

**General Practitioner, Dr C / Paediatric Oncologist, Dr D /
Radiation Oncologist, Dr E / A Public Hospital**

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

(Case 00HDC02720)

Complaint

The Commissioner received a complaint from the complainant, Mr A, concerning the treatment and service his daughter, Miss B, received from Dr C, general practitioner, Dr D, paediatric oncologist, Dr E, radiation oncologist, and a public hospital. Mr A's complaint was detailed in his complaint letter and is summarised as follows:

- *Mr A is unhappy with the service his late daughter, Miss B, received from Dr C at a medical centre.*
- *Miss B had been consulting with Dr C over a long period of time because she was losing her balance, becoming tired and sleepy, vomiting after meals, and later on, her left eye was moving across to her right eye.*
- *Dr C treated Miss B for an ear infection but her condition did not improve. Miss B was referred to an ear specialist but there was still no improvement in her condition.*
- *Mrs F visited Dr C to obtain a referral for Miss B to see a specialist at another public hospital. An MRI scan was performed which showed that Miss B had a tumour on her brain.*
- *Mr A would like to know why Dr C did not seek another opinion about Miss B when she did not show any sign of improvement.*
- *Miss B was taken to the first public hospital for treatment of her tumour. Mr A would like to know why Dr E and Dr D did not begin radiotherapy on Miss B as soon as possible. Mr A is concerned that Dr E and Dr D were more concerned with Miss B's speech recovery rather than getting rid of her brain tumour. After Miss B's return to her hometown, it was found that the cancer had spread down to her spine. Mr A believes that if radiotherapy had been done earlier the cancer would not have spread.*
- *Mr A believes that Dr E and Dr D did not listen to him during meetings to discuss Miss B's treatment.*

Investigation process

The complaint was received on 10 March 2000 and an investigation was commenced on 13 April 2000. Information was obtained from:

Mr A	Complainant / Consumer's father
Miss B	Consumer
Dr C	Provider / General Practitioner
Dr D	Provider / Paediatric Oncologist
Dr E	Provider / Radiation Oncologist
Mrs F	Complainant's wife
Dr G	Paediatrician
Dr H	Clinical Director, Paediatric Haematology/Oncology
Dr I	Neurologist
A Public Hospital	Provider
Ms J	Neuro-paediatric Social Worker
Mr L	Cultural Advisor
Dr M	Clinical Director, Radiation Oncology

Mr N Cultural Advisor

Dr O Neurological Registrar

Dr P Head of the Paediatric Radiation Oncology Unit at an overseas general hospital

Dr Q Paediatric Neurologist

Dr R Neurosurgeon

Miss B's hospital and medical records were reviewed. Independent expert advice was obtained from a general practitioner, a clinical oncologist and a radiation oncologist.

Information gathered during investigation

Background

Miss B was born on 2 March 1992 with spina bifida. Miss B had severe bone deformities affecting her pelvis and right leg. She was unable to walk because of severe underdevelopment and shortening of her right leg. Miss B had a dysraphic spine (incomplete closure of the spine). Her medical history included recurrent ear infections and multiple congenital abnormalities.

Dr C

Dr C was Miss B's general practitioner from 30 July 1993 until 6 March 2000. Mr A and Mrs F are particularly concerned about the visits when Miss B was taken to see Dr C in June 1998 and July 1999. Mr A and Mrs F were concerned about Miss B's health over this period of time as she was losing her balance, becoming tired and sleepy, and vomiting after meals. She developed a problem of her left eye moving across to her right. Mr A was concerned that whenever Miss B saw Dr C, he treated her for an ear infection even though this did not improve her condition. Mr A knew that Miss B was not her normal happy self on these occasions and he noted that other family and friends had noticed this too.

On 9 and 19 June 1998 Dr C saw Miss B. On both occasions fluid was coming out of her left ear. Dr G, paediatrician, examined Miss B at the Outpatient Clinic of the first hospital on 17 June 1999. Because of her deformities, Miss B was regularly reviewed every six months or so in the Paediatric Outpatient Clinic. The appointment with Dr G was one of Miss B's regular paediatric review appointments. Dr G noted that systemic examination showed nothing new except for a discharging left ear and a dry perforation in the right eardrum. Miss B saw Dr C again on 4 August 1998. On this occasion she had a right ear infection and post-nasal discharge. Dr C noted that Miss B's left eardrum had a dry perforation and he prescribed Augmentin (an antibiotic) for the infection.

Dr C did not see Miss B again until 5 July 1999 when she had a headache and had had an upper respiratory tract infection for three days. After examining Miss B, Dr C noted that both her ears were infected. Dr C felt that Miss B had very slight neck stiffness indicating possible cerebral irritation. Dr C treated Miss B's ear infection and arranged to review her the next day to monitor and reassess her condition.

Dr C reviewed Miss B the next day. Her headache had lessened and she did not appear to be ill. Dr C noted that Miss B had no neck stiffness, but both ears were infected, and he suggested review in one week.

On 16 July 1999 Mrs F took Miss B to see Dr C. Mrs F advised Dr C that she and Miss B's teacher had noticed that Miss B had had a turned eye over the past one or two weeks. Miss B had double vision when looking to the left, and she had a squint due to impaired movement of the right eye. Dr C wrote a referral for Miss B to the Ophthalmology Outpatient Clinic at the first hospital.

On 19 July 1999 Mrs F took Miss B to see Dr C. Miss B was complaining of a discharging left ear and headache. Dr C examined Miss B and noted that she looked well, did not have a temperature, and her right ear was normal. Miss B's chest was clear and there was no neck stiffness. Dr C prescribed Augmentin for the left ear infection.

On 26 July 1999 Dr C saw Miss B again. She was unwell and had been vomiting daily with headaches for two weeks. With these symptoms, and the presence of a squint, Dr C diagnosed a serious intracranial cause (a problem within the skull). He immediately referred Miss B as an emergency to the paediatric registrar at the first hospital. A brain scan revealed a large lesion at the back of Miss B's head, causing the brain to press against the skull. The lesion was a posterior fossa tumour with marked hydrocephalus (increased fluid within the brain). Dr H, the Clinical Director of Paediatric Haematology/Oncology, stated that the disease Miss B had carries a very high mortality rate of approximately 70-80% within five years of diagnosis, regardless of the time post-operative radiotherapy begins.

That day, Miss B was urgently transferred by air to the second hospital, where a medulloblastoma (brain tumour) was diagnosed. Her father accompanied her to the city. Miss B's mother had recently had a stroke and was unable to accompany the family. A social worker from Miss B's hometown referred Miss B to the social worker for the neuro-paediatric ward at the second hospital before her arrival, as there was concern about how the family was coping with Miss B's rapid deterioration.

The second public hospital

At Miss B's initial admission, paediatric neurosurgery was sited in the adult neurosurgical ward in this hospital. Dr H noted that this location posed significant disadvantages to both parents and children. However, he stated that despite this there was still good communication between the neurosurgery department, paediatric radiation oncologists and paediatric oncologists. Since January 2000 paediatric neurosurgical patients have been treated in a children's hospital.

When Miss B first presented to this hospital on 26 July 1999, she was admitted to the neurosurgery ward under the care of Dr I, neurologist, for diagnosis and treatment of her brain tumour. A child with a brain tumour is initially admitted to hospital under the neurosurgery team, for assessment, diagnosis and surgical management. However, the diagnosis is discussed and histology reviewed at a joint meeting, the Paediatric Oncology Conference, which is held once a week and involves members of the relevant clinical disciplines. The Conference team contains neurosurgery, haematology/oncology, and

paediatric specialists and clinicians. A management plan is established, usually as a consequence of consensus, and a primary consultant is charged with the responsibility of delivering the treatment plan. Once surgery is completed, ongoing management becomes the responsibility of either a paediatric oncologist or a paediatric radiation oncologist. Members of the Conference do not usually see the family unless requested by the primary consultant or the parents. Miss B's case was the subject of regular Paediatric Oncology Conference sessions.

On arrival at this hospital, Miss B presented with increased blood pressure and intermittent drowsiness.

