tables are used, which are more thorough. Dr B also advised HDC that the information that is now given to patients regarding fertility now includes a Fertility Checklist Form, Information on Sperm Storage and Consent to Store Sperm, Sperm Banking Medical Referral Form, and the Blood and Cancer Centre Fertility Preservation Pathway for Young Males.
- Dr B stated that hospital “now ensure[s] that as part of the initial work up of this vulnerable age group that they have discussions with the AYA Nurse Specialist in addition to the Paediatric Oncologist, as we recognise their specialised skill set in dealing with these complex issues and who have now built up strong links with the Fertility Specialists”. ADHB advised that another senior nurse takes on the roles and responsibilities of the adolescent and young adult nurse specialist when that nurse specialist is on leave, which provides additional support to the Consultant team and acts as a “safety net” to ensure all aspects of youth health are adequately dealt with, including ensuring fertility issues are appropriately addressed.
- A “second on-call” roster has been instituted, which allows the on-call consultant to better manage busy ward rounds and ensure fuller discussions between consultants and patients.
- A Fertility Preservation Working Group has been established with the support of the New Zealand National Child Cancer Network. The Working Group is responsible for developing nationally agreed approaches to minimise the impact of cancer and cancer treatment on future fertility of people of any age (national guidelines).

### **National guidelines**

46. Dr B further advised that national guidelines are in the process of being established, which recognise the difficulty in the issue of fertility in newly diagnosed cancer patients. The draft guidelines state: “Poor recall of discussions of fertility issues may also be a factor, particularly in the diagnosis and pre-treatment phases where a large volume of potentially distressing information is given to those newly diagnosed with cancer and their family/whanau.”
47. Furthermore, the guidelines will specifically address dealing with young people without detailed knowledge of the process involved in collecting a sperm sample. Dr B noted that the draft guidelines emphasise that the process is multidisciplinary, and the oncologist does not have sole responsibility of managing “this complex process”. He also noted that the guidelines “will ensure that I, as well as my colleagues, have accepted standards to benchmark against and will also cement the importance of this aspect of our chemotherapy conversations”. In relation to the guidelines, Dr B said that “this clearly stated standard of care was previously missing”.
48. ADHB submitted:

“The length of time that it has taken to develop and finalise this guideline illustrates that there was no pre-existing clear clinical consensus on the best approach, and that the issues needing to be considered were not straightforward. The guideline has been developed using a robust evidence grading approach in line with that now expected for such documents. The level of evidence available to inform the recommendations in the guideline was not high ...

Given that this is the current state of expert opinion/evidence in 2014 it can be understood that there was considerably less standardisation of approach amongst clinicians working in this area in 2008.”

49. On 31 March 2014, Dr B further submitted:

“The field of fertility preservation in adolescent cancer patients has gained significant momentum in recent years, in New Zealand and around the world. The standards of today are much higher than when [Mr A] presented in 2008 and with respect to Dr Murray many of his comments reflect what is now the position. [Mr A’s] complaint refers to his desire to see change in the way these aspects of care are handled and I believe he can be genuinely reassured by the advances and changes in clinical practice that we have made. The draft New Zealand Guidelines are the fulfilment of a long process that started in 2012 and with their likely acceptance in coming weeks, will provide a benchmark that will promote fertility discussions and preservation options.”

### **Response to provisional opinion**

#### *ADHB*

50. In response to the provisional opinion, ADHB stated:

“ADHB acknowledges that the policies and processes in place at hospital in 2008 were not adequate to ensure the appropriate and timely provision of fertility information to [Mr A]. It sincerely regrets that this was the case.”

51. However, ADHB submitted that “this would have been the case in other centres providing care for young people with cancer at that time”. ADHB submitted that “it is necessary to assess the adequacy of ADHB’s systems and processes by the expected standards in terms of information provision in the circumstances in 2008”. In light of the fact that its systems were not inconsistent with standard practice at the time, ADHB submitted that it should not be found in breach of the Code for its failure in this respect.

