

McKenzie Report

Health and Disability Commissioner

(Case 02HDC18414)



Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

Parties involved

Dr Neil McKenzie	Complainant / Consumer
Mrs Gail McKenzie	Complainant / Consumer's wife
Dr A	Provider / Neurosurgeon
Dr B	Provider / Radiation Oncologist

Complaint

On 4 December 2002 the Commissioner received a complaint from Dr Neil McKenzie regarding the care he received from Dr A, a neurosurgeon, and Dr B, a radiation oncologist, following diagnosis of a brain tumour in April 2001. The complaint was summarised as follows:

Dr A

- *In May 2001 Dr A failed to inform Dr Neil McKenzie of the option of surgery, specifically tumour resection, including its expected benefits, to treat his advanced brain cancer.*

Dr B

- *In May 2001 Dr B failed to inform Dr Neil McKenzie of the option of surgery, specifically tumour resection, including its expected benefits, to treat his advanced brain cancer.*

An investigation was commenced on 3 April 2003.

Information reviewed

- Information obtained from Dr Neil and Mrs Gail McKenzie, Dr A, and Dr B
- Dr McKenzie's records from Mercy and Waikato Hospitals

Information gathered during investigation

Background

On 24 April 2001 Dr Neil McKenzie suffered a convulsion with loss of consciousness during a regular lunchtime run. This was preceded by a four-week history of urgency of defecation and passing urine, and a two-week history of “veering” to the right when walking or driving. He was taken by ambulance to Tauranga Hospital where a CT scan of his head showed a right frontal mass.

Dr McKenzie was discharged from the hospital later that day with a referral to Dr A, a neurosurgeon in Auckland. The referral was made by a specialist in emergency medicine at Tauranga Hospital Emergency Department who also worked as a general practitioner in private practice. Dr A arranged to see Dr McKenzie in Auckland on Friday 27 April.

On 27 April Dr McKenzie had an MRI scan at Mercy Radiology in Newmarket, Auckland, arranged by Dr A. The MRI showed a single 3cm mass in the posterior right frontal area of the brain. The differential diagnosis on the MRI was that of a primary glioma or a secondary (metastatic) tumour deposit.

Later that day, Dr McKenzie consulted Dr A. Mrs McKenzie advised me that she and her husband were informed that the growth seen on the CT and MRI scans was a tumour but that it was uncertain whether it was a primary or secondary growth. Dr McKenzie stated that Dr A recommended a biopsy, to which he agreed. The procedure was scheduled for Monday 30 April at Mercy Hospital.

Dr A advised me that at the consultation on 27 April he explained to Dr and Mrs McKenzie that the growth was likely to be a malignant tumour but that a biopsy was needed to confirm that. He also informed them that the amount of tumour he would remove would depend on “the pathology and what was found at operation”. If the tumour was a metastatic deposit then excision was likely. However, if it was a primary brain tumour then it was unlikely that the tumour would be completely removed, and there was a possibility of his hemiparesis (paralysis of one side of the body) becoming worse if radical excision was undertaken. Dr A stated that “the irresectability of the glioblastomas was mentioned in the pre-operative consultation, although it appears this was not fully understood by Dr McKenzie”. Dr A also stated that other risks associated with surgery were discussed and that Dr McKenzie accepted them.

Mrs McKenzie recalled that her husband was concerned that if the tumour was a secondary growth his “prospects would be bad”. He was hoping that it was a primary growth and anticipated that the tumour would be removed if possible.

In a letter to the referring emergency medicine specialist dated 27 April 2001, Dr A stated:

“We have discussed this at length, but histological examination is necessary and we have agreed to proceed to a craniotomy on Monday 30th April. He is aware of the risks of the surgery and in particular, the possible worsening of his left sided hemiparesis.”

On 29 April Dr McKenzie was admitted to Mercy Hospital as scheduled. He signed a consent form for “craniotomy and removal of tumour”. Mrs McKenzie was under the impression that her husband was there to have the tumour removed rather than just biopsied for the purpose of diagnosis. She “hoped and expected” that Dr A would remove the tumour.

Surgery

On 30 April 2001 Dr A performed a craniotomy and located the tumour using ultrasound. A biopsy of the tumour was performed. The tumour was found to be necrotic and at operation the frozen section confirmed that it was a glioblastoma. Dr A removed only a small piece of the tumour. He explained that “with the poor prognosis associated with glioblastoma and the likelihood of making his hemiparesis worse, and therefore curtailing his ability to continue to enjoy playing his music, I felt that nothing further should be done”.