On 27 July 1999 Ms J, neuro-paediatric social worker, met with Miss B and Mr A to introduce herself and explain her role. Her impression of Mr A was that he was in shock. He spent most of his time with Miss B sleeping in a chair at her bedside. He was not well himself and went to Accident and Emergency on a few occasions. The transfer to the city was so fast that Mr A did not have a change of clothes with him on arrival. Ms J helped him with benefit enquiries, money, and clothing. Ms J also saw Mr A informally when he was walking around the hospital. She states that she probably saw him on the ward two or three times and around the hospital on a few occasions during the first week Miss B was at this hospital.

On 27 July 1999, while on the ward, Miss B had an external ventricular drain inserted on the right side of her head to relieve the hydrocephalus. (A ventricular drain is a tube that is inserted into the ventricle of the brain to divert excess fluid.)

On 2 August 1999 Miss B underwent an operation to have her tumour removed. Miss B had some convulsions prior to the surgery and she was started on anti-convulsant therapy. Post-operatively, it became apparent that there had been incomplete removal of the tumour. Miss B became confused in the post-operative period.

From 5 August 1999 Miss B steadily deteriorated and there was less drainage through the external ventricular drain. Miss B's arms were both very weak, although her legs at that stage had normal power. The plan, as decided at the Paediatric Conference, was for Miss B to have a CAT scan as soon as possible.

The preliminary CAT scan showed that there was probably a slight increase in ventricular dilatation. The right ventricle, where the drain was located, was stretched beyond normal dimensions.

On 6 August 1999 Miss B underwent another surgical procedure to have the external ventricular drain removed and a shunt inserted. She was seen by Dr I, a neurologist. Miss B's vital signs were satisfactory and neurologically she was unchanged, although she had severe limb weakness and mutism. At this time, Miss B had full hearing, sight and awareness, but was unable to vocalise or make any spontaneous sound. The physiotherapist, occupational therapist, and speech therapist saw her daily.

On 11 August 1999, at a post-operative assessment meeting of the Neurological Services multidisciplinary team, it was noted that since the operation on 2 August Miss B had lost

the use of her arms, and that since the shunt insertion on 6 August she had lost the ability to communicate/vocalise.

Dr K, paediatric neurologist, reviewed Miss B on 12 August 1999 and found that although she was unable to move her arms voluntarily when awake, she seemed to have some movement at night. Dr K felt this indicated that pathways to Miss B's upper limbs were intact but he was unable to determine why she had no movement of her arms when awake. Dr K provisionally diagnosed cerebellar mutism as the most likely cause of Miss B's loss of speech and inability to communicate. Dr K expected Miss B's speech to return gradually and noted that her receptive speech and language was probably preserved.

Dr E and Dr D

Dr E is a radiation oncologist and was a member of the Paediatric Conference team that provided care to Miss B. He was appointed primary consultant in regard to Miss B's care once surgery had been completed, as there was no role for chemotherapy. As primary consultant he was responsible for communicating with Miss B's father and other family members. Dr E said that he believed that every effort was made to inform Mr A about what was happening and he always included a Maori translator, Maori social worker and Maori support services when he discussed issues with Mr A. There is no record in the medical notes that any support persons were present on any of the occasions when Dr E met with Mr A. Dr E said that he also called Miss B's granny on three occasions to discuss things with her. Mrs F advised that Miss B's grandmothers had died before Miss B was diagnosed with a brain tumour.

Dr D is a senior paediatric oncologist with expertise in brain tumours. Her involvement with Miss B's treatment and care was as a member of the Paediatric Oncology Conference team. Dr D's role within the team was primarily as a note taker at the various meetings held to discuss Miss B's treatment.

Dr E first met Miss B with her father, on 12 August 1999, 10 days after her neurosurgical operation of 2 August 1999. At this time the perception was that Miss B had a standard risk medulloblastoma (brain tumour). On subsequent multidisciplinary review, it became apparent that there had been incomplete removal of the tumour, placing Miss B at a higher risk. Her chances of surviving five years were estimated at approximately 30%.

On 12 August 1999 Dr E assessed Miss B and found that she had significant post-operative problems resulting from the tumour. Dr E noted that Miss B had a background of disablement from spina bifida, urinary incontinence, malformation of the cerebellum (brainstem), and neonatal subependymal haemorrhage. Neonatal subependymal haemorrhage refers to bleeding under the lining membranes of the ventricles of the brain and of the central canal of the spinal cord. Neonatal subependymal haemorrhage occurs within the first four weeks after birth.

On 13 August 1999 Mr L, a cultural advisor, visited Miss B and her father. He also recorded on the clinical notes that he visited Miss B and her father again on 24 August 1999. Mr L said that he was not the cultural advisor for that particular ward at the time, and he did not attend multi-disciplinary meetings. He thinks he would have become involved because there was a request for a cultural advisor and he was on duty at the time.

He cannot really remember Mr A. He was there to provide cultural support, which was a non-clinical role, and does not discuss clinical issues with consumers or their families. Cultural advisors record discussions with patients in the medical notes.

On 14 August 1999 Dr I's neurological registrar reviewed Miss B. The registrar noted in Miss B's medical record: "*must start radiotherapy within 4/52 [4 weeks] of surgery. [R]efer to [Dr E] MONDAY [16 August]." Dr M noted that this comment was inappropriate, particularly given Miss B's clinical situation. Although increasing treatment delay risks recurrence there is no clear evidence that timeframes longer than four weeks post-surgery compromise survival.

Mr A stated that while Miss B was undergoing treatment at the second hospital, he did not think that his family's views were taken into consideration or that they were even listened to by the team who treated Miss B. Mr A was amazed that the team did not seem to want to commence radiotherapy as soon as possible and that they kept delaying the treatment. By 17 August 1999 Mr A had had enough. He was concerned that the multidisciplinary team, in particular Dr E and Dr D, appeared to be more concerned with Miss B's speech recovery than getting on with treating her. Mr A was also concerned that they had to remain at the hospital for at least another month, away from their family in their hometown. Mr A noted that Miss B was naturally missing her mother and that this could be contributing to her inability to vocalise. At 4.00pm nursing staff observed Mr A packing up personal belongings. Mr A stated that he was going to take Miss B home. Dr E was informed of the situation over the telephone and he advised that he would see Miss B the next day, 18 August. A cultural advisor, Mr N, was contacted immediately and he visited Mr A. In the notes Mr N recorded that Mr A was upset about the delay with Miss B's radiotherapy treatment. Mr N said that he was not assigned to the ward that Miss B was on but was called in because he was on duty. He was told that Mr A had stormed out of the hospital after an argument and was threatening to take his daughter back to his hometown. While Mr N was talking to Mr A, his family arrived from Miss B's hometown on a surprise visit to see him and Miss B. Mr A felt much better on seeing his family.

An urgent family group meeting was held at 6pm with Mr A and Mrs F and their family, Dr O, neurological registrar, Mr N, cultural advisor, and a registered nurse. Mr A and Mrs F were advised that radiotherapy would improve Miss B's chances of surgical and that they would know more after Dr E had visited Miss B the next day. Mr A and Mrs F were advised that it could be a few more weeks before they would be able to go home and that, in the meantime, they had to keep Miss B's best interests in mind. At the end of the meeting the family left to discuss their concerns further with Mr N. Two hours after the meeting it was noted that Mr A and Mrs F and their family all felt better about Miss B's care.

Mr N recalled that Mr A was angry because he was not getting information from the doctor and had to wait a long time for the oncology doctor to speak with him. Mr N's impression was that Mr A had been waiting a period of days rather than hours. Mr N said that staff explained that the tumour had been removed but had spread to the spine. It needed radiation and if radiation was given there was a 60% chance that the patient would survive for five years after treatment.

Ms J stated that she was not present at any clinical meetings held about Miss B but organised a whanau meeting for Miss B and her family to meet with doctors. Ms J was concerned that Mr A did not understand what sort of tumour Miss B had, although Mr A showed her some written information given to him by a doctor. Ms J did not attend the meeting but saw Mr A afterwards and in her opinion he seemed happier.

Ms J said that she did not know how much information Mr A retained, as Miss B's condition was traumatic for him, and his wife was also sick. She said that Mr A thought that Miss B could not have radiation treatment because she could not speak. Ms J was present when a charge nurse and speech language therapist talked to him about the delay in the radiation treatment and explained that it was because the wound had to heal. Ms J said that she felt that Mr A found it easier to talk to her and The cultural advisor because they were other Maori faces.