---

## **Opinion: Introduction**

52. Before discussing my findings I acknowledge the efficient and appropriate clinical care Mr A received overall in relation to his management from the point of diagnosis to the commencement of his chemotherapy. I consider that this demonstrates where

the system worked appropriately and, as a result, Mr A's cancer was managed and treated successfully.

---

### **Opinion: Adverse comment — Dr B**

53. This report considers whether Dr B provided sufficient information to Mr A and his parents (who were at the time his legal guardians).<sup>13</sup> In particular, the report considers whether Dr B provided Mr A and his parents with sufficient information about the potential impact of chemotherapy treatment on fertility prior to that treatment commencing, and the option of obtaining a sperm sample to store sperm for future use.
54. In making this assessment, I am required to assess Dr B's actions against those of his peers. That is, whether his actions were consistent with a reasonable paediatric oncologist at the time and in the given circumstances.
55. The events giving rise to this complaint took place in 2008. Accordingly, when assessing whether Dr B provided sufficient information to Mr A and his parents, I also need to consider what would have been reasonable practice in terms of information provision in these circumstances in 2008.
56. ADHB advised that, at the time, its policy was that issues regarding infertility as a side effect of chemotherapy were matters to be discussed "with the young person and their parents at the time most appropriate in the clinical care by the person on the team with the greatest skill in the area". It also advised that fertility was a "topic included on a checklist to be covered by the Nurse Specialist".
57. Dr B advised that the Adolescent Nurse Specialist, who typically conducts fertility discussions and liaises with fertility specialists, was on leave at the time. Dr B advised that he had a detailed discussion with Mr A and his parents on the morning of 12 June 2008, prior to Mr A's first chemotherapy treatment. However, he accepted that the focus of the discussion was on Mr A's mother's concern about the drugs to be used in the first cycle of Mr A's treatment and that, although the possibility of infertility as a result of treatment was mentioned, it was not emphasised.
58. In contrast, Mr A's mother told HDC that Dr B discussed the treatment and the drugs that would be used but made no mention of infertility. She said that had he done so, she would have paid particular attention.
59. Dr B also provided Mr A and his parents with written information sheets regarding the drugs to be used in Mr A's chemotherapy treatment. However, those sheets did not refer to the potential impact of chemotherapy on fertility.

---

<sup>13</sup> Note that the definition of "consumer" in Clause 4 of the Code includes, for the purposes of Rights 5, 6, 7(1), 7(7) to 7(10), and 10 of the Code, a person entitled to give consent on behalf of the consumer.



60. It was not until after Mr A's first chemotherapy treatment, when the matter was flagged by a nurse and concerns were raised by Mr A's mother, that Dr B fully discussed this matter with Mr A and his parents.
61. Prior to consenting to chemotherapy treatment, Mr A and his parents had the right to the information that a reasonable consumer, in Mr A's circumstances, would expect to receive, including in relation to the risks of treatment and his treatment options.<sup>14</sup> In my view, information about the risk of chemotherapy treatment in respect of fertility, and the option for banking sperm in light of that risk, is information that a reasonable consumer, in Mr A's circumstances, would expect to receive. Even if Dr B did make a brief mention of the risk of infertility during his discussion with Mr A and his parents on the morning of 12 June 2008, I do not consider that he provided sufficient information.
62. Furthermore, I do not consider it appropriate for the detailed discussion to have then taken place after Mr A's first chemotherapy treatment had taken place, on the instigation of his parents.
63. My expert advisor, Dr Andrew Murray, noted that "ideally a discussion about potential fertility preservation options should occur before any patient undergoes potentially sterilising treatment", and that written information about potential side effects should include those involving potential reduction in fertility, and options available to preserve it. However, Dr Murray also noted, "Regrettably this is often overlooked particularly in the first few days of a new cancer diagnosis, as the focus is very much on the timely diagnosis and treatment of the malignancy." Dr Murray referred to a web-based survey, where only 51% of patients felt that concerns about their fertility were addressed adequately. I also note Dr B's reference to the draft national guidelines, which note in the introduction: "Poor recall of discussions of fertility issues may also be a factor, particularly in the diagnosis and pre-treatment phases where a large volume of potentially distressing information is given to those newly diagnosed with cancer and their family/whanau."
64. While I am undoubtedly of the view that information about the risks of chemotherapy treatment in respect of fertility, and sperm banking options, is information that a reasonable consumer in Mr A's circumstances, would expect to receive, I am mindful of the standard of practice at the time and the need to assess Dr B's actions in accordance with the actions of a reasonable peer. It would not be appropriate for me to find Dr B in breach of the Code for failing to provide such information to Mr A in 2008, if a reasonable peer of Dr B would also not have provided that information in these circumstances, in 2008.
65. I accept the evidence of Dr B that, at the time of these events, there was little guidance available to clinicians as to what was accepted practice in this area, and how such discussions should be managed. This is evidenced by the fact that the information sheets provided to patients by ADHB did not mention the risks of treatment in relation