Dr A quoted medical literature stating as follows: “Glioblastomas have frustrated every attempt at successful therapy. This is mainly because the tumour is well beyond the reach of local control when it is first detected clinically or radiologically.”¹ He also quoted another source stating: “... glioblastomas are among the most malignant human neoplasms with a mean total length of disease ... of less than one year”.² Dr A explained that survival times relative to the degree of tumour resection are not substantially different:

“With the above in mind, surgical options have to be tailored to the individual. The patient’s clinical status notwithstanding, the tumour’s site and size being the determining factor as to what surgical option is best. The adage of ‘first do no harm’ remains paramount in neurosurgery and in Dr McKenzie’s case the risk of a hemiparesis and the inability to continue with his music for the short time he had left was a major consideration.”

Postoperative consultations with Dr A

Mrs McKenzie advised me that on 1 May 2001, the day after the operation, Dr A informed her husband (while still in the hospital’s Intensive Care Unit) that he had been unable to remove the tumour and was awaiting the histology report.

On 3 May Dr A told Dr McKenzie the biopsy result. Dr McKenzie stated that Dr A informed him and his wife that the growth was a malignant primary glioblastoma and that he had a terminal condition. Dr A told him that there was no surgical option “that would make any difference”, the only option being palliative therapy.

Mrs McKenzie advised me that because Dr A told her husband and her that “there was nothing he could do”, “no surgery would be of benefit” and “nobody survives these things”, they did not ask Dr A about the option of further surgery. According to Mrs McKenzie, the meeting with Dr A was unscheduled, took place at 7am and was brief (about five minutes).

¹ Atlas of Tumour Pathology – Tumours of the Central Nervous System, P C Burger and B W Scheithauer, page 67, published by the Armed Forces Institute of Pathology, Washington, DC.

² World Health Organization Classification of Tumours – International Agency for Research on Cancer (IARC) – Pathology and Genetics of Tumours of the Nervous System, P Kleihues & W K Cavenee, page 38.

Dr A confirmed that on 3 May he discussed the diagnosis of malignant tumour with Dr McKenzie and his wife, and explained the “grave prognosis” and that “his mainstay of treatment would be radiotherapy”. He said this was accepted by Dr and Mrs McKenzie and that he arranged for Dr McKenzie to be seen by Dr B, a radiation oncologist, later that day – before he was discharged from hospital. In a letter of referral to Dr B, Dr A wrote: “At present [Dr McKenzie] has no neurological deficit ... He is a delightful chap and hopefully we can do our best by him.”

When asked whether at that time he was aware of the availability of more aggressive surgery for glioblastomas, Dr A stated:

“Aggressive surgery for glioblastomas has been around for as long as I have been in neurosurgical practice but has never been shown to prolong longevity significantly and has certainly never been shown to be curative. Although only a biopsy was taken, this was discussed with the McKenzie family. I explained that I did not perform radical surgery for fear of damaging him, and this was accepted.”

Mr Robert McKenzie, Dr McKenzie’s son, advised me that on the afternoon of 3 May he spoke to Dr A by telephone. He said that Dr A informed him that the tumour his father had was a “very bad tumour” and did not offer further surgery as a “possible solution to a longer life”. He said he was told by Dr A that the family “could be looking at six weeks, worst case”. Mrs McKenzie recalled that her family was told by Dr A that “only about 5% of people [diagnosed with this type of tumour] survived to the two year mark”. In a letter to Dr McKenzie’s insurer dated 6 June 2001, Dr A stated that Dr McKenzie’s prognosis was “poor and life expectancy would be likely to range from six months to two years”.

There was no further contact between Dr McKenzie or members of his family and Dr A after this date. The appointment for a postoperative check scheduled for 23 May was subsequently cancelled by Dr McKenzie. Dr A advised me that at this meeting “the pros and cons of further surgery could have been discussed in detail with Dr McKenzie and his family, but unfortunately by that time they had decided on a different path, which they were quite entitled to do, and no further contact was made by them after their cancellation of this appointment”.

Consultation with Dr B

On 3 May 2001, at approximately 6pm, Dr B came to the hospital to see Dr McKenzie as arranged by Dr A. Present with Dr McKenzie were his wife, mother-in-law (Mrs Valerie Hansen) and son Robert, who had arrived from England a few days earlier.

