

**General Practitioner, Dr C**

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

**(Case 11HDC00647)**



Health and Disability Commissioner  
*Te Toihau Hauora, Hauātanga*



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## Executive summary

### *Background*

1. In 1995, Mrs A was diagnosed with Huntington's disease (HD). Dr C is a general practitioner (GP) who provided medical services to Mrs A until 2010.
2. In 2002, Dr C discussed Mrs A's future care with her. Mrs A was adamant she wished to remain living in her own home. Dr C promised to ensure that Mrs A would be able to do so. It was agreed that Dr C would visit Mrs A regularly. Once or twice a year, Dr C discussed Mrs A with psychiatrist Dr D. Dr D last saw Mrs A in 1999.
3. Mrs A became increasingly reclusive. She refused home help and other support. From 2005 she refused to allow Dr C into the home and, thereafter, most of their documented contact was by telephone. Dr C said there were also unrecorded face-to-face contacts on the balcony of the flat. Mrs A was prescribed a nutritional supplement, and when she needed a repeat prescription or delivery she would telephone Dr C or her practice.
4. Mrs A's daughter, Ms B, repeatedly expressed concerns to Dr C about her mother's living conditions. Mrs A periodically refused to have contact with Ms B; at these times Ms B was dependent on Dr C to ensure her mother was safe.
5. In 2006, Mrs A had an overnight admission to hospital. Dr C advised the clinicians that support and cares were in place for Mrs A and took her home. No competence assessment was undertaken.
6. During the four years that followed, Dr C had limited face-to-face contact with Mrs A although, on one occasion, Dr C had an hour-long conversation with Mrs A through a curtain, but was able to see only her feet. Dr C monitored Mrs A by visiting the flat to check for signs of life, such as whether the television was on, and whether there were flies or smells.
7. In 2008, Mrs A's landlord contacted Dr C to say that there was a leak coming from Mrs A's bathroom into the garage below. Mrs A told Dr C that she had fixed the toilet and no repairs were necessary. Mrs A had just turned off the water supply to the toilet so it was not able to be flushed, although she continued to use it.
8. From 2000 until 2010 Dr C prescribed a nutritional supplement, "Ensure", without taking adequate steps to assess Mrs A's weight or nutritional status.
9. In 2010, after it was discovered that Mrs A was living in conditions of extreme squalor, Dr C certified that Mrs A was incompetent with regard to decisions about her personal care and welfare.

### *Decision summary*

10. Dr C failed to assess Mrs A's competence. In addition, Dr C assumed responsibility for Mrs A but failed to ensure the provision of adequate care and support. Accordingly, in my view, Dr C failed to provide services of reasonable care and skill,

and breached Right 4(1)<sup>1</sup> of the Code of Health and Disability Services Consumers' Rights (the Code).

11. By prescribing for a patient she had not reviewed for an extended period, and forming a relationship that went well beyond the normal doctor–patient relationship and involved her acting as the gate-keeper for any contact by support services, Dr C did not comply with professional standards and breached Right 4(2)<sup>2</sup> of the Code.
  12. By failing to keep adequate records, Dr C also breached Right 4(2) of the Code.
  13. Adverse comment is made about Dr D providing support for Dr C's decisions when he had not seen Mrs A since 1999.
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### Complaint and investigation

14. Ms B complained to the Commissioner about the standard of care provided to her mother, Mrs A. Mrs A subsequently advised that she supported the complaint.
15. The following issue was identified for investigation:

- *Whether Dr C provided Mrs A with an appropriate standard of care between 2002 and 2010.*

16. The parties directly involved in the investigation were:

Mrs A	Consumer
Ms B	Complainant
Dr C	Provider
Dr D	Provider

Also mentioned in this report:

Ms E	Rehabilitation Service Co-coordinator
Dr F	Doctor at public hospital

17. Information was reviewed from: Ms B, Dr C, Dr D, the District Health Board, the Huntington's Disease Association, Ms E, the Police, Mrs A's landlords, and Mrs A.
  18. Expert advice was obtained from vocationally registered general practitioner Dr David Maplesden, and is attached as **Appendix A**.
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<sup>1</sup> Right 4(1) states: "Every consumer has the right to have services provided with reasonable care and skill."

