
Northland Health

Report on Opinion - Case 97HDC8872

Investigation The Commissioner commenced an investigation on her own initiative under section 35(2) of the Health and Disability Commissioner Act 1994 as to whether Northland Health Limited (Northland Health) had complied with the Code of Health and Disability Services Consumers' Rights in regard to the decision to cease providing dialysis service to Mr Rau Williams.

Information The investigation commenced on 25 September 1997 following Mr Williams' brother's complaint to the Human Rights Commission, which consulted with me.

Information was obtained from:

Brother of consumer and whanau spokesperson
The Current Chief Executive, Northland Health
The Former Chief Executive, Northland Health
The Chief Medical Advisor, Northland Health
A Physician, Northland Health
A Senior Maori Liaison Officer
Two Maori Liaison Officers
A Social Worker
Nephew-in-law of consumer
The Chief Human Rights Commissioner
A Human Rights Commissioner

**Facts
Gathered**

Introduction

Mr Rau Williams died from renal failure on 10 October 1997. He had been refused admittance to the End Stage Renal Failure programme ("ESRF programme") on 3 September 1997 and dialysis treatment was withdrawn on 17 September 1997. There was some concern that Mr Williams had been refused dialysis treatment inappropriately.

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Procedures and Guidelines for entry into the Northern Region's End Stage Renal Failure Programme ("Guidelines")

Guidelines were established to manage the process for entry into the End Stage Renal Failure Programme. The Guidelines were developed "*to ensure comparable service across the region, determine when it is not appropriate to offer life prolonging therapy and to decide priorities for therapy on the basis of greatest probable benefit*". They are contained in a booklet dated 24 July 1996 and are the Guidelines appropriate in considering the services provided to Mr Williams.

The aim of the process is described as being "*to ensure that, so far as possible within the available resources, all patients are offered access to the treatment modality which is most suitable clinically and socially and which offers the greatest opportunity to benefit*".

Both refusal of treatment and withdrawal of treatment are contemplated within the Guidelines and it is noted that "*occasions occur where to commence or continue dialysis is futile and withdrawal is medically indicated and these will be fully discussed with the person and their whanau/family*".

The Guidelines include the medical clinical perspective for those in end stage renal failure who will not be offered the option of dialysis. While medical factors will be of importance, the Guidelines state that "*the full assessment procedure and guidelines for people in End Stage Renal Failure (ESRF) will include assessments related to sociocultural, economic and rehabilitative status of the individual and his/her family or whanau. While the medical clinical assessment is undertaken by physicians, and is an integral part of the process, it forms part of the assessment by the full health team and is not considered in isolation*". Attachment 1 (Medical Clinical Perspective).

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The use of dialysis is contemplated as part of the assessment process:

“As many as 25% of people present in advanced renal failure and there is a necessity to instigate dialysis quickly ... once the person is adequately dialysed and a full assessment made, the decision to withdraw treatment, should the guidelines so indicate, may become contentious for the patient, family and staff.”

Non-exclusive guiding principles are set out to assist clinicians to decide whether to offer a place on the ESRF programme or to withdraw treatment. These principles are:

“

- *Treatment would be of little physical and physiological potential benefit to the patient*
- *End stage disease in any other system which will not be improved by treatment*
- *Disease processes from which the patient will die within two years*
- *The compliance potential is not positive in that the patient is not able to co-operate with an active therapy*
- *Treatment is not in the best interests of the person as perceived by the assessing team, or is considered futile. (Examples would include those patients suffering from a severe dementia who are unable to feed, dress or toilet independently.)”* (p.8 of the Guidelines)

Some single factors are identified which may determine success at dialysis. Factors *“which in isolation are likely to determine that an individual is not suitable for treatment of End Stage Renal Failure”* include:

“CNS/Mental Function

Dementia (moderate to severe), very low IQ, a disabling psychiatric disorder which is unlikely to respond to further therapy, previous major stroke with persisting severe functional disability.

Basis: There must be the ability to co-operate with active therapy.”

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There is an emphasis throughout the Guidelines on the importance of cultural, spiritual and other advice and support, rather than on clinical or medical criteria alone.