Dr McKenzie advised me that Dr B confirmed that his condition was terminal with a likely prognosis of six to 12 months. He said that Dr B “stressed” that he agreed with Dr A’s opinion that the tumour was inoperable (and incurable) and that the only option that might be of benefit was palliative radiotherapy.

Dr B recalled:

“When I saw Dr McKenzie I explained to him that in [Dr A’s] opinion the risks of attempting a significant resection were probably greater than the possible benefits. I

explained to him that new damage to the motor strip could produce permanent paralysis of the left side of his body and even with more aggressive surgery his lesion could not be cured.”

Dr B advised me that if major tumour removal is deemed too risky, an open biopsy should be performed to establish diagnosis. As the tumour was very close to the “motor strip”, that is the procedure Dr A had performed. Dr B stated:

“... I am not a neurosurgeon and I am not able to offer a professional opinion as to the potential resectability of Dr McKenzie’s tumour. However based on [Dr A’s] intra operative findings and his great experience and skill I had every faith that his judgment to biopsy only represented probably the best solution to a very complex problem and probably one that minimized the risk of disability.”

Dr B stated that he indicated to Dr McKenzie that radiotherapy was offered “with the aim of slowing down of the progression of the tumour and preserving his neurological status as it is for as long as possible”. As radiotherapy was not available privately and could not be offered locally through the public system because of Dr McKenzie’s out-of-area status, Dr B requested radiotherapy for him through Waikato Hospital.

Dr McKenzie stated that Dr B raised the possible option of using temozolomide, a chemotherapeutic agent, but that it could only be obtained through participation in a double-blind drug trial. Mrs McKenzie advised me that she and her husband did not consider this to be a good option as there was no certainty that he would be given the drug.

When asked what treatment options were discussed with the McKenzie family on 3 May 2001, Dr B stated:

“I did not offer Dr McKenzie any specific treatment options as he was not an Auckland Region patient and I could not treat him in Auckland. I referred him to the Oncology Department at Waikato Hospital for further treatment. The options of potential therapies that may be offered at Waikato included radiotherapy, chemotherapy at disease progression and re-operation should the disease progress and be surgically resectable.”

Mrs McKenzie had a slightly different recollection, as follows:

“I remember explicitly that my husband asked that if we were to move up to Auckland, whether Dr B would be able to treat him. We also talked at length about the trial being done with Temozolomide. We were told that they had strict guidelines on regions and treatment within your region. Then we resigned ourselves to the fact that we’d have to go to Waikato. We asked if we would be able to pay for the radiotherapy and have it done privately by him. We then found out that you cannot have private radiotherapy in NZ.”

When asked about the McKenzie family’s response to the proposed management of the tumour, Dr B stated:

“The responses of Dr McKenzie and his family seemed to me to be one of understandable shock at hearing the severity of the illness but at no stage did they raise any further questions of management with me and were happy for him to be referred to Waikato. At no stage did I indicate to them that I was his oncologist but rather that I saw him as a professional courtesy in order to expedite his referral to the Oncology Department at Waikato.”

When asked whether at that time he was aware of the availability of more aggressive surgery for glioblastomas, Dr B stated:

“The stated goal of surgery is maximal safe resection of tumour and this has been the case for at least 10 years. The main factor complicating very wide resection was the proximity of the motor strip and risks of hemiparesis. The role of neurosurgery was not discussed with Dr McKenzie as I am not a neurosurgeon and Dr McKenzie was under the care of an excellent neurosurgeon. I believe that Dr McKenzie and his family had the opportunity to discuss these issues when they saw the neurosurgeon on the ward. Had they raised these issues with me I would have referred them back to the neurosurgeon as surgical techniques are not my area of special expertise.”

Dr B acknowledged that the extent of tumour resection in glioblastomas and its role in prolonging survival is controversial. However, he stated:

“I did not recommend further excision for two reasons. Firstly I was never asked by Dr McKenzie or his family whether or not he should have further resection and secondly, the decision to resect and the extent of resection is best left only to trained neurosurgeons who have an understanding of the risks of major catastrophic motor losses especially when the benefits of resection remain controversial.”

Mrs McKenzie advised me that the meeting with Dr B lasted about half an hour. She confirmed that the issue of further surgery was not raised by the family or Dr A. After the meeting the family drove back to Tauranga.