<sup>2</sup> Right 4(2) states: "Every consumer has the right to have services provided that comply with legal, professional, ethical, and other relevant standards."

## Information gathered during investigation

### *Huntington's disease*

19. Huntington's disease (HD) is a hereditary neurodegenerative disorder caused by a defect on chromosome 4.
20. According to *A Physician's Guide to the Management of Huntington's Disease*:<sup>3</sup>
  - Each child of an affected parent has a 50% chance of developing the disease.
  - There is currently no treatment that can stop, slow, or reverse the progression of HD.
  - Most people with HD develop the symptoms in their forties or fifties, although there may be subtle changes much earlier.
  - HD manifests as a triad of motor, cognitive, and psychiatric symptoms that begin insidiously and progress over many years until the death of the individual.
  - The average survival time after diagnosis is about 10–20 years, but some people have lived 30 or 40 years with the disease.
21. According to "Huntington disease: Management":<sup>4</sup>
  - Depression, paranoia, delusions, and hallucinations can develop at any point in the illness, and approximately one-half of patients will meet diagnostic criteria for depression. The suicide rate of people with HD is 7%.
  - Cognitive decline is inevitable in HD. The dominant cognitive feature of HD is executive dysfunction with diminished ability to make decisions, multi-task, and switch from one set of cognitive goals to another. Patients typically lack insight into their cognitive deficits.
  - Weight loss and cachexia<sup>5</sup> are common features of HD, despite efforts to maintain appropriate caloric intake. A high calorie diet is frequently needed owing to the high metabolic requirements in patients with HD.
  - Therapy is focused on symptom management and supportive care in order to optimise quality of life. Despite these difficult circumstances, practitioners must be vigilant in caring for patients with HD and their families. The best care is provided by an interdisciplinary team that addresses the broad physical and psychological needs of patients and families, and manages new issues as they arise through long-term follow-up.
  - Use of physiotherapy, occupational therapy, and home care may allow for prolongation of community living. Speech therapy and dietary services are beneficial in managing dysphagia and weight loss. Gait and balance issues should be assessed by a physiotherapist, and a walker and/or wheelchair used

<sup>3</sup> Nance, MA, Paulsen, JS, Rosenblatt, A, and Wheelock, D, *A Physician's Guide to the Management of Huntington's Disease* (3<sup>rd</sup> ed) (New York: Huntington's Disease Society of America, 2011).

<sup>4</sup> Suchowersky, O, "Huntington disease: Management", UpToDate, 10 February 2012: <http://www.uptodate.com/contents/huntington-disease-management>.

<sup>5</sup> Cachexia is the loss of body mass that cannot be reversed nutritionally. Even if the affected patient eats more calories, lean body mass will be lost, indicating that a primary pathology is in place.

as indicated to prevent falls. Hip protectors are recommended to decrease the risk of hip fractures, since falls are common in the late stages.

- Dysphagia<sup>6</sup> and aspiration pneumonia<sup>7</sup> are common causes of death in patients with end-stage HD. The potential use of a gastric feeding tube, and other end-of-life issues (eg, home care versus outside care, resuscitation, other aggressive medical interventions, guardianship, and advanced medical directives) should be discussed with the patient and family before motor symptoms and cognitive decline become severe, and before the patient loses the ability to communicate.<sup>8</sup>

*Information about HD available in 1999*

22. In response to the provisional opinion Dr C commented that the above references are from 2011 and 2012. She stated that HD is a rare condition and that knowledge about HD has improved in recent years.
23. The 1999 publication, *A Physician's Guide to the Management of Huntington's Disease*<sup>9</sup> includes the following information:
  - It is important to remember ... that patients and their families can still benefit greatly from an accurate diagnosis, prognosis, education and support.
  - The average survival time after diagnosis is about 15 to 20 years, but some patients have lived 30 or 40 years with the disease.
  - In the middle stage, patients will probably not be able to work or drive and may no longer be able to manage their own finances or perform their own household chores, but will be able to eat, dress and attend to personal hygiene with assistance. Chorea<sup>10</sup> may be prominent, and patients will have increasing difficulty with voluntary motor tasks. There may be problems with swallowing, balance, falls and weight loss. Problem solving becomes more difficult because patients cannot sequence, organize, or prioritize information.
  - In the advanced stage of HD, patients will require assistance with all activities of daily living. Although they are often non verbal and bedridden in the end stages, it is important to note that patients seem to retain fair comprehension.
  - Psychiatric symptoms may occur at any point in the course of the disease, but are harder to recognize and treat late in the disease.