Dr E advised that if Mr A had ever raised his concerns about the delay in starting radiotherapy treatment with Dr E, the social workers, Miss B's general practitioner or the paediatrician, Dr E would have taken further steps to address Mr A's concerns.

Mrs F said that her husband often contacted his sister, who was a registered nurse, to discuss Miss B's condition and the treatment being provided. Mr A's sister was asked to provide information but was unable to do so.

The second public hospital noted that it is to be expected that a father with a seriously ill child with a poor prognosis would experience distress and frustration. "Both [Mr A's] frustration, and his threats to take his daughter home to [...], appear to have been induced by a number of factors ... frustration alone is not proof of poor communication."

On 18 August 1999 Dr E saw Miss B and her family. Dr E advised Mr A and his family that due to Miss B's irritable behaviour and her inability to lie still, she would require a general anaesthetic for her proposed radiotherapy over the next six weeks. Dr E advised Mr A that Miss B would be exposed to some increased risk of cerebral hypoxia (lack of oxygen to the brain) due to repeated general anaesthetics, and that this could also compromise her recovery. Dr E advised Mr A that he felt radiotherapy would have significant potential side effects, which would possibly be aggravated by six weeks of general anaesthesia in a prone position, and by Miss B's congenital abnormalities. Dr E explained to Mr A and his family that recent studies did not reveal that the time factor was of the greatest single importance in determining outcome. Dr E believed that Mr A understood the proposed management plan.

From 18 to 24 August 1999 Miss B remained on the ward and was reviewed by members of the multidisciplinary team. On 24 August Miss B was prepared for discharge home to her hometown the next day. Mr A noted that it would be good for them to be closer to family and relatives. On 25 August 1999 Miss B was discharged into the care of Dr G, a paediatrician at the first hospital. Mr A dressed Miss B and they left for the first hospital at 10.10am with an escort nurse.

Because of the significant problems, Dr E discussed Miss B's proposed radiotherapy treatment with Dr I, neurosurgeon, on or about 3 September 1999. They decided that it would be better to defer Miss B's radiotherapy for a month and to review her with repeat

MRI scans after the month had passed. Miss B's treatment was deferred in view of the damage to her nervous system and the hope that improvement of her condition might occur.

Dr E saw Miss B again at the second hospital on or about 3 September 1999. A clinic note, dictated by Dr E on 3 September 1999, states that he saw Miss B with her family on the neurosurgery ward. The clinic note records that Dr E explained to the family that he found it virtually impossible to plan for Miss B's radiotherapy treatment given that she would have to lie face down for long periods during the treatment.

While at an international conference overseas in September/October 1999, Dr E took the opportunity to speak to Dr P, Head of the Paediatric Radiation Oncology Unit at an overseas general hospital, about Miss B. Dr P is an internationally recognised expert on paediatric brain tumours. Dr P felt that radiotherapy on a child like Miss B would risk delaying or impeding recovery.

Dr E saw Miss B with her family on 28 September 1999 while an MRI scan was being performed. Dr E personally attended the scan to assess whether Miss B could be positioned adequately for safe radiation treatment and to have further discussions with Mr A during and after the scan. Dr E advised Mr A of the matters he had discussed with Dr P. Dr E explained that prior to the medulloblastoma, Miss B had been able to cope reasonably well, but her recovery post-operatively was significantly delayed. He told Mr A that it would be inadvisable to offer radiotherapy under general anaesthetic for fear of permanently compromising Miss B's recovery. Dr E also advised Mr A that although there was a risk of tumour progression, it was preferable to allow for maximum recovery, to enable safe and effective administration of radiotherapy. Mr A took his daughter home at the end of that day. Dr E said that staff were not aware that he was planning to do this.

The MRI scan showed no post-surgical damage or tumour recurrence and Miss B's spine was reported to be free of tumour. At that stage Miss B still had imperfect control of her torso (truncal ataxia) and she had to be strapped into a wheelchair. Miss B had significant dyspraxia (loss of co-ordination) and had persistent incontinence of urine as well as reduced arm movements.

Preliminary plans were made for Miss B's radiotherapy including an anaesthetic consultation. Dr E documented the following in the medical records for 28 September 1999:

“On balance, given [Miss B's] congenital abnormalities, residual neurological deficits + [and] absence of recurrence [of the tumour] on repeat MRI + the requirement for G.A. [general anaesthetic] – defer RT [radiotherapy] for 6-8 weeks. Review in [...] by Paediatricians + Neurosurgery. If there is improvement in Neurology to proceed with RT. Discussed with family rationale for deferment.”

Dr E advised that, in his view, the family appeared to be in agreement with the stated plan. Miss B's case was discussed at the Paediatric Conference on 29 September and it was decided to defer Miss B's radiotherapy for a further two months to allow full recovery.

On 29 September 1999, Dr E referred Miss B to Dr Q, paediatric neurologist. Dr Q saw Miss B the same day and noted that she was making steady progress and that her prognosis for continued recovery was excellent. At this visit Mr A advised Dr Q that Miss B had made exceptional progress over the past month. She was now alert and speaking, and had improved use of her upper body and limbs. Miss B was still unable to sit upright in her wheelchair without the need for straps or restraints. Mr A advised Dr Q that Miss B had been a bright child with normal growth and development. Miss B was walking with the aid of crutches before one year of age, was quick to learn to speak and had been learning well in school.

Dr Q noted on examination that Miss B was alert and co-operative. She could speak in single words and short phrases although she had poor articulation. Miss B could count, add two and two, and name animals. She was quick to follow motor commands. Her face movements were symmetric and her tongue and palate appeared normal. She was able to move her tongue voluntarily in all directions but had marked speech dysarthria (disorder of pronunciation of words; inability to articulate words), and could not sustain a sound or sing.

Dr Q noted on upper body examination that Miss B had mild proximal weakness on the right upper side of her body, but otherwise full strength. There was marked ataxia (imperfect control of voluntary function/movement) on finger/nose testing on the right, and mild unsteadiness on the left. Fine movements were performed poorly bilaterally but she was able to isolate individual digit movements. Tendon reflexes were present and symmetric. On examination of the lower part of her body, Dr Q noted that Miss B had movement in her right foot and that sensation was intact. On her left Miss B had good strength and intact sensation to touch, and her tendon reflexes were present. Miss B was unsteady sitting in her chair and she felt more comfortable strapped in. Dr Q noted that Miss B was making steady progress following her operation. In Dr Q's opinion the prognosis for Miss B's continued recovery was excellent. Dr Q advised Dr E accordingly in a letter dated 29 September 1999.

On 1 October 1999, at a Paediatric Oncology Conference, a multidisciplinary team decision was made to further defer Miss B's radiotherapy. The minutes of the Conference state the following:

“... [Miss B] was evaluated by [Dr Q] (report available) and [Dr D] discussed her improvement with [Dr G] in [...]. [The neurosurgeon] feels that nothing but her medulloblastoma will cause her demise in the long term and her underlying abnormalities have been coped with by the extended family.

MRI on 28.9.99 shows no post-surgical damage or recurrence of tumour ... and the spine is free of tumour deposits.

It was decided that she should continue with aggressive rehabilitation and will have another MRI in 2 months' time when she will be reassessed for RT [radiotherapy], which is the only curative treatment for medulloblastoma. It may well be that she has tumour progression in the meantime.”

Dr E noted that the team decided to defer Miss B's radiation therapy for a further two months to allow for full recovery. Dr E said that this was discussed with the social workers, and Mr A and family, and they appeared to be in agreement with this plan.

Miss B was referred back to the care of Dr G, paediatrician at the first hospital, to await full recovery prior to commencement of radiotherapy in two months' time.

While Miss B was at the first hospital, Dr D had telephone discussions with Dr G and Dr R, neurosurgeon, in order to help Dr E arrange Miss B's radiotherapy. Miss B was still quite well at the time.

On 2 December 1999 Dr R reviewed Miss B and noted that she had made a good post-operative recovery. Dr R wanted to refer Miss B back to the city for radiotherapy. On 3 December 1999 the multidisciplinary team discussed this matter at a Paediatric Oncology Conference:

"... [Miss B] has recovered significantly: her speech is improving and she uses her arms. However, she still has some truncal ataxia and has had episodes of vomiting during the last week. CT scan reviewed now (without old CTs or MRIs) shows no sign of recurrent medulloblastoma or increased ICP [intracranial pressure]. [Dr R] saw her in [...] yesterday and thought that she had improved and that it was time to review her re radiotherapy. To inform [Dr E]."