For example, the Guidelines recognise that those people being assessed for entry to the ESRF programme should have "*the opportunity for support and assistance from a cultural advisor*" (as well as other professional staff). There is also an obligation on provider staff to advise "*of the range of cultural, spiritual and other professional advice*" which best meets the needs of the individual and the whanau.

Mr Williams' Medical History

Mr Williams had a medical history of Type II diabetes. The major complications of this disease are kidney and brain damage.

Mr Williams was admitted to Whangarei Hospital in September 1996. He subsequently developed acute renal failure. After initial refusal of dialysis by hospital clinicians, he was subsequently provided with dialysis and recovered sufficiently to be discharged home.

In the period from November 1996 to June 1997, Mr Williams' renal function gradually deteriorated. However, he did not require dialysis during this period, or hospital treatment. In April 1997 the responsible physician saw Mr Williams as he was approaching end stage renal failure.

In June 1997 Mr Williams reached end stage renal failure. He had an irreversible non-functioning kidney and without a mechanical process to clean his blood Mr Williams would die. The only treatment was a kidney transplant but in New Zealand it can take up to seven years to receive a transplant during which time the patient survives on dialysis. Dialysis can be peritoneal dialysis or haemodialysis. Both are heavily reliant on active patient participation. "*Scrupulous precision and cleanliness are mandatory. The insertion of tubing into the gut cavity, leakages, prospect of infection and failure require of the patient a great deal of courage and perseverance. The procedure is unpleasant. Haemodialysis requires even more understanding and patient perseverance with a prospect of the blood outside the body for cleaning causing a range of complications*". (Chief Medical Advisor, Page 8 of Affidavit)

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Although there are three phases before full assessment for the ESRF programme, because of Mr Williams' acute presentation, he was given the Phase 4 full assessment to determine whether he would be placed on the programme.

Clinical Issues

On 9 June 1997 Mr Williams had an elective Tenckhoff catheter insertion in order to provide home based Continuous Abdominal Peritoneal Dialysis (CAPD). He was discharged home with outpatient follow up but was re-admitted to Whangarei Hospital on 20 June 1997. He was failing to cope at home. It was reported that there was no food in his house (meals being particularly important in diabetic compliance) and his mental activity thinking (mentation) was slow.

Initial attempts to teach dialysis method to Mr Williams were difficult and it was thought that uraemia (the presence of excessive amounts of urea and other nitrogenous waste compounds in the blood normally excreted by the kidneys in urine) may have contributed to the slow mentation. Mr Williams showed an inability to learn or retain information about the dialysis process. He was admitted for hospital CAPD in order to discover whether his cognitive functions would improve for further training in the dialysis method and to enable Northland Health to conduct an assessment as to Mr Williams' suitability to enter the ESRF programme.

On 17 July 1997 Mr Williams was admitted to the Intensive Care Unit with a staphylococcal septicaemia. Following his admission to the Intensive Care Unit there was a further deterioration in Mr Williams' mental function, probably as a result of hypoxic encephalopathy during a period of extreme hypertension.

A re-assessment for eligibility on the ESRF programme was performed. This included a multi-disciplinary assessment of Mr Williams' cerebral functions. A psychiatric review, a psychological assessment and tests to exclude treatable reasons for dementia were performed during August/September 1997.

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The clinicians concluded that Mr Williams was suffering from moderate dementia. As a result, Mr Williams was assessed as not suitable for treatment for end stage renal failure, as set out in the Medical Clinical Perspective section of the Guidelines.

Consequently, Mr Williams and his Northland whanau were advised on 3 September 1997 that his assessment period would end on 17 September 1997 and that interim dialysis treatment would be discontinued as he would not be accepted onto the ESRF programme. A letter to Whangarei Area Hospital described reaction to this decision. *“To discontinue treatment seems to me to be a form of euthanasia without even having his consent. By denying further treatment ... you have effectively denied him life. Once the care is removed on September 17, [his] health will decline leading to his demise... [the physician] has stated on several occasions that [he] will pass away within two or three weeks from the removal of treatment.”*

The clinical conclusion was reviewed by an independent specialist in another major centre, and by specialists in other centres. They responded in the negative to Northland Health's question on whether, in their opinion, Mr Williams would be eligible for end stage renal treatment. These specialists were not advised that Mr Williams was currently on dialysis.