There was no further contact between Dr and Mrs McKenzie and Dr B after this date. Dr B advised me that this was despite his offer of free advice in the future and giving them his mobile and home telephone numbers. Had Dr McKenzie contacted him, he “would have been happy to address any of his questions and to provide him with appropriate literature, as I do for all patients who ask these questions of me”.

Subsequent events

Events leading to the second opinion

Mrs McKenzie advised me that on 5 May 2001, two days after seeing Drs A and B, Dr McKenzie and their other son, James, searched the internet for information on glioblastomas. Several days later she and her husband were told by their friends of an item that screened on the *Holmes* television programme on 8 May involving Jesse Hills, an 8-year-old-boy from Whakatane, who had undergone brain tumour surgery in Sydney, Australia after reportedly being told by doctors in New Zealand that the tumour was inoperable. The tumour was similar to the one her husband had. Dr Charles Teo was

named as the surgeon who had performed the operation. Dr McKenzie explained that it was through the media that he found out that aggressive surgery was the best option for his type of tumour.

Mrs McKenzie advised me that after the 3 May consultations with Drs A and B, she and her husband did not contact either doctor to discuss the additional information they had obtained about the option of further surgery. Dr A's manner and brevity, and the fact that they were told by him and Dr B that the tumour was inoperable, were cited as the reasons for the lack of further contact.

On 11 May Dr McKenzie had a CT scan at Tauranga Hospital, which showed that the tumour size remained unchanged.

Mrs McKenzie advised me that a day or two after hearing of Jesse Hills' case, her husband telephoned a friend in Sydney, who made enquiries on his behalf regarding the identity of the neurosurgeon mentioned in the *Holmes* programme. Through this contact Dr McKenzie obtained contact details for Dr Teo at Prince of Wales Private Hospital in Sydney. Dr McKenzie telephoned Dr Teo's rooms and discussed his case with Dr Teo's assistant. He was asked to courier his MRI scans and was informed that Dr Teo would call him back if something could be done. The scans were couriered on Monday 14 May 2001. The following evening, Tuesday 15 May, Dr Teo telephoned Dr McKenzie and told him that he was confident that he could remove the tumour. Dr McKenzie saw Dr Teo in Sydney on Thursday 17 May. Surgery was scheduled for Monday 21 May.

On 14 May 2001 Dr B wrote to a radiation oncologist at Waikato Hospital, requesting radiotherapy for Dr McKenzie. Mrs McKenzie advised me that the appointment for radiotherapy at Waikato Hospital arrived while she and her husband were in Australia. Because more precise radiation treatment was available in Sydney, they decided to have the radiotherapy there. No radiotherapy treatment was received by Dr McKenzie at Waikato Hospital.

Further surgery

On 21 May 2001 Dr McKenzie underwent a complete resection of the tumour performed by Dr Teo at the Prince of Wales Hospital, with no resulting hemiparesis. In a letter to the emergency medicine specialist at Tauranga Hospital dated 22 May 2001, Dr Teo stated:

“Thank you for asking me to see Dr Neil McKenzie for a second opinion regarding his malignant glioma ... I discussed the various options available to Dr McKenzie including repeat surgery for further debulking of the tumour, no further surgery and radiotherapy and chemotherapy. He understands the various pros and cons of all the options and has chosen repeat surgery. I made it quite clear to Dr McKenzie that surgery was certainly not curative and that further resection would surely be associated with high risk. He also understands that there is no good scientific evidence to suggest further sub-total resection of this tumour would necessarily increase his life span. ... He underwent surgery yesterday with an excellent almost complete macroscopic removal of the glioma with no new neurological deficits ... he will consult the radiotherapist as soon as possible.”

A copy of the letter was sent to Dr A.

Postoperative management

In a letter dated 24 May 2001 and addressed “To Whom It May Concern”, Dr Teo stated:

“This patient has been treated by ... and myself over the past week, for a malignant brain tumour (glioblastoma multiforme). Normally, the prognosis of these tumours is not favourable (less than 12 months).”

In a letter to Dr A dated 28 May 2001, a radiation oncologist at Prince of Wales Private Hospital stated that the plan was to commence Dr McKenzie on cycles of temozolomide and radiotherapy. On the same day Dr McKenzie lodged an application for a “Terminal Illness” claim with his insurer. In a letter to the insurer dated 6 June 2001, Dr A stated:

“His [Dr McKenzie’s] prognosis is poor and life expectancy would be likely to range from six months to two years. Any further surgery or treatment is palliative.”