On 10 December 1999 Miss B was discussed again at a Paediatric Oncology Conference. The following matters are noted in the minutes for this meeting:

"Was awaiting neurological recovery before proceeding to radiotherapy. Two weeks ago had vomiting which seemed to settle but re-presented 2 days ago. An MRI was performed in [...] on 8.12.99 and the films are awaited. It was felt that [Miss B] needed radiotherapy now – she has had many delays. [Dr E] stated that planning would take 2 weeks and it was felt that she would be ready to start radiotherapy in the new year."

However, Miss B suffered a relapse between 10 and 17 December 1999 and developed recurrence of her tumour followed by the development of leptomeningeal disease. (The brain is enclosed within three different meninges, or membranes, one of which is called the leptomeninges.)

Miss B's condition deteriorated and on 26 December 1999 she was admitted to the paediatric oncology ward at a children's hospital. Consultants and junior staff on the ward saw Miss B on a daily basis. Dr D was the consultant over the Christmas and New Year period of 1999/2000. Miss B's tumour was documented to have progressed through the meninges and the spine. On 31 December 1999 Dr M became involved with Miss B's case and in planning treatment. At assessment he said it became apparent that the technical difficulties to provide safe and adequate radiation treatment were potentially more difficult than indicated in the medical records. "Her severe spinal deformity with kyphoscoliosis combined with the other medical problems meant that technically adequate treatment to the spine would have been almost impossible." He said that it was clear to him from meeting

Mr A that Mr A's distressed state meant that he had significant difficulties in retrospectively accepting the consequences of the decision to defer treatment.

From this time onwards, Miss B underwent radiotherapy with palliative rather than curative intent.

Mr A noted that during the two months prior to the commencement of Miss B's radiotherapy treatment, the cancer had spread to her spine. In Mr A's opinion, if curative radiotherapy had been commenced earlier, the cancer would not have spread. Mr A was upset that Dr E and Dr D did not listen to his views during the meetings that were held to discuss Miss B's treatment. Mr A felt that Dr E and Dr D and other members of the multidisciplinary team made choices for his daughter that were not really theirs to make; the decisions should have been made by her family.

Dr D saw Mr A and Mrs F in a team meeting on 28 January 2000. Present at the meeting were a social worker, a chaplain, a nurse specialist, a Child Cancer Foundation representative, a Maori support person and an interpreter. Miss B's transfer back to her hometown for terminal care was discussed. The meeting lasted about two hours. Miss B's change of treatment from curative to palliative was discussed in detail at the meeting. The discussion covered pain control, constipation, hypertension, post-radiotherapy drowsiness, and headaches and vomiting due to increased intracranial pressure.

At the meeting, Mr A and Mrs F were obviously distressed about the poor outlook for their daughter, and in particular about:

- the time it had taken for Dr C to diagnose Miss B's brain tumour;
- whether Miss B had deteriorated because of the surgical procedure she underwent on 6 August 1999 to have the external ventricular drain removed and a shunt inserted;
- the delays with Miss B's radiotherapy treatment.

Mr A and Mrs F queried whether their or one of Miss B's siblings' white blood cells could be used in order for Miss B to have full radiotherapy treatment of the head, posterior fossa and spine. However, such treatment was not possible and this was explained to Mr A and Mrs F.

The chaplain pointed out that although Mr A and Mrs F had many questions to work through in the grieving process, they had to think of what Miss B needed the most, which was care and especially comfort.

On 2 February 2000 Dr D saw Miss B in the Haematology/Oncology Clinic for final palliative radiotherapy treatment to the cranial posterior fossa. After the treatment Miss B returned to her hometown. Dr D discussed her care with Dr G. Dr G was to arrange hospice and community nurse support for Miss B in her hometown.

On 4 February 2000 Miss B was admitted to the first hospital. She presented with problems of constipation and difficulties at home with her care. Mr A and Mrs F were not happy to stay on the ward so Miss B was discharged home on leave on 7 February 2000. At the time, Mr A and Mrs F felt let down by a lack of support, although a social worker, and hospice, palliative care and home care nurses were involved in Miss B's care.

On 9 February 2000 Dr C wrote a referral for Miss B to the local hospice in her hometown. However, her parents were reluctant for her to go there at that stage and continued to care for her at home. On 6 March 2000 Dr C visited Miss B and her parents at the request of the hospice, as Mr A in particular was reluctant to accept hospice advice or care. Dr C was aware that Mr A was angry about Miss B's illness and that he was having difficulty accepting her deteriorating condition. Miss B was eventually admitted to the hospice soon after Dr C's visit and she died on 12 March 2000.

Dr H noted that because of the nature of the tumour it is highly likely that the outcome would have been identical for Miss B, in that the disease would have recurred, and there may have been a serious adverse outcome if attempts had been made to deliver radiotherapy.

Dr M, Dr H, the second public hospital and Dr E all emphasised that considerable efforts were made to discuss with Mr A the exceedingly difficult issues central to Miss B's care. While retrospectively Mr A did not understand the decisions, there was no indication during treatment that he did not understand. The second public hospital advised me: "It is a core function of Paediatric Oncologists and Radiation Oncologists to communicate with distressed families, and they are very good at it."

Dr M noted: "[I]t is difficult to know what more could be done without inappropriately placing responsibility for complex medical decisions on [Mr A], or, equally inappropriately, excluding him from the process. My encounter with [Mr A] suggested that he did understand his role in the decision making process. He did have significant difficulties in coming to terms with the complexities of the situation particularly given a background of difficult issues he was facing and the distress of having a severely ill child."

The second public hospital stated that the Code does not give patients the right to treatment on demand. The consensus of the clinicians was that radiation treatment should not be offered at that time. Although these matters were discussed with Mr A it is up to the clinical team to decide whether treatment should be offered at that time or deferred.

Sadly, on 21 October 2001, during the course of my investigation, Mr A died of natural causes.

Independent advice to Commissioner

General practitioner

The following expert advice was obtained from Dr Shane Reti, an independent general practitioner:

"With regard to the information forwarded to me by the office of the Health and Disability Commissioner, and in my own personal and professional opinion as a medical practitioner given the above information is correct, in confidence, I would make the following points:

1. WERE CORRECT AND APPROPRIATE STANDARDS APPLIED?

Yes. For each presentation to the general practitioner over this period, an appropriate examination and investigation occurred.

2. SHOULD ANY OTHER DIAGNOSES HAVE BEEN CONSIDERED?

No. For the information given, the presenting signs and symptoms, and the past history, an appropriate differential diagnosis was made.

3. SHOULD [MISS B] HAVE BEEN REFERRED TO A SPECIALIST EARLIER?

No. There is nothing in the notes to warrant referral to a specialist earlier than was otherwise undertaken. It is unlikely that there is any connection between the ear infections and the cerebral tumour. Furthermore, [Miss B] had been seen and fully examined by a paediatrician 1 month earlier who had commented:

- a. [Miss B] was generally well.
- b. She had an ear infection needing specialist follow up.

All of these features should have been reassuring to a general practitioner.

SUMMARY

It is my opinion that overall, the management of this patient was appropriate for a reasonable general practitioner. Unfortunately, this child had a rare, asymptotically late presenting brain tumour.”

Oncologist

The following expert advice was obtained from an independent oncologist with paediatric oncology experience:

“This report is based on the letter from [Mr A], [Miss B’s] father, the letter provided by [Dr D] dated 25 August 2000 to the Health and Disability Commissioner, and photocopies taken from the [second public] hospital records with respect to the care of [Miss B].

To assist my report I have summarised the events as I understood them. This is given in the form of a summary and should not be over interpreted at this stage.

- | | |
|---------|---|
| 26.7.99 | [Miss B] admitted under neurosurgery under the care of [Dr I] with symptoms suspicious of posterior fossa tumour. |
| 27.7.99 | External ventricular drain inserted. |
| 3.8.99 | Resection of posterior fossa tumour, estimated remnant 1.5%. |
| 6.8.99 | Placement of ventriculoperitoneal shunt, cerebellar mutism and paresis of upper limbs noted about this time. |

3.9.99 Seen by [Dr E] (radiation oncologist). Decision to wait one month to start radiation in view of damage to nervous system and hope that improvement might occur. Notes state that this was explained to family.