---

<sup>14</sup> Right 6(1) of the Code.

to fertility, and there was no apparent clear guideline or process for managing such discussions other than the inclusion on a nursing checklist.

66. I also accept the evidence of Dr B and ADHB that this is an area in which there has been significant development since 2008, both within ADHB and nationally, and that these developments are, in part, in recognition of the inadequacies of the systems that were in place at that time.
67. In these circumstances, while I consider that Mr A was entitled to information about the risk to fertility from chemotherapy treatment and the options for responding to that risk, it is not clear to me that Dr B's actions in this case were inconsistent with the actions of his peers in 2008. For this reason, I find that Dr B did not breach the Code in respect of the information he provided to Mr A and his parents in 2008.
68. However, I am critical of Dr B's decision to discuss the option of Mr A providing a sperm sample on the afternoon of 13 June 2008, in the absence of Mr A's parents. As chemotherapy had commenced, it was too late to collect a viable sperm sample. Furthermore, it had already been noted that Mr A was very distressed following his diagnosis. While I appreciate that in some cases it may be appropriate for a provider to have such conversations with a young patient without family members present, in the circumstances of this case I consider that the decision by Dr B was unwise. Dr B should have ascertained the suitability of having such a discussion with Mr A, in the absence of his parents, who were also his support persons, prior to engaging in that discussion. I suggest that Dr B carefully consider the appropriateness of his actions in this case, and its role as a contributing factor to Mr A's ongoing concerns about these matters.
69. I consider that there is much to be learnt from this case. The consequences of overlooking such discussions are significant and, as noted by Dr Murray, "often irreversible". I am reassured by the changes that Dr B has made to his practice, as well as the developments at ADHB and nationally through the development of the national guidelines. Nevertheless, this case offers clinicians working in this area a reminder of the importance of such discussions, and I trust that it encourages all providers working in the area to adopt the national guidelines and ensure that future practice in the area is improved, both within ADHB and nationally.

---

### **Opinion: Breach — ADHB**

70. ADHB has an organisational duty of care in respect of the care it provides. I consider that, in this case, ADHB failed in that duty of care to Mr A, because it did not have adequate policies and procedures in place to ensure the appropriate and timely provision of fertility information to him.
71. ADHB advised that, at the time, its policy was that issues regarding infertility as a side effect of chemotherapy were something to be discussed "with the young person



and their parents at the time most appropriate in the clinical care by the person on the team with the greatest skill in the area". It also advised that fertility was a "topic included on a checklist to be covered by the Nurse Specialist".

72. However, at the time of these events, the Adolescent Nurse Specialist was on leave, and there was no apparent system in place to ensure that the checklist was covered by someone else in the nurse specialist's absence. As noted by Dr B, this meant that the important "back-up" mechanism offered by the Adolescent Nurse Specialist, which should have been in place to ensure that good quality fertility information was provided to Mr A, was absent. This resulted in a missed opportunity for fertility discussions to occur with Mr A and his parents prior to the start of his chemotherapy treatment.
73. Furthermore, the patient information sheets ADHB made available to patients regarding the chemotherapy drugs to be used in their treatment did not include information about risks in relation to fertility. In my view, this was inadequate. I accept Dr Murray's advice that "[w]ritten information about potential side effects should include those involving potential reduction in fertility, and options available to preserve it".
74. In response to the provisional opinion, ADHB submitted that, while it accepts that it did not have sufficient systems in place to ensure the timely provision of fertility information to Mr A, this was not inconsistent with standards at the time. ADHB submitted:

"[I]t is necessary to assess the adequacy of ADHB's systems and processes by the expected standards of practice in terms of information provision in these circumstances in 2008."
75. I accept that at the time of these events there was little guidance for clinicians as to what was accepted practice with respect to the provision of fertility information. However, the risk of chemotherapy treatment in respect to fertility was not new or unknown information in 2008. ADHB did in fact have a process in place for the provision of fertility information to patients undergoing chemotherapy. However, this did not include a system for ensuring that the checklist was covered in the nurse specialist's absence. Accordingly, the processes put in place by ADHB failed in Mr A's case.
76. As noted by both Dr B and my expert advisor, Dr Andrew Murray, the first few days of a new cancer diagnosis can be very distressing and an emotional time for patients and their families. Accordingly, in circumstances such as this case, information about fertility can easily be missed in discussions between providers and consumers, as the focus will be on timely diagnosis and treatment. For this reason, it was particularly important that ADHB had in place adequate "back up" mechanisms to ensure that the provision of such information did not fall through the cracks. In this case, that should have included appropriate cover for the nurse specialist, and adequate and accurate written information. In my view, ADHB's failure to ensure such mechanisms were in

place in 2008 was inadequate. Accordingly, in my view, ADHB breached Right 6(1) of the Code.

---

## Recommendations

77. Dr B has agreed to comply with the following recommendations of my provisional opinion:
- Provide a written apology to Mr A. The apology should be sent to HDC within three weeks of the date of this report, and it will be forwarded to Mr A.
78. ADHB has agreed to comply with the following recommendation of my provisional opinion:
- Review its current policies, information sheets and practice with regard to discussions of infertility with patients undergoing chemotherapy, and report to HDC within three months of the date of this report.

I also recommend that ADHB provide a written apology to Mr A. The apology should be sent to HDC within three weeks of the date of this report, and it will be forwarded to Mr A.

---

## Follow-up actions

79. • A copy of this report with details identifying the parties removed, except the expert who advised on this case and ADHB, will be sent to the Medical Council of New Zealand and it will be advised of Dr B's name.
- A copy of this report with details identifying the parties removed, except the expert who advised on this case and ADHB, will be sent to the Royal Australasian College of Physicians in Paediatrics, the Australian and New Zealand Children's Haematology/Oncology Group, DHB Shared Services, and the Health Quality and Safety Commission, and placed on the Health and Disability Commissioner website, [www.hdc.org.nz](http://www.hdc.org.nz), for educational purposes.

## Appendix A — Independent advice from Dr Andrew Murray

The following expert advice was obtained from Dr Andrew Murray, an obstetrician and gynaecologist with expertise in reproductive endocrinology and infertility:

“Report by Dr Andrew Murray MBChB FRANZCOG CREI

Complaint: Care of [Mr A] by [Dr B], Paediatric Oncologist at [the hospital]

In writing this report I acknowledge that I have read and agreed to follow the ‘Guidelines for Independent Advisors’ provided by the HDC.

I am a consultant Obstetrician and Gynaecologist (FRANZCOG 2003) with subspecialty expertise in Reproductive Endocrinology and Infertility (CREI 2006) having obtained my initial medical degree through Otago University (MBChB 1994). My fellowship in reproductive endocrinology and infertility was commenced at Monash IVF, Melbourne, and subsequently with Fertility Associates, Wellington. I have been Medical Director of Fertility Associates, Wellington since 2007. Other current roles include Fertility Specialist for Capital Coast Health, Wellington and Senior Lecturer teaching reproductive medicine for Wellington School of Medicine.

I have been asked to provide preliminary advice to the Commissioner in relation to the care provided to [Mr A] by [Dr B] in respect to the following:

1. The adequacy of treatment provided to [Mr A] prior to his first chemotherapy treatment. In particular the expected level of discussion/consideration in relation to infertility as a side-effect of chemotherapy treatment and the option of providing a sperm sample in 2008;
2. The likely consequences of delaying the first chemotherapy treatment by 1–2 days;
3. The likelihood that [Mr A] would have provided a viable sperm sample *prior* to the first chemotherapy treatment; and
4. The likelihood that [Mr A] would have provided a viable sperm sample *following* the first chemotherapy treatment.

