

SUPREME COURT OF QUEENSLAND

S.C. NUMBER:

115/24

First Applicant

Dr Hope Nakawa

AND

Second Applicant

Gold Coast University Hospital

AND

Respondent

Verity Mirovsky

by her litigation
guardian

Sister Beatrice of the Sisters of Light

Agreed Facts

Diagnosis

1. Verity Mirovsky has just turned 17 years old and lives on the Gold Coast, Queensland, with her parents and younger brother. She also has an older sister who recently married and lives in Brisbane. Her older sister is thinking of starting a family in the next year or two. When Verity was 15, she was diagnosed with a rapidly growing brain tumour, known as a glioblastoma.

Past treatment

2. Verity underwent immediate surgery in 2022 at Gold Coast University Hospital. The Gold Coast University Hospital is a government-owned and run hospital and is an agency of the government of Queensland. During surgery, the surgeon removed a 5cm mass from Verity's brain. Due to the tumour's location, a mass of 2cm in diameter remained which could not be removed.
3. From February 2022 - February 2024, Verity participated in four 12-week courses of chemotherapy at the Gold Coast University Hospital. According to the evidence of her

treating oncologist Dr Hope Nakawa, chemotherapy had halted the growth of the remaining tumour at 2cm but had not been able to shrink or remove it altogether.

4. On Thursday 25 April 2024, Verity suffered a severe headache and presented to Gold Coast University Hospital. Scans performed on that day showed that the tumour had grown to 4cm. Scans repeated on Thursday 9 May 2024 indicated the tumour had grown to 6cm.
5. Because of the rate of tumour growth, Dr Nakawa recommended that Verity undergo genetic testing to more precisely identify the nature of her glioblastoma and identify the most effective viral agent. Verity gave her consent to genetic testing. As part of the testing, comprehensive genetic information was also obtained.

Prognosis and treatment options

6. On Wednesday 15 May 2024, after the results of the genetic testing were received, Dr Nakawa called a family meeting with Verity, her mother Nadya and her father Dmitri. She explained that if the tumour continued to grow at this rate, she estimated Verity may have only 10 - 15 weeks to live.
7. Dr Nakawa also stated that in her opinion, a further round of chemotherapy is unlikely to be effective. Given the rate of the tumour's growth, it is likely to give Verity an additional four weeks of life, compared to receiving no treatment.
8. Dr Nakawa consulted with Dr Neal Gooding, the head of oncology at Gold Coast University Hospital and a leading cancer researcher. Dr Gooding confirmed Verity's diagnosis and clinical prognosis. Dr Gooding also stated that based on Verity's genetic testing results, she would be eligible to participate in a clinical trial of oncolytic viral therapy, which shows extraordinary promise beyond conventional methods of chemotherapy, radiation therapy and immunotherapy.
9. Given Verity's genetic testing results, Dr Nakawa presented to the family the option of oncolytic viral therapy, which in her opinion has the strong potential to kill Verity's cancer and induce remission. There is currently a clinical trial underway at Gold

Coast University Hospital, and because of her type of cancer, Verity would be eligible to participate in this trial.

10. Oncolytic viral therapy is a form of immunotherapy which involves using genetically modified viruses (such as the herpes virus, measles virus or cocksackie virus) to identify and kill cancer cells in the body. Because oncolytic viruses, like other viruses, are targeted by the immune cells, they are often removed from the body before they have a chance to perform their work. To prevent this, oncolytic viral therapy uses chimeric antigen receptor cells (CARs) as carriers for the oncolytic virus, enabling them to bring the virus directly to the tumour site.
11. The CARs will be obtained from embryonic stem cells, which are pluripotent and able to be developed into any type of bodily cell, including brain cells.¹ This enables them to specifically and accurately target the tumour in Verity's brain.
12. Dr Nakawa presented to the family evidence concerning Dr Gooding's research. Early findings based on a cohort of 20 patients trialing targeted oncolytic viral therapy have demonstrated the following: In 25% of patients, the therapy is ineffective, and the tumour continues to grow. In around 25% of patients, the tumour growth is slowed while intravenous treatment continues, and in around 50% of cases, the tumour shrinks or disappears. The survival rate at 12 months is 70% and at three years is approximately 50%.²
13. Dr Nakawa explained that immunotherapy is also possible with adult stem cells, but this requires finding a suitable match for Verity's cells, and given the short timeframe remaining, it would not be possible to find a match and culture the cells with the oncolytic virus in time.