Approximately 20.9.99 appointments for radiation planning, mould room, and treatment to start approximately 2 weeks later. Subsequently postponed.

Last week of September 1999 Paediatric Neurologist assesses [Miss B] and notes that she is improving well but still ataxic sitting in a chair.

MRI reported no sign of recurrence but queries two spots of increased intensity.

1.10.99 Decision at Paediatric Oncology Conference to defer radiation, a further MRI in two months, and if improving neurologically for radiation then. Notes state this was discussed with the family ([Dr E]).

3.12.99 Review by [Dr R] at peripheral clinic, and to now be referred back for radiation.

10 – 17.12.99 Relapse, readmission, this time under Haematology/Oncology 17.12.99 – 29.12.99.

26.12.99 First indication in notes of child being seen by [Dr D].

31.12.99 [Dr M] describes relapse at least in brain and explains to father about palliative radiation.

13.1.00 Spinal metastases and therefore limit treatment to palliative whole brain radiation only, 6.1 – 17.1.00. Note – notes record family meeting, setting up of palliative care and follow up by Haematology / Oncology.

My overall opinion is that [Dr D] did provide treatment / services to the late [Miss B] with reasonable care and skill, as best can be judged on these notes. She did not actually assess [Miss B] until 26 December and at that stage the notes document a full assessment of the situation, also appearing to accommodate the rather complex social issues.

The specific standards that apply in caring for a child with a malignancy is an appropriate level of oncology knowledge, and carrying out the medical aspects of the management appropriately. It also includes explanation of the malignancy, its treatment and the options in a form which the child and their family can understand. From the notes it would appear that [Dr D] did fulfil these requirements once she became responsible for the patient at the Christmas holiday period of 1999. The management provided by [Dr D] at that time appeared appropriate to her medical status at that time, and it was an appropriate change to palliative therapy together with institution of palliative care.

I think there are a number of matters which are relevant to this case and which need further consideration.

It appears from the medical records that there were a number of times when consultants have talked to [Mr A] and sometimes other family members, and explained the current situation for [Miss B], and have then documented that they have done this. What is less clear is whether [Mr A] understood the outcome of these discussions. It is evident from [Dr M's] note of 31.12.99 that he thought there was some difficulty with understanding. There is evidence that [Mr A] had significant concerns in one of the family meeting reports, and it also seems that the father wasn't always present because of problems with his own health and his wife's health. It is difficult to tell from the notes to what extent [Mr A] was involved in decision making at the time the radiation was deferred. The notes suggest that he was very concerned to get on with radiation promptly, and at one stage wished to take his daughter home because the doctors didn't seem to be getting on with radiation.

To me, one of the main difficulties here was the multidisciplinary way in which the care was provided. [Miss B] was initially under the care of the [n]eurosurgeon, and while she was recovering from the neurological event which is a known complication of posterior fossa surgery, she remained under the neurosurgeon's care. She was discussed regularly at the Paediatric Oncology Conference, and a very clear direction was provided early on that radiation should be given despite her postoperative complications, which were expected to be temporary. However, the Paediatric Oncology Meeting of 1 October 1999 decided on a wait of two months and one wonders if the specialist paediatric neurologist report was not fully considered, and whether in fact it might have been possible to give [Miss B] radiation under anaesthetic. I suspect that if she had been under the direct care of one of the paediatric oncologists that they would have pushed harder to proceed on with her potentially curative treatment rather than waiting a further two months. However, the note from the group conference on that day notes that [Miss B] might well recur prior to the end of the two month wait.

Once [Miss B] was readmitted under Haematology / Oncology, it seems from the notes that all her needs were being addressed despite it being a rather difficult time over the Christmas / New Year period.

I don't feel that [Dr D] should take any sole responsibility for decisions made at the Paediatric Oncology Conference. She was the note taker on a number of occasions and recorded [Miss B's] management plan, and where it is documented, senior experienced consultants in the field of neurosurgery, paediatric oncology and radiation were usually present. [Dr D] appears to have been the messenger liaising with the GP, and one could query the appropriateness of this when at this time she had not met the patient. I wonder if the Haematology / Oncology Service could review this aspect of their care together with the appropriate timing of the handover from Neurosurgery to Haematology / Oncology. In retrospect I think [Miss B] could have been formally transferred to Haematology / Oncology earlier, and could have become the responsibility of one of the Paediatric Oncologists.

I don't feel [Dr D] should be held responsible for not querying the management plan when decisions had been made by a group of relatively experienced senior clinicians.

In summary, I do not think that one can censure [Dr D] in this case, but I feel there are major issues for the interactions between Neurosurgery and Paediatric Oncology (Haematology / Oncology). The crucial time point for decision making was late September – early October when [Dr D] was not involved with [Miss B] other than as a ‘scribe’ and the responsibility really lay with the other consultants. I understand that the issues with respect to delaying the radiation will be referred to an appropriate Radiation Specialist.

I think this was an extremely difficult case. It would be difficult for the clinicians not to be clouded by [Miss B’s] pre-existing mobility problems, and be concerned about the ultimate neurological outcome for her. One would be very concerned not to add further complications and possible permanent toxicity by rushing into radiation when she already had significant neurological impairment. Such decisions come down to judgement. In retrospect [Mr A] felt his views weren’t taken into account, and this concern needs to be acknowledged, and will be regretted by all of those involved. I don’t think however this was the responsibility of [Dr D] at that time.

I would be interested what particular issues [Mr A] felt were not covered by [Dr D], for it appeared that the management after 26 December was less controversial and appeared to follow the usual standards of care for children in this situation.”

Further oncology advice

After receiving the second public hospital’s response to the provisional opinion I sought further expert advice my clinical oncologist advisor.

“You write requesting additional expert advice on this complaint. You have sent me a copy of the original complaint and also indicated that you would like further expert advice following my review of the responses from [the second public hospital], other information provided, and advice that in light of this new information my opinion remains unchanged.

Particular points:

1. Whether it was appropriate for [Dr D] to communicate with the other practitioners involved in [Miss B’s] care when she had not seen the patient, and
2. [Miss B] should have been transferred from the neurological team to the care of the Oncology team earlier in her stay in hospital, and also any other comment.

The new information does clarify some points. The letter from [Dr E] dated 26 February 2002 gives information of actions he undertook with respect to [Miss B’s] care which are not all recorded in the hospital notes. It seems that more time has been spent with [Mr A] than evident in the initial case notes. I feel the information suggests that efforts to communicate with [Mr A] were at the expected level, and unfortunately, his daughter’s condition deteriorated too quickly for repeated attempts over time to enable him to fully understand the situation.

The letters from [the second public hospital] more clearly set out the way their multidisciplinary team functions. I think it is interesting that in January 2000, just after

[Miss B] was treated, they moved the paediatric neurosurgical patients to [the children's hospital], as outlined in [Dr H's] letter of 18.2.02. The multidisciplinary case conference is a common mechanism for managing paediatric oncology patients, and good minutes are provided with the documentation. I note when I re-read my report with respect to the paediatric oncology conference that I wrote 'the paediatric oncology meeting of 1 December 1999 decided on a wait of two months'. It was in fact the meeting of 1 October 1999. At that meeting of 1 October 1999 the difficulties of giving radiation were alluded to, but were not fully explored. [Dr M's] letter which does not appear to be dated indicates that when he became involved to plan [Miss B's] treatment on 31 December 1999 it was 'apparent that the technical difficulties to provide safe and adequate radiation treatment were potentially more difficult than indicated in the medical records ... meant that technically adequate treatment to the spine would have been almost impossible'. This should have been recognised earlier if this were the case, and the team may have made a decision not to give radiation therapy.

The above comments highlight the difficulty of deciding the safest course for this girl with life threatening medulloblastoma and major other co-morbidities. In such a situation there is no 'right answer', and the challenge is to involve family and other carers in the quandary, and have them participating in the decision making. Unfortunately, the desired outcome of parents feeling informed and involved in the decisions about their child's care was not achieved here. The new information suggests [the second public hospital] tried hard.