A copy of that letter was sent to Dr McKenzie.

On 27 November 2001 the *Bay of Plenty Times* reported that the previous week Dr McKenzie returned from Sydney “with the ‘all clear’ from a follow-up check-up with Dr Teo and MRI scan ...”. On 18 February 2002 Dr McKenzie had a CT scan performed at Tauranga Hospital. It showed no recurrence of the tumour.

On 10 October 2002 Dr McKenzie’s case featured on the *Holmes* television programme, with interviews with an Auckland neurosurgeon and Dr Teo. The neurosurgeon stated that Dr Teo was offering patients an operation they can have in New Zealand funded by the public health system, but that to suggest that removal of a growth visible on a scan was a cure, was to offer patients a false sense of hope; such tumours are resistant to radiotherapy, chemotherapy and surgery. Dr Teo denied that the surgery he performed offered patients false hope and said that he makes it clear to his patients that the surgery may not extend their life.

Mrs McKenzie advised me that at no stage was she or her husband told by Dr A or Dr B that the surgery could be done in New Zealand and that they “were told point blank that nothing could be done other than palliative therapy”.

In response to the comments on the *Holmes* programme regarding the availability of the surgery in New Zealand, Dr A stated that “radical surgery is performed in neurosurgical units in public hospitals and in private institutions when it is deemed safe and, hopefully, beneficial to the patient”. In response to the same comments Dr B stated:

“... I agree that Dr Teo does not offer anything substantially different from what is offered in the public system in New Zealand. This relates to my earlier comment that the goal of surgery is maximal safe resection of tumour and this is certainly practised in New Zealand. The neurosurgeon performed resection very close to the motor cortex and the patient awoke [to] no new deficits. I believe that keeping the balance between the two sometimes conflicting dictates of the stated goal is very important especially as there is very little definitive literature on the extent of resection and the likelihood of cure and if

the balance shifts the other way the patient could be left with hemiplegia and no improvement in outcome.”

Deterioration

Mrs McKenzie advised me that her husband had “a very good quality of life” until November 2002 when the tumour recurred. In a letter to the emergency medicine specialist at Tauranga Hospital dated 11 November 2002, the radiation oncologist at Prince of Wales Private Hospital stated that Dr McKenzie “was very well until about 2-3 weeks ago when he began to feel unwell, somewhat fatigued, disinterested, with some head heaviness. This prompted his re-evaluation, MR scan indicating obvious recurrence in the right parietal ... Neurological assessment today indicates no evident abnormality. This patient has a recurrent [glioblastoma] with a short disease free interval. The prognosis overall is not great however it is still suitable for surgical resection.”

On 26 November 2002 Dr McKenzie was reviewed by Dr Teo. In a letter to the emergency medicine specialist at Tauranga Hospital, Dr Teo stated:

“I saw Neil in my office today. Unfortunately, a follow-up MRI scan has demonstrated recurrence of his malignant glioma. ... Given the size of the recurrence, I have offered repeat surgery, but he understands that there is no chance of cure and this may not prolong his life significantly. He also understands that surgery carries risks and these risks include but are not confined to death, stroke, speech disturbance, blindness, etc. He has made it very clear that he would like us to go ahead with surgery and I will schedule this for tomorrow.”

Mrs McKenzie advised me that the recurring tumour was successfully removed by Dr Teo and that her husband did not develop hemiparesis after the surgery.

On 4 December 2002 Dr McKenzie advised me that he was “tumour free”.

In January 2003 Dr and Mrs McKenzie returned to Sydney for further surgery. Mrs McKenzie advised me that at this time there was no evidence of a tumour, but her husband had developed “mild” left-sided hemiparesis due to radiation necrosis.

In February 2003 Dr McKenzie was reviewed by a doctor at the Waipuna Hospice in Tauranga, after experiencing convulsions. As Dr McKenzie enquired about chemotherapy, he was referred to an oncologist at Tauranga Hospital.

Mrs McKenzie advised me that a repeat MRI in March 2003 showed “some area for concern”. As a result she and her husband decided on further surgery by Dr Teo. A fourth operation was performed on 24 March by Dr Teo. The histology report stated the diagnosis as recurrent glioblastoma and chronic radiation changes. Mrs McKenzie advised me that at this stage her husband developed full left-sided hemiparesis. Dr McKenzie died in Tauranga on 12 May 2003.