¹ For the purposes of this moot, please assume that treatment with embryonic stem cells is legally permitted in Australia. (In fact, using embryonic stem cells for treatment or research is currently prohibited in Australia.)

² Although the medical facts presented are broadly accurate, certain details such as percentage risks, have been invented. Please assume that all medical evidence presented in this moot is accurate. Do not conduct any research confirming or contradicting this material.

14. Oncolytic viral therapy can also be performed using the patient's own CAR cells. However, given the heavy and repeated doses of chemotherapy Verity has already undergone, in Dr Nakawa's opinion it will be difficult to get a sufficient quantity and quality of CARs to ensure treatment success. Further, this method involves delays, as it requires CARs to be harvested from Verity, genetically transduced with the virus, then reintroduced into the body. Dr Nakawa estimated that due to the delays and the likely insufficiency of suitable CARs, treatment using Verity's own cells has about a 10 - 20% chance of reducing the growth of the cancer.
15. By contrast, there is a plentiful supply of embryonic stem cells already available in the laboratory, and given their pluripotent nature, no issues with donor matching arise. Treatment with virus-infused CARs could commence immediately.
16. Oncolytic viral therapy with either embryonic stem cells or adult stem cells follows the same process. Treatment consists of a one-hour intravenous infusion every week for six months, which can be performed as a day procedure.

Side effects

17. Common side effects for all types of oncolytic viral therapy include constipation, nausea and vomiting, fatigue and flu-like symptoms. Around 20% of patients also experience convulsions or seizures. A smaller proportion of patients will experience mental confusion, and some will experience psychotic delusions. These side effects will not persist after treatment is completed.
18. There is also a risk that the oncolytic virus may infect healthy cells as well as stimulate overall immune activity. Sometimes oncolytic viruses may cause the immune system to attack healthy cells, and their use may carry some risk of infection. Because of the experimental nature of this treatment, the magnitude of this risk is as yet unknown.

Verity's decision

19. At the 15 May meeting, Verity stated that, 'I would be willing to participate in the oncolytic viral therapy, but only if it can be done using cells which are not derived from embryos.' She, together with her parents and wider family, is an active member

of the Christian church “God’s Little Children”.³ One of the teachings of the church is that human life begins at conception, and all life is precious to God. Verity also stated that:

‘Embryonic stem cells are the most vulnerable of God’s little children. They cannot speak up for or protect themselves. I cannot agree to the treatment you suggest if it involves killing any of these precious children of God.’

20. Dr Nakawa has explained that there is a large supply of embryonic stem cells from embryos which are surplus to the IVF process, which would otherwise be destroyed. Using embryonic stem cells for treatment enables them to give life to people who are sick like Verity.

Verity’s father’s opinion

21. Verity’s father, Dmitri, pleaded with Verity to accept the option of CAR treatment with embryonic stem cells. In his view the destruction of surplus embryos cannot outweigh the prospect of Verity’s imminent death, especially when there is such a promising treatment available which has a high chance of a cure for Verity’s tumour. He stated:

‘Verity you are one of God’s little children, and he is offering you this chance of a complete cure. The lives of the embryos involved cannot be more valuable to God than your life. Those embryos are never going to have a chance at life anyway – if you don’t agree to this treatment, they will end up being destroyed.’

Verity’s second decision

22. Dr Nakawa asked for a private meeting with Verity, without either of her parents present. This occurred on 18 May 2024. Dr Nakawa reiterated to Verity that oncolytic viral therapy using CARs derived from embryonic stem cells has a high chance of remission and is the only method which offers the possibility of a cure. She stated: ‘On a conservative estimate, you have a 50% chance of a complete cure of your brain tumour with this method of treatment.’

³ For the purposes of this moot, please assume that ‘God’s Little Children’ is a recognized religion. In fact, this church and its religious beliefs are purely hypothetical.