Re Question 1:

The description by the [second hospital's] doctors about their multidisciplinary meeting, and their reasoning behind delegating [Dr D] to communicate to the General Practitioner sounds reasonable. Hospital consultants often talk about patients they have not seen to other medical people, and this after all is one of their roles – helping guide other doctors because of their greater knowledge and expertise in a particular specialist area. But, a consultant is cautious about giving definitive advice about a patient he/she has not seen. In retrospect it would have been advantageous in [Miss B's] somewhat unusual case for the communicating specialist to have had first hand knowledge of [Miss B] and her family. This is the background to my questioning the 'appropriateness' of [Dr D] being the messenger liaising with GP. I am puzzled because if [Dr E] was the lead consultant, why didn't he liaise with [Miss B's] other doctors? In 'usual circumstances' [Dr D] communicating would probably have worked well, but in this challenging case, recognised as such by the team members, it may have contributed to a deferring of decision making, and uncertainty for the family.

Re Question 2:

I think the neurosurgical and paediatric oncology services have addressed some of their interaction issues by the transfer of the paediatric neurosurgical patients to [...] where they are under the day to day care of paediatric oncologists. It presumably was not possible to do this at the time [Miss B] was being treated, but the fact that such patients are now transferred to paediatric oncology suggests that the importance of this was recognised and is currently the management plan. It would have been optimal for [Miss

B] to be transferred to the paediatric oncology ward earlier, but how much this contributed to the outcome is hard to determine.

In summary, the reports from [the second hospital] fill some gaps that were not evident in the original clinical notes, and in particular the extent of the effort of [Dr E] to talk to [Miss B] and her father. The impressions I gained from the notes with respect to the multidisciplinary care of [Miss B], and the location of care, appear to have been addressed by [the second hospital], even predating the time of the complaint. If [Miss B] presented again it would still be an extremely challenging case, to try and make the right decision about timing of radiation. The social set up was challenging. I feel it comes down to the question of degree. I feel that it would be preferable for a doctor involved with the child to liaise with other medical practitioners with respect to her care, rather than someone who had never actually met her whenever possible. I still feel concerned that there was a two month gap between October and December when [Miss B] was home awaiting further rehabilitation, with the question of radiation remaining undecided. After reading the most recent responses I tend more to feel that [Mr A] would need a lot more time than is ever available to help him reach a full understanding, and that indeed he may never have got to that situation.”

Radiation oncologist

The following expert advice was obtained from Dr Chris Atkinson, an independent radiation oncologist:

“[Miss B], then aged 7, presented in August 1999 with symptoms and signs consistent with a posterior fossa tumour. The MRI scan imaged tumour was excised on 02 August 1999, and on 06 August of 1999 a shunt was inserted. A medulloblastoma was confirmed, which was largely but incompletely excised.

Following the shunt procedure [Miss B] developed cerebellar mutism, which clearly significantly complicated her pre-cancer neurological state, which was not normal because of a congenital spinal deformity, a deformed right leg and urinary incontinence.

All consultants that were involved with [Miss B's] care, including [Dr E], believed [Miss B] should have cranio-spinal radiation treatment in order to prevent progression of the disease in the posterior fossa, where small volume disease remained following surgery, and to prevent spinal cord metastases. The controversial decision was when this radiation treatment should begin given [Miss B's] significant vasospastic damage following the shunt insertion, particularly as radiation treatment would technically require general anaesthetics on a daily basis for six weeks, with the potential for some additional hypoxia to an already damaged and subsequently healing central nervous system. The critical feature of [Miss B's] management is thus the clinical judgement on when definitive radiation treatment should begin in her case. Clearly there is a balance between the risk of tumour recurrence because of a delay to begin radiation treatment, and radiation treatment compounding [Miss B's] already poor quality of life, if radiation treatment should delay her rehabilitation following the central nervous system injury suffered following the shunt insertion.

Given the complexity of this problem, the communication of these balanced risks to [Miss B's] family, and in particular her father [Mr A], was of paramount importance. [Mr A] needed to be aware of the reasons for delaying his daughter's radiation treatment, and be party to the decision making. I believe the balance of these risks, the communication of these risks and the ultimate decision to delay her definitive radiation treatment are the crux of this complaint.

When [Miss B] did re-present having shown significant neurological improvement in December 1999, but promptly then declared progressive and metastatic cancer, I believe her management from that point in time was entirely appropriate. She received high quality palliative care, and it is clear from [Dr M's] notes, that a major attempt was made to explain to [Mr A] the palliative nature of treatment.

[Dr E's] letter to the Health and Disability Commissioner, dated 30 August 2000, is a clear summary of his approach to [Miss B's] management. He appropriately noted [Miss B's] pre-cancer clinical problems of urinary incontinence and a dysgenic right hemipelvis. He clearly wished to proceed to radiation treatment to the cerebrum and spinal axis with a boost to the posterior fossa. His concern was that given [Miss B's] post-shunt additional neurological problems when she was unable to follow commands, had poor trunk and neck control, she would therefore require a daily anaesthetic, for all six weeks of her radiation treatment. He believed she would be exposed to an increased risk of cerebral hypoxia because of these anaesthetics and that this might compromise her recovery. Indeed this was also the opinion of [Dr P], Paediatric Radiation Oncologist, [at an overseas medical school], whom [Dr E] consulted I understand in October 1999. I think it is clear therefore that [Dr E] wished to treat [Miss B] with appropriate Craniospinal radiation treatment, but was fearful that her neurological state following surgery was poor and recovery of her quality of life to the state that she enjoyed prior to the diagnosis of the cancer, would be delayed or even permanently impaired by beginning radiation treatment too soon. I believe [Dr E] has shown an appropriate level of Oncology knowledge in that he has clearly wished to balance the need to control the cancer with the need to maintain an acceptable quality of life for this little girl.

What however is less clear is how well [Mr A] was informed of these decisions, and in addition it is controversial whether [Miss B] needed to wait all of the two months of October and November, prior to commencing radiation treatment.

The paediatric oncology conference of 13 July 1999 states that 'the literature suggests treatment should proceed despite mutism and survival is compromised by delaying radiotherapy by more than four-weeks post surgery. It was felt that radiotherapy should be proceeded with after discussion with the family'. [Miss B] had a month at home in [...] from approximately the last few days of August until the last few days of September, 1999. [Dr E] reviewed [Miss B] with her father at the time of her repeat MRI scan on 28 September 1999, where no post-surgical damage or recurrence of tumour was noted. He arranged for a consultation with [Dr Q] asking, 'Please could you evaluate her current neurological status and indicate if you feel that further recovery of her deficits is possible over the next few months.' [Dr Q], Paediatric Neurologist, wrote to [Dr E] on 29 September 1999, and suggested, '[Miss B] is

making steady progress following resection of a medulloblastoma and placement of a ventriculo-peritoneal shunt. She has had paralysis of her upper extremities and cerebellar mutism which are gradually improving. Her current deficit consists of a marked cerebellar speech defect, mild proximal weakness on the right, and marked right appendicular ataxia. She also has truncal ataxia. Her prognosis for continued recovery is excellent. I understand that [Miss B] is to begin a course of cranial and spinal radiation.'

The paediatric oncology conference of 01 October 1999 suggests that [Dr Q's] report was discussed and that 'it was decided that she should continue with aggressive rehabilitation and would have another MRI in two months' time when she will be reassessed for radiation treatment which is the only curative treatment for the medulloblastoma. It may well be that she has tumour progression in the meantime.'

These two reports seem to be at odds with one another. [Dr Q] appears to be comfortable that radiation treatment could proceed from the time of her assessment on 29 September 1999, but the paediatric oncology conference consensus view was that [Miss B] should wait for a further two months prior to commencing radiation treatment, a view taken by [Dr E]. I think it is impossible to say clearly whether the decision to delay for a further two months is completely correct, or completely incorrect. Again, the decision calls for judgement balancing the significant risk that a delay to start treatment would allow recurrence to occur, which in fact happened, versus a belief that a further period of 'brain healing' may allow [Miss B] to have a better quality of life than if radiation treatment was commenced immediately. It was therefore essential that [Mr A], [Miss B's] father, understood the implications of further delay with respect to the risk of recurrence versus the risk that [Miss B's] neurological status and quality of life could be impaired by 'starting radiation treatment too soon'.

[Dr E] states quite clearly that he believed [Mr A] understood these contrasting risks and concurred with a decision to delay radiation treatment. That [Mr A] should subsequently make a complaint to the Health and Disability Commissioner suggests that he did not fully understand the implications of such a delay.