The decision by Northland Health to stop dialysis treatment was reviewed on two occasions by the High Court and the decision made by the High Court not to intervene was appealed to the Court of Appeal.

In his first judgement Justice Salmon concluded that as there was “no suggestion that the ...medical staff are acting in bad faith... they must be allowed to act in accordance with their clinical judgement. It is totally inappropriate for the Court to attempt to direct a doctor as to what treatment should be given to a patient.” (p.13) He therefore refused to make an order restraining Northland Health from discontinuing dialysis treatment or requiring treatment to be resumed.

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Mr Williams' brother made a complaint to the Human Rights Commission. He complained:

"The Whanau had been given false hope by the dialysis treatment and we believe that not only is it cruel to take my brother off this treatment now, it is also unethical. With regards to respecting individual dignity I would like to believe that Northland Health provide services that affirm, respect, and allow for the cultural expressions and customs of tangata whenua, and that informed consent, provision of information and respect for the rights of individual Maori, whanau, hapu, iwi, are a part of Northland Health's policy.

From what we have witnessed with my brother's treatment, Whanau input into his treatment and care has been given little regard. Cutting him off his machine has occurred despite pleas to reconsider the situation giving no consideration what so ever to the Whanau or my brothers wishes, due to a clinical decision which has not been elaborated on." [sic]

The complaint was withdrawn after a two day conciliation by the Human Rights Commission. After the process of conciliation the direct whanau were satisfied with the outcome which included an offer to transport Mr Rau Williams to Te Puke if he so wished.

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Mr Rau Williams' nephew-in-law then made a further application to the High Court. Again Justice Salmon refused to make an order on the basis that *"the decision not to accept Mr Williams on the programme was a clinical one without a significant administrative component and that the medical staff of NH [Northland Health] approached the decision made in a thorough and conscientious way. The Judge was also satisfied that the resources issue, if it played any part in the decision, was a minor component and that the guidelines were principally clinically based, being directed at assisting in the making of a clinical decision, not a resource-based decision."* The appeal to the Court of Appeal to overturn this judgement was dismissed. *"The evidence was such as to leave no tenable basis for argument that NH [Northland Health], or any of the doctors involved, failed in their responsibilities, either legally or from the point of view of good medical practice."*

The Court of Appeal noted that in the first High Court action *"judicial review proceedings had not challenged the decision-making process and that the particular application of the "Guidelines for Entry into the Northern Region's End Stop Renal Failure Programme" ("the guidelines") in this case had not been raised"*.

Cultural and Spiritual issues

The Guidelines required the clinical team undertaking an assessment to include a *"cultural advisor to provide advice to staff on the particular cultural perspective of the patient"* and a *"chaplain (if desired)."* They also required a psycho-social assessment including cultural expectations (page 6 of the Guidelines). Northland Health advised that:

- Two Kaiawhina were part of the assessment team to ensure cultural advice was available throughout the process, which included at least six family conferences.
- A chaplain was not included as part of the team as this was not requested by the family.
- Mr Williams' psychological assessment included questioning in Maori.

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Maori Liaison staff were interviewed by the Kaiwhakahaere from the Commissioner's Office. The senior Maori Liaison member of staff informed the Commissioner that she was informed of the decision not to accept Mr Williams on to the ESRF programme after it had been made and was told it was a clinical decision. She stated "*I could not understand why he was put back on to dialysis only to be informed when he was stabilised that he did not meet the criteria to continue with treatment.*"

One concern articulated by the Maori Liaison staff was that they were given short notice of a meeting at which clinical staff were to advise the whanau on the clinical decision which had been made.

No Kaumatua was offered by the clinical staff and despite advice from Northland Health that a chaplain was involved in the assessment team, the records of the family meetings fail to show the chaplain's presence. Mr Williams himself declined the involvement of the Hospital Chaplain, although at the request of the Northland whanau, a Ratana Minister provided spiritual comfort to Mr Williams.