23. Dr Nakawa made clear to Verity that in the absence of treatment, she could expect to die within 10-15 weeks. She asked her to carefully consider the option of stem cell viral therapy.
24. Verity listened carefully to all the information provided by Dr Nakawa. She then made this statement, which Dr Nakawa recorded on her mobile phone:

‘I understand that without the CAR viral therapy, it’s likely I will die within 10-15 weeks. I know you’ve said that with this type of treatment, there could be a 50% chance of going into remission. I don’t want to die, and I would really love to be cured from this cancer which has taken up the last two years of my life.

But unfortunately, I just cannot accept that some embryos, which are precious to God, will die to produce the CARs that you need to use in my treatment.

I can’t say that my life is more important than the lives of those embryos. An embryo is a human being just like me, and every bit as deserving of protection as me. Mum, Dad and I have been to so many rallies over the years, protesting against abortion. Even when I’ve been sick, I have still been signing petitions and writing things online. It would seem totally inconsistent now if I suddenly decided not to care about the lives of these embryos just because it suited me to use them for my own treatment.

I know you said chemotherapy will only bring me a few more weeks of life. I really don’t want to go through that again if it’s not going to bring more benefit than that. I’d rather be able to eat, and enjoy food, for my last few weeks on this earth. I can’t enjoy anything when I’m having chemotherapy.

Although I know the success rate of oncolytic viral therapy with my own cells is significantly lower, there is still a chance of achieving a cure. I’d prefer to take my chances on this treatment, rather than be complicit in the destruction of innocent lives.’

25. After this statement, Dr Nakawa referred the matter to the hospital ethics committee, which recommended she seek a court order to clarify the legal situation.

Genetic test results

26. To further complicate matters, Verity's genetic test results came back with the unexpected news that Verity has the BRCA1 gene mutation.

27. On 24 May 2024, Dr Skye Bleweyes, a specialist medical geneticist, was called in to advise Verity and Dr Nakawa on what this means. She explained to Verity that this is an inherited gene mutation which is passed down through families. When properly functioning, the BRCA1 gene is a 'tumour suppressor gene' which makes proteins that regulate cell growth. The BRCA1 gene mutation impairs the gene's ability to regulate cell growth, which can result in uncontrolled cell growth, leading to the development of cancerous cells and tumours.

28. The presence of these genes means that Verity now also has hereditary breast and ovarian cancer syndrome (HBOC), a genetic condition that means Verity has an increased risk of developing breast and ovarian cancers at a younger age. Dr Bleweyes explained that not everyone with the BRCA1 gene develops cancer. However, those with HBOC syndrome have a significantly increased lifetime risk of breast and ovarian cancer than those without the disease. Specifically, the lifetime risk of breast cancer increases from 12% to 55-70% for women with the BRCA1 gene mutation. Similarly, the lifetime risk of ovarian cancer is dramatically increased from 1% to around 40% for carriers of the BRCA1 gene mutation.

Disclosure recommendation

29. Dr Nakawa, as Verity's treating oncologist, discussed the implications of Verity's genetic test results with Verity immediately after Dr Bleweyes had left the room. She recommended Verity's mother be informed of the results. Dr Nakawa also recommended informing Verity's siblings (particularly her sister) that Verity has the BRCA1 gene, so they can undergo testing to see whether they also carry the BRCA1 gene.

30. Dr Nakawa explained that if Verity's mother or sister has the BRCA1 gene, they are at greatly increased risk of developing breast or ovarian cancer in future. It is important that they know this, so that they can take preventative measures, such as regular checks to enable early detection of cancer when it is most treatable. Recommended prevention includes twice-yearly mammograms to check for breast cancer and twice-yearly ultrasounds to screen for ovarian cancer, starting from age 30. Increased awareness also enables people to be alert to symptoms and seek diagnosis and treatment earlier.
31. Dr Nakawa told Verity that current screening programs for breast cancer recommend mammograms to women over the age of 45 if there is no increased risk. As Verity's mother is currently 43, if she is not informed of the risk, it may be two years before she undergoes regular preventative screening. Screening for ovarian cancer is not currently recommended for the general population, because of the relatively low incidence of this type of cancer in those who do not have the BRCA1 gene.
32. Dr Nakawa further mentioned that if Verity's siblings find out they have the BRCA1 gene, they therefore may choose not to have children, or to conceive children using donor gametes, to avoid the risk of passing the genetic mutation to any future children.