I think it is clear from [Dr M's] report of 31 December 1999, that [Dr M] perceived some difficulty with respect to [Mr A's] understanding of [Miss B's] situation. [Mr A] had significant other family problems to contend with, and clearly at one stage was so frustrated at his perception that [Miss B's] treatment had not begun, that he threatened to take his child home to [...].

In my opinion [Dr E's] management was appropriate in that he clearly understood the need and how, to treat [Miss B's] cancer, but was also acutely aware that radiation treatment could markedly impair her neurological condition further, resulting in an unacceptable quality of life. He appropriately requested reassessment by a paediatric neurologist ([Dr Q] in late September) and took that opinion to the paediatric oncology conference; the minutes seem to suggest that there was a collective decision to delay commencement by a further two months.

Paediatric cancer patients are always treated by a multi-disciplinary team, and it appears as though [Dr E] has sought appropriate advice to back up his decision, to delay [Miss B's] treatment for a further two months, by referring her case back to the multidisciplinary meeting. The consensus view appears to have been to delay radiation treatment.

My personal opinion would be that a case could have been made at that time to commence radiation treatment earlier, particularly if more weight had been based on specifics of [Dr Q's] report.

My major concern with [Miss B's] management relates to communication. It is very difficult to impugn from the notes given to me to consider, whether [Mr A] truly understood the implications of delaying radiation treatment. With the 'benefit of hindsight', it appears that an incorrect decision was made; treatment was delayed, the cancer relapsed, and this proved fatal. It is also fair to say that all clinicians involved in [Miss B's] care balanced the need to treat with radiation treatment, [with] their fears that her quality of life would be poor because of delayed rehabilitation from the cerebellar event that occurred after the shunt.

Perhaps the most compelling feature of [Miss B's] case is that although she was managed by a multi-disciplinary team, at each point in a patient's care, one clinician needs to take responsibility and to convey the opinions of the group clearly to the patient's family. Although [Dr E] states quite clearly he thought that he had communicated these concerns to [Mr A], I think it is clear that [Mr A] did not fully comprehend the complexity of his daughter's case, and indeed may well have had a clear opinion if he had. He may for instance have wished that radiation treatment was begun earlier, accepting an increased risk of poor recovery from his daughter's cerebellar mutism.

In summary I do not believe [Dr E's] treatment of the late [Miss B] was inappropriate. Although a decision to delay [Miss B's] treatment by a further two months in late September 1999 could be challenged with the benefit of hindsight, it appears as though that was a consensus and collective decision and not made by [Dr E] in isolation.

I believe [Miss B's] case suggests that the communication of the members of the multi-disciplinary group could be improved, and that the communication to family members, particularly with respect to a complex balancing of risks and benefits from definitive treatment, could also be improved.

Given the complexity of [Miss B's] case I would have expected some record within the chart that clearly displayed such a discussion of risks versus benefits of delaying radiation treatment, had taken place."

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 4

Right to Services of an Appropriate Standard

- 1) *Every consumer has the right to have services provided with reasonable care and skill.*

...

- 5) *Every consumer has the right to co-operation among providers to ensure quality and continuity of services.*

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. ...*

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; ...*

RIGHT 7

Right to Make an Informed Choice and Give Informed Consent

- 1) *Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise.*

Opinion: Breach – The second public hospital

In my opinion the second public hospital breached Right 4(5) of the Code.

Right 4(5)

Care co-ordination

Dr D was not directly involved with Miss B's care until late December 1999, other than as a 'scribe' at the paediatric oncology conferences where senior experienced consultants in the fields of neurosurgery, paediatric oncology and radiation were usually present. She was the note taker on a number of occasions and recorded Miss B's management plan. Dr D also appears to have been the messenger for the multi-disciplinary team, liaising with Dr C, Dr G (paediatrician) and Dr R (neurosurgeon) while Miss B was in the care of the first public hospital.

My oncology advisor queried the appropriateness of Dr D acting as the liaison person between the second hospital and Miss B's general practitioner and the other medical practitioners who were caring for Miss B, when Dr D did not play an active role in treating Miss B until late December 1999. Dr D did not meet Miss B and her family until late December 1999.

After reviewing the responses to my provisional opinion from staff at the second hospital, my oncology advisor noted that Dr E was the lead consultant and questioned why he did not liaise with Miss B's other doctors. She stated that the team's explanation of why Dr D was delegated to talk to Miss B's other health providers seemed reasonable and that clinicians often talk to other medical people about patients they have not seen. However, my advisor concluded that given Miss B's unusual circumstances it would have been advantageous for the communicating specialist to have knowledge of her and her family. "In this challenging case, recognised as such by the team members, [the fact that Dr D did not have personal knowledge of Miss B or her family] may have contributed to a deferring of decision making and uncertainty for the family."

It was important that the information conveyed to the family was consistent and that Miss B received quality and continuity of care. For this to occur, the liaison person needed to be familiar with all the issues relating to Miss B and her family, not just the clinical issues. I do not consider that Dr D was the appropriate initial liaison person with other providers. She had not met Miss B or her family and was familiar only with the clinical issues. The decision to use Dr D as intermediary was made by the multidisciplinary team, for which the second hospital must take responsibility.

In these circumstances, in my opinion the second hospital breached Right 4(5) of the Code by failing to take appropriate steps to ensure co-ordination of Miss B's care.

Opinion: No breach – Dr C**Right 4(1)**

Miss B had the right to have medical services provided to her with reasonable care and skill. Between June 1998 and late July 1999 Dr C saw Miss B on eight occasions. In July 1999 Dr C saw Miss B five times. She had a variety of symptoms, including headaches, and problems with her ears and eyes.

My general practitioner advisor's opinion was that Dr C appropriately examined and investigated Miss B at each consultation and, given the symptoms she presented with, made the appropriate differential diagnoses. It was unlikely that there was any connection between the recurring ear infections and the tumour. There was nothing in the notes to warrant Dr C referring Miss B to a specialist earlier than was otherwise undertaken.

Dr G, paediatrician, examined Miss B on 17 June 1999. He noted that Miss B looked well and systemic examination showed nothing new, except for a discharging left ear and a dry perforation in the right eardrum. This examination would have reassured Dr C.

When Miss B presented to Dr C on 26 July 1999 after vomiting daily with headaches for two weeks, he promptly and appropriately referred her on to the paediatric registrar at the first public hospital.

I accept my expert advice that Dr C's management of Miss B was appropriate. Miss B had a rare type of tumour that presented late and did not show the usual symptoms.

Accordingly, in my opinion Dr C treated Miss B with reasonable care and skill and did not breach Right 4(1) of the Code.

Opinion: No breach – Dr E**Right 4(1)**

My radiation oncology advisor's opinion was that Dr E's management of Miss B was appropriate. Dr E clearly understood the need to treat Miss B's cancer, but he was also acutely aware that radiotherapy treatment could markedly impair her neurological condition, resulting in an unacceptable quality of life. My advisor stated that Dr E appropriately requested reassessment of Miss B by Dr Q, a paediatric neurologist.

All the consultants involved in Miss B's treatment and care, including Dr E, believed that Miss B should have radiotherapy treatment in order to prevent the brain tumour progressing or moving to her spine. The difficulty for the consultants was when the radiotherapy treatment should begin, given the problems that arose following the shunt insertion.

My radiation oncology advisor stated that Dr E sought appropriate advice to back up his decision to delay Miss B's treatment for a further two months, by referring her case back to the multidisciplinary team conference. The consensus view was to delay radiotherapy treatment.

I accept my expert advice that Dr E's management of Miss B was appropriate. Accordingly, in my opinion Dr E treated Miss B with reasonable care and skill and did not breach Right 4(1) of the Code.

Right 5(1)

Mr A felt that Dr E did not listen to him and his family during Miss B's treatment. Dr E was the primary consultant responsible for communicating with Mr A. Dr E said that he spent a large amount of time talking with Mr A and advising him about the complex issues involved in Miss B's care and surrounding the proposed radiotherapy treatment. I accept that Dr E made genuine and sustained efforts to communicate effectively with Mr A and provided him with a full account of Miss B's condition, prognosis, possible treatment, and the risks and benefits of that treatment, and discussed the rationale for deferral of treatment.