In providing advice this I have no conflicts of interest to declare.

### **Adequacy of initial discussion:**

With advances in cancer treatment, particularly childhood and adolescent cancer, survival rates have increased dramatically. [Agarwal et al. 2004; Lass et al. 2001; McVie, 1999]. Consequently many children and adolescents can expect to live well into their adult years. It is now estimated that 1 in 250 young adults will be cancer survivors by 2014 [Blatt, 1999]. Several studies have documented the importance of at the very least discussing potential implications on fertility, and if possible preservation of fertility.

Regrettably this is often overlooked particularly in the first few days of a new cancer diagnosis, as the focus is very much on the timely diagnosis and treatment of the malignancy. In a web based survey only 51 per cent of patients felt

concerns about their fertility were addressed adequately [Partridge et al J Clin Onc 2004].

In the present case [Dr B's] report describes 'mentioning' infertility as an issue, but not 'emphasising' it during his meeting with [Mr A] and his parents on the morning June 12, 2008 (the day chemotherapy was due to be initiated).

Written information sheets provided to [Mr A] regarding the potential side effects make no mention of potential infertility. Separate information about fertility preservation options was not provided.

Ideally a discussion about potential fertility preservation options should occur before any patient undergoes potentially sterilising treatment. Even if the option of fertility preservation is not taken up, patients want to have the options discussed.

### **Consequences of delaying the first chemotherapy treatment by 1–2 days:**

With respect to the likely consequence of delaying the chemotherapy for Ewings Sarcoma for 1–2 days (presumably to allow time for considering and arranging sperm cryo-preservation) — commenting on this is beyond my scope of expertise.

Having said that, if fertility preservation, particularly sperm banking is required, it is usually possible for it to be arranged acutely within this time frame.

### **The likelihood of viable sperm sample prior to the first chemotherapy treatment**

The likelihood of obtaining viable sperm prior to initiating chemotherapy at age 14 is high.

Although [Dr B] states that [Mr A] was Tanner Stage III, successful sperm retrieval is possible even before masturbation has commenced in adolescents through testicular sperm retrieval.

Understandably this is a difficult issue to raise with a young man and his family who are already in a distressed state dealing with a cancer diagnosis, and the treatment that lies ahead. Discussing personal issues such as masturbation in an emotionally stressed individual is difficult.

The exact age at which sperm production first begins is unknown and probably varies based on individual factors. Enlargement of the testes represents a transition from Tanner stage I to II, and it is around and after this time that spermatogenesis likely begins, even prior to the adolescent growth spurt [Nielsen et al. 1986; Hirsch et al 1985]. Nevertheless, adolescent males with cancer, ranging from age 14 to 17 years, have been found to be good candidates for sperm banking [Bahadur et al. 2002a; Kliesch et al. 1996].

After the first round of chemotherapy, but only after the issue of fertility was raised by a nurse, was the option of fertility preservation discussed with [Mr A] and his family. [Mr A] has stated that he felt pressured and unsupported at this stage.

While adult male cancer patients may be more willing to accept the notion of sperm banking to preserve future fertility, adolescents may be intimidated and

embarrassed by the concept. Their fertility wishes may not be realized for many years, and the long-term psychosocial impact of infertility on survivors of childhood cancer remain largely unknown [Zebrack and Zeltzer, 2003]. In addition, opinions vary regarding the most appropriate age for discussing sperm banking and who should be responsible for addressing this issue.

In one study of the 68 patients in their study who collected semen samples, 50 of them completed the study. They found that 80% of the patients made the decision to bank sperm with their parents, and that all of the patients who banked sperm felt that they were making the right decision to do so. Patients and parents alike wanted information about semen cryopreservation. The authors concluded that because semen quality was dramatically reduced, even by one course of gonadotoxic therapy, that sperm banking should be offered to all eligible patients prior to therapy. Parents played an important role in the decision to bank sperm [Ginsberg et al. 2008].