Verity's decision concerning disclosure

33. Verity listened carefully to Dr Bleweyes' explanation of the BRCA1 genetic mutation and HBOC syndrome. She also listened to Dr Nakawa's explanation of why disclosure of Verity's diagnosis is important for the health of her mother and sister.
34. However, Verity refused to consent to the disclosure of her genetic information to either her parents or her siblings. She stated:
- ‘God has predetermined the course of each person's life, and what will be will be. We should not attempt to predict the future, but rather trust in the providence of God to enable each of us to deal with our circumstances as they arise. What's more, at present, my parents have enough devastating news to deal with, without potentially being worried about their own decline and death.’

35. Dr Nakawa does not want to risk damaging the therapeutic relationship between herself and Verity by disclosing Verity's genetic information without her consent. It is important to her that Verity is able to trust her, so she can continue to provide potentially curative treatment. However, she is very concerned that the delay in disclosing the risk may be detrimental, particularly to Verity's mother.
36. Dr Nakawa sought legal advice from the hospital in-house counsel, asking whether she could legally disclose the information to Verity's mother and siblings, despite Verity's refusal. The in-house counsel told Verity the situation was legally unclear and recommended that she apply to a court for an order authorising disclosure if that was what she wanted to do.
37. Dr Nakawa telephoned Verity on the morning of Monday 27 May 2024. Dr Nakawa told Verity that she would like her to reconsider her objection to the optimal CARs treatment, and that she should disclose her genetic information to her family members. If Verity did not change her mind before 30 June 2024, Dr Nakawa told her that she would commence court proceedings to ensure that Verity's health, and the health of her family, were given the priority they deserve.

Application

38. Verity remained steadfast in her views relating to her medical treatment and unwillingness to disclose genetic information to her family. On Monday 1 July 2024, Dr Nakawa and Gold Coast University Hospital commenced proceedings in the Supreme Court of Queensland. They seek the following:
1. a declaration in the court's *parens patriae* jurisdiction that Dr Nakawa and Gold Coast University Hospital be authorised to administer CAR treatment with embryonic stem cells to Verity; and
 2. a declaration that Dr Nakawa must disclose Verity's genetic information (specifically, that she carries the BRCA1 gene) to her mother and siblings, either:

a. because it is required under the *Privacy Act 1988* (Cth) or the *Information Privacy Act 2009* (Qld); or

b. because Dr Nakawa has a common law duty to disclose genetic information.

39. Because Verity has not disclosed her genetic information to her parents, and because Verity's father does not support Verity's refusal of CAR treatment, the Supreme Court has appointed a litigation guardian to represent Verity's interests. The person appointed is the head of a local religious order, Sister Beatrice of the Sisters of Light. Legal Aid funding has been provided to support a lawyer for Sister Beatrice.

40. Verity has chosen not to appear in court, so as not to alert her parents to the application relating to disclosure of her genetic information. She is content to rely on Sister Beatrice to represent her wishes. Sister Beatrice supports Verity's wishes.

Nature of moot

This moot is to be conducted as a joint first instance application to the Supreme Court of Queensland by the first and second applicants. Both applicants are represented by the same counsel. Parties are required to engage with all aspects of the application. However, it is at the discretion of the parties as to how issues are divided between the Senior and Junior Counsel.

Parties are not permitted to seek to vary the orders sought, nor to introduce any other or alternative ground, order, or declaration.

Relevant facts

The relevant facts as noted above are agreed facts. The parties may not deviate from, nor seek to change these facts. No new facts or evidence may be introduced.

Relevant law

The law to be applied is the common law of Australia as currently applied in the jurisdiction of Queensland. Commonwealth and Queensland legislation should be referred to where appropriate. Foreign case law may be referred to if Australian case law does not deal with a particular issue.