However, I note Mr A's concerns that Dr E was not listening to him, and, as relayed by the Cultural advisor, that Mr A was not getting information from the doctor and had to wait a long time for the doctor to speak with him. Dr E said that he used a translator, Maori support workers and social workers to assist him to discuss issues with Mr A. I can find no evidence in the medical records that this occurred. The only record of multi-disciplinary meetings held with the family is for the meetings on 17 August 1999 and 28 January 2000 (Dr E was not present at these meetings). The Cultural advisor and social worker interviewed during my investigation also indicated that they rarely, if ever, attended meetings with clinicians and that their role was to support the family.

Although I have some concerns about the communication that occurred, I do not believe it is appropriate to single out Dr E as responsible for any shortcomings.

Accordingly, in my opinion Dr E did not breach Right 5(1) of the Code.

Opinion: No breach – Dr D

Right 4(1)

My oncology advisor's overall opinion was that Dr D assessed and treated Miss B appropriately. When Dr D assumed responsibility for Miss B in late December 1999, she conducted a full assessment, appropriately instituted palliative care and explained this to Mr A and his family.

I accept my expert advice that Dr D's management of Miss B was appropriate to her medical status. Accordingly, in my opinion Dr D treated Miss B with reasonable care and skill and did not breach Right 4(1) of the Code.

Right 5(1)

Mr A felt that Dr D did not listen to him and his family during Miss B's treatment. Dr D had no direct involvement with Miss B's care until late December 1999. Dr D saw Mr A and his wife in a team meeting on 28 January 2000. The meeting lasted about two hours. Miss B's change of treatment from curative to palliative was discussed in detail at the meeting. The discussion included pain control, constipation, hypertension, post-radiotherapy drowsiness, and headaches and vomiting due to increased intracranial pressure.

The crucial time point for decision-making in regard to Miss B's proposed radiotherapy was late September/early October when Dr D was not involved with Miss B other than as a 'scribe', and the responsibility for Miss B's treatment lay with the more senior consultants on the multidisciplinary team.

Accordingly, in my opinion Dr D is not responsible for the lack of effective communication with Mr A, and did not breach Right 5(1) of the Code.

Opinion: No breach – The second public hospital

Rights 5(1), 6(1) and 7(1)

Mr A stated that while Miss B was undergoing treatment at the second hospital he did not think that his family's views were taken into consideration or that they were even listened to by the team that treated Miss B. Evidence from Mr N, cultural advisor, suggests that Mr A was intensely frustrated and angry because he was not getting information from the doctor and had to wait a long time for the doctor to speak with him. Ms J was the social worker for the ward. Her impression was that Mr A may not have retained very much information because of his illness, his trauma over Miss B's condition, and his wife's illness. On arrival at this hospital Mr A was shocked and disorientated having arrived in the city without even a change of clothes. Ms J also conveyed the picture of a man who found it easier to talk about his feelings and concerns with her and the cultural advisor because they were other Maori faces. Mrs F confirmed that her husband sought a great deal

of advice and information from his sister, who is a registered nurse. Unfortunately, it was not possible to obtain further information from Mr A, who died during the course of my investigation.

Both my oncology advisors, in their initial advice, expressed concerns about the level and adequacy of the communication with Mr A and whether clinicians gave Mr A the opportunity to make choices and decisions about his daughter's treatment.

In their responses both this hospital and Dr E stated that, as evidenced by the notes, clinicians, particularly Dr E, spent a lot of time with Mr A on a number of occasions explaining Miss B's condition, prognosis, and the risks and benefits of radiation therapy. They discussed the complexities of Miss B's circumstances and how this affected her treatment.

Dr E also stated that extensive use was made of social workers, Maori support services and translators when communicating with Mr A. However, apart from two meetings that Dr E was not involved with, there is no mention of the involvement or presence of social workers, the cultural advisor and translators when clinical matters were discussed with Mr A. The social worker and the cultural advisor mentioned in Miss B's notes stated that they were not present when clinical matters were discussed by clinicians and that they would have no role in such discussions, as their role is to support the consumer and the family, not to discuss clinical findings.

It is important to record interactions with the family in the clinical notes and it is equally important to record who was present when complex clinical issues were discussed. On the evidence available it appears unlikely that Maori support persons and social workers were present at all of the consultations clinicians had with Mr A. The presence of such support persons would have been valuable. I also note Ms J's comments that she felt that Mr A was more comfortable talking to her and the cultural advisor as they were other Maori faces.

The importance of communicating with or having people present from a patient's or family's own culture cannot be underestimated. Due to the time pressures and constraints experienced by senior clinicians, social workers and The cultural advisor may be able to spend more time with patients and their whanau and get to know them in a way that a senior clinician may be unable to. The cultural advisor and social workers may have a better feel for issues that need further discussion. It is possible that Mr A felt that he could not express himself freely to the clinicians because he did not feel comfortable with them for cultural reasons and also because he did not see them as often as he saw ward staff and other support workers, and so did not have such a good relationship with them.

Dr M said that in his opinion Mr A was aware of his role in the decision-making process. This hospital correctly stated that the Code does not give patients the right to treatment on demand. The Code gives patients the right to make an informed choice and give informed consent to clinical decisions about care (Right 7(1)). However, a patient cannot demand care that is clinically inappropriate. In this case the decision to defer radiation was a finely balanced one. The decision appears to have been made by the team and communicated to Mr A. It is not clear that his views were sought until after the decision was made. It is also

possible that Mr A felt as though he was being talked to and not with. In such a finely balanced and complex case the patient or her parent or guardian should be a partner in decision making. Their views should be actively sought and considered. It is not clear that this was done.

There were a number of times when different health professionals talked to Mr A and other family members and attempted to explain Miss B's current status. Care needs to be taken to ensure that explanations are consistent and that the primary consultant is made aware of any continuing issues the patient or family have about the information that they are receiving. Some of the misunderstanding in this case may have arisen because of the differing explanations received from the doctors in neurosurgery as distinct from that provided by the oncologists. As my oncology advisor noted, the risks of this happening could have been minimised if Miss B's care had been transferred from neurosurgery to oncology at an earlier point in time.

I note my clinical oncologist advisor's comments and the comments of Dr H in regard to children with brain tumours being admitted to an adult ward, and the difficulties this could potentially cause both in terms of clinical management and presumably also with regard to communication. I am pleased to see these concerns have been addressed, with children like Miss B now being treated at the children's hospital.

This hospital also noted that Mr A's frustration was not proof of poor communication and that the father of a seriously ill child could be expected to experience distress and frustration. His threats to take his daughter home could have been caused by a number of factors, including missing family support. The hospital further stated that grief about the outcome could have contributed to Mr A's dissatisfaction with the care provided. The clinicians were not aware during treatment that Mr A did not understand the information given to him, was misinterpreting information, and had concerns about treatment being delayed. If the clinicians had been aware, they would have made further efforts to discuss matters with him.

After reviewing the hospital's responses to my provisional opinion, my oncology advisor was of the view that the hospital tried hard to involve family and to have them participate in decision making. She stated:

"I feel the information suggests that efforts to communicate with [Mr A] were at the expected level, and unfortunately, his daughter's condition deteriorated too quickly for repeated attempts over time to enable him to fully understand the situation ... I tend to feel that [Mr A] would need a lot more time than is ever available to help him reach a full understanding, and that indeed he may never have got to that situation."

Having read the responses from the clinicians at the hospital, and in the absence of evidence from Mr A, I accept that the hospital took all reasonable steps to comply with its legal obligations and did not breach Rights 5(1), 6(1), and 7(1) of the Code. However, as noted above, I have some reservations about the communication that in fact occurred.

Actions

I recommend that the second public hospital take the following actions:

- Provide an apology to Mrs F. This letter should be sent to my Office and will be forwarded to Mrs F.
 - Review its practice in light of this report.
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Other actions

A copy of this opinion will be sent to the Medical Council of New Zealand.

For educational purposes, a copy of this opinion with identifying features removed will be placed on the Health and Disability Commissioner website, www.hdc.org.nz, and sent to:

- the Royal Australian and New Zealand College of Radiologists
- the Australasian Chapter of Palliative Medicine of the Royal Australasian College of Physicians
- the Paediatric Society of New Zealand
- the Royal Australasian College of Physicians
- the Associate Minister of Health
- the Deputy Director-General, Maori Health, with a recommendation that copies of the opinion be distributed to the District Health Boards.