### **The likelihood of viable sperm sample prior to the first chemotherapy treatment**

As mentioned above sperm samples obtained following the initiation of chemotherapy are often sub-optimal in terms of concentration, motility and morphology (sperm shape). In addition, several studies have demonstrated high rates of chromosomal abnormalities in the sperm once chemotherapy has started. [Tempest et al 2007, Robbins et al. 1997]. Consequently the likelihood of obtaining viable sperm after the first chemotherapy treatment was low.

### **Summary**

The option of sperm cryopreservation should be discussed with all pubertal and adult patients who may have their fertility compromised, before such treatment is initiated. Written information about potential side effects should include those involving potential reduction in fertility, and options available to preserve it. In the present case there would have been a reasonable chance of retrieving sperm either through masturbation or through testicular aspiration. It is likely that this could have been arranged without unduly delaying the needed cancer treatment, or eventual cancer prognosis. Sperm obtained following initiation of chemotherapy is often abnormal, and for this reason most fertility clinics would not bank such samples.

It is understandable that the issue of fertility preservation is overlooked in the acute stages of cancer diagnosis and treatment, however the consequences of not considering these options are regrettably often irreversible.

### **References**

Agarwal A. (2000) Semen banking in patients with cancer: 20-year experience. *Int J Androl* 23(Suppl 2): 16–19.

Blatt *J Med Pediatr Oncol* 1999.

Partidge A, et al (2004) Web-Based Survey of Fertility Issues in Young Women With Breast Cancer *J Clin Oncol* 22:4174–4183.

Bahadur G., Ling K.L., Hart R., Ralph D., Wafa R., Ashraf A., et al. (2002b) Semen quality and cryopreservation in adolescent cancer patients. *Hum Reprod* 17: 3157–3161).

Bahadur G., Ozturk O., Muneer A., Wafa R., Ashraf A., Jaman N., et al (2005) Semen quality before and after gonadotoxic treatment. *Hum Reprod* 20: 774–781.

Ginsberg J.P., Ogle S.K., Tuchman L.K., Carlson C.A., Reilly MM., Hobbie W.L., et al. (2008). Sperm banking for adolescent and young adult cancer patients: sperm quality, patient, and parent perspectives. *Pediatr Blood Cancer* 50: 594–598.

Ginsburg E.S., Yanushpolsky E.H., Jackson K.V. (2001) In vitro fertilization for cancer patients and survivors. *Fertil Steril* 75: 705–710.

Hirsch M., Lunenfeld B., Modan M., Ovadia J., Shemesh J. (1985) Spermarche — the age of onset of sperm emission. *J Adolesc Health Care* 6: 35–39.

Kliesch S., Behre H.M., Jurgens H., Nieschlag E. (1996) Cryopreservation of semen from adolescent patients with malignancies. *Med Pediatr Oncol* 26: 20–27.

A., Akagbosu F., Abusheikha N., Hassouneh M., Blayney M., Avery S., et al. (1998) A programme of semen cryopreservation for patients with malignant disease in a tertiary infertility centre: lessons from 8 years' experience. *Hum Reprod* 13: 3256–3261.

McVie J.G. (1999) Cancer treatment: the last 25 years. *Cancer Treat Rev* 25: 323–331.

Nielsen C.T., Skakkebaek N.E., Richardson D.W., Darling J.A., Hunter W.M., Jorgensen M., et al. (1986) Onset of the release of spermatozoa (spermarche) in boys in relation to age, testicular growth, pubic hair, and height. *J Clin Endocrinol Metab* 62: 532–535.

Robbins et al. (1997) Chemotherapy induces transient sex chromosomal and autosomal aneuploidy in human sperm. *Nature Genetics* 16, 74–78.

Tempest et al. (2008) Sperm aneuploidy frequencies after chemotherapy in testicular cancer and Hodgkin's lymphoma patients. *Hum Reprod* 23 (2) 251–258.

Zebrack B.J., Zeltzer L.K. (2003) Quality of life issues and cancer survivorship. *Curr Probl Cancer* 27: 198–211.”