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<sup>6</sup> Dysphagia refers to difficulty in eating as a result of disruption in the swallowing process. Dysphagia can be a serious threat to a person's health because of the risk of aspiration pneumonia, malnutrition, dehydration, weight loss, and airway obstruction.

<sup>7</sup> Aspiration pneumonia is bronchopneumonia that develops owing to the entrance of foreign materials into the bronchial tree, usually oral or gastric contents (including food, saliva, or nasal secretions). Depending on the acidity of the aspirate, a chemical pneumonitis can develop, and bacterial pathogens (particularly anaerobic bacteria) may add to the inflammation.

<sup>8</sup> These two articles are included for reference only. It is accepted that they were published after the events involved in this opinion and so Dr C would not have known of them at the relevant time.

<sup>9</sup> Rosenblatt, A, Ranen, NG, Nance, MA, and Paulsen, JS, *A Physician's Guide to the Management of Huntington's Disease* (2<sup>nd</sup> ed) (New York: Huntington's Disease Society of America, 1999).

<sup>10</sup> Chorea is an abnormal involuntary movement disorder, one of a group of neurological disorders called dyskinesias.



- At times the lack of definitive treatments can be frustrating, but careful attention to the changing symptoms and good communication between professionals, family members, and affected individuals all contribute to the successful management of the disease.

### *Background*

24. In 1992, Mrs A discovered that her mother had been diagnosed with HD. General practitioner Dr C referred Mrs A (then aged 34) to consultant psychiatrist Dr D for pre-symptomatic testing. Dr D first met with Mrs A in December 1992. In his letter to Dr C, Dr D noted that at that time, Mrs A was asymptomatic and essentially seeking information about HD. Dr C said that she had little information about Mrs A's mother and how she was affected by HD.
25. Dr C worked as an independent contractor at a health centre. Her first contact with Mrs A had been in 1986, when Mrs A was pregnant with her younger daughter, Ms B. Dr C remained Mrs A's primary care provider until 2010. Dr C worked limited part time hours.
26. In 1995, Mrs A underwent pre-symptomatic testing for HD, and the results stated: "[Mrs A] will develop signs and symptoms of Huntington's disease in the future. [Mrs A] was found to have an amplified CAG repeat of 44 on one chromosome and a normal repeat of 18 on the other."<sup>11</sup>
27. At that stage, Mrs A was living with her young daughter, and had assumed the supervisory caring duties for her mother. Mrs A's older daughter was flatting.
28. On 3 May 1995, Dr D recorded that Mrs A was probably currently clinically depressed and could be developing early symptoms of HD. Dr D told HDC that they "embarked on a variety of treatments for her mood, with some reasonable success over the next few years".
29. By 1997, Mrs A was developing difficulties with initiation, forgetfulness and labile emotions. Dr D suspected that these were symptoms of pre-cortical dementia. Mrs A had developed some choreiform movements,<sup>12</sup> and was struggling to cope with the organisation required in everyday life, although she declined home help.
30. On 4 February 1999, Dr D saw Mrs A and recorded that "she was appearing disheveled, she had choreiform movements as expected due to a diagnosis of Huntington's disease, but clearly gives a history that she is not managing particularly well at home, both with respect to her mood and also her ability to organise her domestic responsibilities".

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<sup>11</sup> The CAG repeat is part of DNA, and is used as an indicator of the likelihood of a person developing HD. In most people, the CAG repeat occurs 10–28 times, but in a person with HD it can occur 36–120 times.

<sup>12</sup> Choreiform means pertaining to or resembling chorea, which is a disorder of the nervous system characterised by jerky involuntary movements.

31. From September 1999, Mrs A declined further outpatient appointments with Dr D. He offered to visit her at home but she deferred any scheduled visits. Dr D's involvement with Mrs A was then confined to conversations with Dr C about Mrs A from time to time, and completing an annual "special authority" application for Ensure, a nutritional supplement.<sup>13</sup>
32. From 2001, Dr C began visiting Mrs A at home. In March 2002, automatic payments were set up for the provision of medical services, at a rate of \$18 per month. On 7 June 2002, the payments were increased to \$40 per month.