Dr McKenzie survived nearly two years from the date of the first surgery performed by Dr Teo (in May 2001). Dr A had given Dr McKenzie a prognosis of six months to two years’ survival. Mrs McKenzie stated that she did not think her husband would have survived the

two years had he not had the surgery. She advised me that when they initially went to Sydney, her husband was “very very sick” – he was having epileptic seizures, and kept losing his balance. Following surgery all seizures stopped and his balance was “OK”. Mrs McKenzie said that after the surgery her husband was “good for 18 months” and, even if he had not lived that long, he would not have had the quality of life he enjoyed.

Reason for complaint

Mrs McKenzie stated that the key aspect of her and her husband’s complaint is that Dr A and Dr B did not offer them the option of further surgery or raise it as a possibility. She and her husband “were told point blank that nothing could be done other than palliative radiotherapy”. In an article that appeared in *New Zealand GP* (7 August 2002), Dr McKenzie was reported as being “angry” that he had to learn about the surgical brain tumour treatment via a television current affairs programme and stated that he should not have had to learn of his options in that way. Mrs McKenzie advised me that at no stage were they told by Dr A or Dr B that the surgery could be done in New Zealand as mentioned in the *Holmes* programme.

Mrs McKenzie stated that Dr A did not enquire into her and her husband’s views when deciding not to perform further surgery (greater excision of the tumour). She did not accept his concern about the risk of hemiparesis, which would prevent her husband from being able to play his much loved music, as an explanation for not offering or performing further surgery. Mrs McKenzie said that it was up to the patient to make that decision and that it was “our call, not his”. Her husband was aware of that risk prior to the craniotomy on 30 April 2001.

Mrs McKenzie said that although Dr B was a radiation oncologist and not a neurosurgeon, she would have expected him to explore all options – “I think he did have an obligation [to explain the option of surgery] because he was sent as [Dr A’s] representative.” Dr B commented:

“I did not talk about more aggressive resection firstly because it is not my specialist area and secondly because I felt that surgery had achieved the stated goals and was in line with international guidelines ...”

Response to Provisional Opinion

In response to my provisional opinion, Dr A commented as follows:

“I have received and read your report on the complaint from the McKenzie family regarding surgical treatment for Dr Neil McKenzie’s glioblastomas and have reviewed my explanation of treatment options.

Your conclusion that I am in breach of the Patients’ Code of Rights is, with respect, not correct. Certainly I have quite a different opinion. Without repeating all that I said in my earlier letter, I would like to emphasise the following:

An appointment time had been arranged for a post-operative visit in my rooms following discharge from Mercy Hospital, at which time the pros and cons of further surgery could have been discussed in detail with Dr McKenzie and his family, but unfortunately by that time they had decided on a different path, which they were quite entitled to do, and no further contact was made by them after their cancellation of this appointment.

The irresectability of glioblastomas was mentioned in the pre-operative consultation, although it appears this was not fully understood by Dr McKenzie. I suspect we may underestimate the amount of information absorbed by patients in times of crisis and unfortunately we have no way of determining how information is processed by an individual. However, at all times in my management of Dr McKenzie I believed I was doing the best for him.

In conclusion I would be grateful if you would amend your opinion to delete the conclusion that I have breached the Code of Patients' Rights. In saying this, I should make it clear that I most certainly regret that the family have been unhappy with my treatment and I have no hesitation in apologizing for this."

Code of Health and Disability Services Consumers' Rights

The following Rights in the Code of Health and Disability Services Consumers' Rights are applicable to this complaint:

RIGHT 5

Right to Effective Communication

- 1) *Every consumer has the right to effective communication in a form, language, and manner that enables the consumer to understand the information provided. ...*
- 2) *Every consumer has the right to an environment that enables both consumer and provider to communicate openly, honestly, and effectively.*

RIGHT 6

Right to be Fully Informed

- 1) *Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive, including –*

...
 - b) *An explanation of the options available, including an assessment of the expected risks, side effects, benefits, and costs of each option; ...*

Opinion: Breach – Dr A

Dr McKenzie complained that in May 2001 Dr A did not inform him of the option of surgery, specifically brain tumour resection and its expected benefits.