Maori Liaison staff advised the Commissioner that "*we believe Maori needs and values were taken into account but it is acknowledged that in hindsight due to the Kaumatua not being involved some aspects of Kaupapa may not have been followed. This however did not affect care given to the patient or the ultimate outcome for the patient.*"

Maori staff informed the Commissioner that Northland Health's Maori Services Kaumatua and Minister should have been involved in the process and they offered this advice to Northland Health early on in the process.

One Maori Liaison Officer advised the Court: "*When decisions need to be made in Maoridom we go to the elders of a family, the whaea (mother) or koro (father).*"

Consumer Groups

The process of full assessment under Phase 4 of the Guidelines also includes reference to the fact that "*The consumer groups (Auckland District Kidney Society) will contribute through the sharing of information about life with renal placement therapy through the ESRF programme.*"

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Northland Health in their initial response to the Commissioner advised “*In the case of Northland Health, this usually involves patients who are actually on the End Stage Renal Failure programme, with Society representatives visiting Whangarei Hospital about twice a year. However, in the case of Mr Rau Williams who was not on the programme, he was counselled by another patient who was himself receiving dialysis treatment. This same patient also spent a day in Mr Williams’ home to advise him and exchange information.*”

Northland Health later advised the consumer’s name.

Further inquiry revealed that the “*patient who advised and exchanged information with Mr Williams was Rau’s brother-in-law, who was a patient in Ward 14 at the time Rau was there. Because of this relationship [he] spent time with Rau... no other consumer group or consumer, Maori or otherwise, was offered to Rau or his whanau.*” (Maori Liaison staff.)

**Code of
Health and
Disability
Services
Consumers’
Rights**

RIGHT 1

Right to be Treated with Respect

- 3) *Every consumer has the right to be provided with services that take into account the needs, values, and beliefs of different cultural, religious, social, and ethnic groups, including the needs, values, and beliefs of Maori.*

RIGHT 4

Right to Services of an Appropriate Standard

- 1) *Every consumer has the right to have services provided with reasonable care and skill.*
- 2) *Every consumer has the right to have services provided that comply with legal, professional, ethical, and other relevant standards.*
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Opinion:
No Breach

Right 4(1)

In my opinion, Northland Health did not breach Right 4(1) of the Code of Health and Disability Services Consumers' Rights in relation to the medical clinical decision to withdraw dialysis from the treatment options for Mr Williams.

The decision by the clinical team was the subject of considerable review. Firstly, there was a further opinion sought from an independent specialist in Auckland. There was also advice sought from clinical colleagues in other areas throughout New Zealand, with all five respondents agreeing that Mr Williams would not have been given a place on a dialysis programme in their area. While these opinions were all based on limited clinical information, their unanimity reassured Northland Health that a correct medical clinical decision was being made.

This has since been reinforced by two High Court judgements and a Court of Appeal decision as the result of the second High Court decision being appealed.

"It follows from the careful process adopted in this case and the clinical judgements to which it led that it could not be said that Northland Health was in breach of its duty under s151 of the Crimes Act to provide the necessities of life. Equally in the present context it could not be said that its actions of refusing to provide dialysis treatment would "deprive" Mr Williams of life in terms of s9 of the Bill of Rights."

(page 21 Court of Appeal judgement)

In my opinion, the decision not to admit Mr Williams to the ESRF programme based on the medical clinical criteria was undertaken with reasonable care and staff therefore complied with Right 4(1).

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**Opinion:
Breach**

Right 4(2) and Right 1(3)

In my opinion Northland Health breached Right 4(2) and Right 1(3) of the Code of Health and Disability Services Consumers' Rights by not complying with certain aspects of the ESRF Guidelines, particularly those relating to consumer advice and consultation, as well as its obligation to advise Mr Williams and his whanau of the range of cultural, spiritual and other professional advice.

The Court of Appeal commented "*It is enough to recall the five or six meetings held in the course of the 10 weeks ending in early September which members of the family attended and the range of clinical and other information and opinion which was gathered and exchanged in that process. We can see no possible basis for a finding of procedural error*".

The Court reviewed the clinical decision. Application of the procedural aspects of the guidelines were not challenged in the judicial review hearings.

The Guidelines recognised that if a decision is made to withdraw treatment the matter "*may become contentious for the patient, family and staff*". I have looked at the non-clinical process and in my opinion the whanau were not adequately consulted. Maori liaison staff were so concerned about the process that they withdrew from their professional roles to support and korero with the whanau members. Maori staff confirmed they had not been involved in the pre-assessment or assessment for suitability for dialysis, but rather were informed after the decision was made and told it was a clinical decision. Maori staff had advised management quite early on in the process to involve the hospital's Kaumatua and Maori minister and this advice was not followed.

Chaplain

In terms of the Phase 4 assessment under the ESRF programme, Northland Health was required to include in the assessment process as part of the clinical team a chaplain (if desired) and a cultural advisor who could advise staff on the particular cultural perspective of the patient. The process required a psycho-social assessment including cultural/religious factors and cultural expectations.

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**Opinion:
Breach,
continued**

There is some confusion within Northland Health's response. The Chief Medical Advisor advised that a chaplain was "*actively involved with the care of this patient.*" However while a Maori minister was offered to and declined by Mr Williams, Mr Williams' Northland whanau had asked for a minister and this did not occur.

As a result there was a failure to satisfy the requirements of the ESRF Guidelines, which state:

"Provider staff will ensure that each person and their nominated support people are aware of the range of... spiritual... advice,... which best meets individual needs and needs of their family/whanau. The decision to use such services is at the discretion of the person and their family/whanau or nominated support people."

In my opinion, a chaplain was not appropriately involved in the team as required by the Guidelines. While Northland Health said a chaplain was not included in the team as this was not requested by the family, a chaplain was requested and obtained to assist Mr Williams, but was not part of the assessment team itself.

Additionally, the failure to adequately document the process by which the clinical team consulted with Mr Williams and his whanau about involving a chaplain as part of the clinical team involved in the assessment was not an appropriate standard of record keeping. This was also a breach of Right 4(2).

Cultural Advisor

In my opinion, a cultural advisor was also not appropriately offered as part of the clinical team. The ESRF Guidelines state:

"All people being assessed for entry shall have the opportunity for support and assistance from a cultural adviser ... appropriate to their requirements. Provider staff will ensure that each person and their nominated support people are aware of the range of... cultural... advice, ...which best meets individual needs and needs of their family/whanau. The decision to use such services is at the discretion of the person and their family/whanau or nominated support people."

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**Opinion:
Breach,
continued**

The Maori Liaison staff advise that they were acting as “*patient/whanau support*” in the meetings which formed part of the assessment. At no time was a “cultural advisor”, as defined in the ESRF programme Guidelines, part of the clinical team. A cultural advisor is defined as “*an elder or a person with recognised authority and experience whose specific role is to advise on culture and that the spoken culture / language is understood by clinicians, the person involved and their family.*”

In Maoridom, an elder with recognised authority is usually a Kaumatua. Northland Health had a Kaumatua on staff at that time.

The Maori Liaison staff confirm that “*in hindsight, due to the kaumatua not being involved, some aspects of kaupapa may not have been followed.*” In my opinion, as no Kaumatua was appointed as a cultural adviser, the spiritual values and needs of this Maori consumer and his whanau were not met. In particular, if Northland Health had taken advice from an elder/Kaumatua, it is likely it would have been advised to consult with Mr Williams’ direct whanau in Te Puke.

There was also a failure to adequately document the involvement of the Maori Liaison staff and, importantly, in what role they attended meetings with Mr Williams, his whanau and the clinicians. This failure to adequately document who the cultural advisor was, and how that person was to be identified, led to confusion in the roles of the Maori Liaison staff and was a breach of Right 4(2).

Consumer Groups

The Guidelines also require the input of consumer groups in order to share information about how life is affected by renal placement therapy. In my opinion this aspect of the Guidelines was not met. While Mr Williams’ brother-in-law spoke with him, such information by a relative did not meet the requirements of the Guidelines. In my opinion this failure to follow the Guidelines was a breach of Right 4(2) and Right 1(3).