On 27 April 2001 Dr A saw Dr McKenzie with the scans indicating the presence of a brain tumour likely to be malignant. To establish whether it was malignant and whether it was a primary or secondary growth, Dr A recommended biopsy. According to Dr A, Dr McKenzie was informed that the amount of tumour that would be removed would be dependent on “the pathology and what was found at operation” – if the tumour was metastatic, excision was likely; if the tumour was a primary, then it was unlikely that the whole tumour would be removed because of the increased risk of hemiparesis associated with radical excision. Dr McKenzie signed a consent form for “craniotomy and removal of tumour”.

Naturally, Dr and Mrs McKenzie were hopeful that the tumour was a primary growth that could be surgically removed. Indeed, Mrs McKenzie was under the impression that the primary reason for his surgery was to remove the tumour. Dr and Mrs McKenzie did not challenge the amount of tumour resected on 30 April 2001, in the immediate postoperative period or subsequently.

After the surgery Dr A saw Dr McKenzie on two occasions, 1 and 3 May 2001. On the second occasion Dr McKenzie, with members of his family present, was informed by Dr A that he had a malignant primary glioblastoma and that it was inoperable. Based on his knowledge that aggressive surgery of glioblastomas has not been shown to be curative or to significantly prolong longevity, Dr A offered palliative radiotherapy as the only management option. He explained that he did not perform radical surgery because he did not want to “damage” Dr McKenzie by causing paralysis.

The prognosis associated with glioblastomas is very poor – they are resistant to all known forms of treatment (chemotherapy, radiotherapy and surgery) and a wider excision of the tumour carries an increased and significant risk of hemiparesis. However, Dr A’s stance that radical surgery was not a realistic option for Dr McKenzie – although consistent with mainstream neurosurgical opinion in New Zealand – did not absolve him of his obligation to provide his patient with full information (all the information that a reasonable patient in Dr McKenzie’s circumstances would expect to receive) about alternative neurosurgical treatment options. At a time when New Zealand patients are not infrequently referred to Australia for medical care (even in the publicly funded system), this includes information about treatment options available (albeit in private) in Australia. Dr McKenzie was entitled to that information to be able to make an informed choice.

It would not be reasonable to expect Dr A to offer to perform a procedure that he did not believe was a viable option. But he needed to raise the option of further surgery, which he knew to be a viable option, and explain why he thought the risks outweighed any potential benefit.

As Mrs McKenzie pointed out, the decision was ultimately “our call, not his”. Surgeons have a responsibility to locate their own opinions within the spectrum of professional views

about possible procedures and to contextualise their recommendations, rather than simply “announce” their stance.

There is no evidence that Dr A discussed any option other than palliative radiotherapy with Dr McKenzie. He did not offer to refer Dr McKenzie to another neurosurgeon for a second opinion. He certainly did not engage in the sort of discussion that Dr Teo (in his letter of 22 May 2001 to the emergency medicine specialist at Tauranga Hospital) is reported to have had with Dr McKenzie.

One of the key problems in this case is the timing and manner of Dr A’s communication with Dr McKenzie and his family. The postoperative consultation on 3 May was relatively brief, and was unscheduled. Given the diagnosis and the gravity of the prognosis, the appropriateness of the time allocated by Dr A for discussion must be questioned. Dr A could not be expected to “drop everything” on an early morning ward round and engage in a lengthy discussion with Dr McKenzie and his family. But the full consultation should have been scheduled for (around) three days later, not three weeks later.

Had longer time been allocated, at an early date and a time convenient for Dr McKenzie and his family, a fuller discussion would have been possible and the matters that gave rise to this complaint may not have arisen.

I note Dr A’s comment in response to my provisional opinion that “we may underestimate the amount of information absorbed by patients in times of crisis and unfortunately we have no way of determining how information is processed by an individual”. That, of course, is a reason for taking extra time and care in explaining information about a life-threatening illness.

I accept Dr A’s statement that at all times he believed he was doing his best for Dr McKenzie. However, by failing to arrange an appropriate time and place to enable effective communication, and to provide full and contextualised information, Dr A deprived Dr McKenzie and his family of the opportunity to weigh the very limited options for themselves.

Dr A took brief and incomplete clinical notes of his consultations. It would also have been prudent for Dr A to take more detailed notes of his consultations and discussions with Dr McKenzie and his family.