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**Opinion:
Breach,
*continued***

Summary

The Guidelines are there to ensure family and friends participate with the consumer to achieve the best possible outcome. As a decision not to proceed with dialysis is a notice of the impending death of the patient, discussion/korero, in a culturally appropriate way, is fundamental. In my opinion Northland Health Limited focused on the clinical indicators without recognising the importance of the wider needs of the consumer and his whanau. This did not mean individual staff did not care. Some staff were faced with not understanding Maori issues of wellness while Maori staff found themselves in an ethical dilemma, torn between their obligations to their own people and their obligations to their employer.

Similar decisions on dialysis occur throughout New Zealand every week, with consumers and their families privately working through the issues together with staff and the hospital. In this case Northland Health made its decision without fully recognising the importance of the process for Mr Williams and his whanau, without giving sufficient weight to the fact that the clinical decision was a life decision, and without sufficient support and recognition to cultural and spiritual needs. For Maori, cultural needs can only be met if the hospital and staff understand the four cornerstones of Maori oranga/wellness and deliver services within these concepts which I relate to the Code as follows:

- ***Te Wairua Maori***

This is the non-material, spiritual essence of a person. It is the life force that determines who you are, what you are and where you are going to and provides a vital link with the ancestors. The Code recognises this aspect under Right 1, the right to respect.

- ***Te Hinengaro***

This concept is generally interpreted as referring to mental health (illness and wellness). It recognises that the mind, thoughts and feelings cannot be separated from the body or soul. Together they determine how people feel about themselves and thus their state of health. The Code's holistic approach to consumer wellness and the aim of enhancing the consumer's quality of life is consistent with te hinengaro.

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**Opinion:
Breach,
*continued***

- ***Te Tinana***

This is the physical body / the present representation of the ancestors. Maori believe that the mind, body and soul are all closely inter-related and influence physical well being. Physical health cannot be dealt with in isolation, nor can the individual person be seen as separate from the family. Right 8 of the Code, the right to support, is important in respect of the latter point.

- ***Te Whanau***

Finally, the concept of te whanau deals with the linking of relationship from a common ancestor. Today, this means grandparents. Te whanau is encompassed in the Code's fundamental principles. Taking into account the needs of Maori means providers must recognise the relationship between individuals and their whanau. The wellbeing of the individual cannot be enhanced without recognition of the importance of whanau wellbeing to that individual. Similarly, whanau wellbeing is enhanced by the individual wellness of its members.

In my opinion Northland Health's failure to comply with the Guidelines and document their non-clinical actions resulted in a breach of Right 4(2) and its failure to provide a service that took into account the needs, values and beliefs of Maori was in breach of Right 1(3).

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Actions

I recommend that Northland Health takes the following actions:

Dialysis

- ensures that training programmes are implemented for clinical and social services staff, in order that they can carry out their functions in terms of the ESRF programme.
- ensures the manner of any consultation takes into account the Maori processes of receiving and disseminating information so that the consumer and his/her whanau are fully informed.
- makes available consumer groups to meet the Guidelines' requirements and consults with the Auckland Kidney Society in finalising this.
- documents actions taken to meet the Guidelines in the consumer's notes, including the consultation between the various providers, meetings with the consumer, family/whanau and support, as well as consumer groups.

General

- Northland Health Ltd must ensure all staff are appropriately trained to meet the cultural needs of Maori including understanding the Treaty of Waitangi and concepts of Maori wellness/oranga. Statistics indicate that 51% of Northland Hospital's patients are Maori and therefore this training is required to ensure Right 1, the right to respect, can be met.
- I note that Northland Health have established a Maori Directorate and appointed a Manager to that Directorate. I have also been informed that it now obtains advice and input from its Kaumatua in similar dialysis cases and has recently appointed an additional Kaumatua in the Far North.

Other Actions

This opinion is a matter of public record. Additionally copies will be forwarded to the Medical Council of New Zealand, the Minister of Health, the Ministry of Health, the Health Funding Authority and the Crown Company Monitoring and Advisory Unit.