It may be countered that Dr McKenzie and his wife do not appear to have questioned Dr A about his proposed management plan or asked about any other available treatment options. Dr A seems to have been left with the impression that Dr McKenzie and his family accepted his assessment and the proposed palliative radiotherapy. He may have expected that any further questions would be raised at the scheduled appointment at his rooms on 23 May (three weeks later) or that he would be telephoned for advice in the interim. But from the family’s perspective, the gloomy prognosis given at the brief 3 May meeting may well have made any further discussion seem pointless. They may also have felt too shocked to question Dr A’s judgement.

It could also be argued that, as a medical practitioner, Dr McKenzie had some understanding of brain tumour pathology and referral processes, and was in a better position than most patients to raise any concerns with Dr A. However, the duty to volunteer information about treatment options is not dependent on the patient asking questions, and Dr McKenzie, a general practitioner, saw Dr A in his specialist capacity. In these circumstances I consider that Dr McKenzie was entitled to all the information an “ordinary” patient would expect; indeed, given the particular circumstance of his being a general practitioner/patient, arguably even greater information disclosure was required.

In summary, Dr A had an obligation to inform Dr McKenzie of the option of wider resection of the tumour – even if he did not recommend it or was unwilling to perform it himself – and to facilitate discussion of the feasibility of that option. By failing to discuss the option of further surgery with Dr McKenzie, and the risks, side effects and benefits of the procedure, Dr A breached Right 6(1)(b) of the Code.

Opinion: No breach – Dr B

Dr McKenzie complained that in May 2001 Dr B did not inform him of the option of surgery, specifically brain tumour resection and its expected benefits.

Dr B saw Dr McKenzie on only one occasion, on 3 May 2001 at the request of Dr A, to discuss and arrange palliative radiotherapy for Dr McKenzie. He saw Dr McKenzie in his capacity as a radiation oncologist, not as a neurosurgeon. Although Dr B agreed with Dr A’s view that the risks of attempting a wider resection of the tumour were greater than the possible benefits, he did not offer or hold himself to be offering neurosurgical advice.

On 3 May no specific treatment options were offered by Dr B. Because radiotherapy was available only in public hospitals and Dr McKenzie lived in Tauranga, Dr B arranged for him to have radiotherapy at Waikato Hospital. As Dr McKenzie or his family expressed no reservations about the proposed radiotherapy and seemed happy with the referral to Waikato Hospital, Dr B was not aware that Dr McKenzie was unhappy with the proposed management of his tumour. I am satisfied that had Dr B been made aware of any concerns, he would have referred Dr McKenzie back to Dr A so the concerns could be dealt with. Although Dr B made himself readily available to Dr McKenzie and his family, and provided his mobile and home telephone contact numbers, they did not contact him again.

Given that the referral was for the purpose of discussing and arranging palliative therapy, and that he was not aware of any reservations or concerns Dr McKenzie and his family had about the proposed management, Dr B did not have an obligation to inform Dr McKenzie of the option of further surgery. Accordingly, in my opinion Dr B did not breach the Code.

Other comments

The extent of tumour resection in glioblastomas and its role in prolonging survival appears to be controversial. While there is a consensus that glioblastomas are incurable, there is a divergence of opinion whether radical surgery significantly prolongs longevity and whether the risks associated with radical surgery outweigh the potential benefits. The practice of radical excision of glioblastomas appears not to be widely accepted in Australia and New Zealand, and the Sydney-based surgeon who performed surgery on Dr McKenzie has been criticised by colleagues for performing such surgery.

As Commissioner it is not my function to comment on the merits and benefits of different medical procedures, or whether the radical surgery in this case ultimately extended or improved the quality of Dr McKenzie's life. However, what this case highlights is the need for medical practitioners (and other health professionals) to ensure that all relevant information, including availability of treatment options, is explained to patients in a way that facilitates discussion, to enable them to make an informed choice.

Actions

I recommend that Dr A:

- apologise in writing to Mrs McKenzie for his breach of the Code. This apology is to be sent to the Commissioner's Office and will be forwarded to Mrs McKenzie.
 - review his explanation of treatment options available to patients, in light of this report.
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Further actions

- A copy of this report will be sent to the Medical Council of New Zealand.
- A copy of this report, with identifying features removed, will be sent to the Royal Australasian College of Surgeons and the Royal Australian and New Zealand College of Radiologists, and placed on the Health and Disability Commissioner website, www.hdc.org.nz, for educational purposes.