*2002 discussion*

33. Dr C stated that in 2002 she had a conversation with Mrs A about her future care. Dr C recorded on 30 October 2002: "contact [Dr D]. He will alert [the Needs Assessment and Service Co-ordination agency (NASC)] re ? March need for place. I will contact [the NASC] re [home help]"<sup>14</sup>.
34. Dr C stated that she visited Mrs A with the intention of raising the possibility of Mrs A going into institutional care, because the people who were supporting Ms B were considering that Ms B would move out of the home the following March. Dr D indicated that he would inform the NASC that he would be looking for institutional care for Mrs A in residential care, and that Dr C should forewarn Mrs A.<sup>15</sup> Dr C stated that Mrs A "just got incredibly distraught at the prospect which almost escalated out of control".
35. Dr C said that Mrs A did not want to go into an institution as she was adamant she could not live with others, and that: "[Mrs A's] overwhelming sense of paranoia and panic at being seen by anybody meant she refused to be institutionalised. She could not imagine surviving being institutionalised and was quite definite she would kill herself should she be forced to live in an institution." Dr C also noted that Mrs A liked to watch [TV] at night and sleep during the day,<sup>16</sup> and did not wish to be parted from her cats.
36. Dr C said that, in her view, although the residential care service was not the only place that a person with HD could be admitted to, people of Mrs A's degree of disability were more suited to residential care. However, Dr C considered that this residential care service would not have suited Mrs A, because she could not have taken her cats there and they have people moving around all the time. However, in

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<sup>13</sup> From 2000, Mrs A was prescribed Ensure, a nutritional supplement often used by people unable to eat or experiencing undesirable weight loss, through age, infirmity or disease. In order to qualify for subsidised supplements, a "special authority" application had to be completed by a relevant specialist. (In April 2011, Pharmac introduced changes that included allowing vocationally registered GPs to complete these applications.)

<sup>14</sup> This is an agency through which people are able to access community support such as home help. It also facilitates admission into residential care for people who require higher levels of care and support.

<sup>15</sup> This residential care service is a not-for-profit provider of disability, youth and social services. Its services include homes providing specialist residential care for people aged 16–65 with long-term physical and neurological disabilities.

<sup>16</sup> Mrs A's body clock had switched so that she was often awake at night and asleep during the day. Attempts to correct this with medication were unsuccessful.

response to the provisional opinion Dr C restated her view that there were no facilities that could take Mrs A at the time of these events. She stated that the situation would have been different if the current facility had existed at that time.

37. Dr C said she considered Mrs A's reasons to be well thought out and well reasoned. Dr C stated:

“She certainly was pressing me to promise that I wouldn't put her into an institution, and I do recall thinking this through as she was saying things and figuring out that it was no different to any other terminally ill patient, and I am supposed to be able to look after terminally ill patients. And I envisaged her getting physically unable to look after herself and not be able to stop me bringing in assistance into the house.”

38. Dr C stated that she decided that being at home was the best of the options available to Mrs A: “[Mrs A] persuaded me that her hermetic existence was the best of a poor set of options and in fact, one which she would enjoy.” Dr C noted that at this time, Mrs A had been symptomatic for at least seven years. Dr C understood that the typical life expectancy for a person with HD was ten years from the onset of symptoms, and felt able to support Mrs A to live independently for a further three years.
39. Ms B told HDC that both Dr C and her mother told her that Dr C promised that she would ensure that her mother was never put into an institution. In contrast, Dr C said that she “never said never”. Dr C said that she did promise she would look after Mrs A at home, but “I was aware obviously that if she got to a state that required committal then I had to do that”. Dr C said that she did not consider it to be in Mrs A's interests to discuss with her the circumstances in which she would not be able to remain at home.
40. Dr C stated that when she had this conversation with Mrs A in 2002, she believed Mrs A was competent to make that decision, but no formal assessment of her competence was undertaken.
41. When asked whether she conducted a formal competence assessment of Mrs A at any stage, Dr C stated: “I don't know what you mean by formal. I would have thought that every time I visited her I was assessing her.”

42. Dr C also stated:

“Over subsequent years, I was aware that [Mrs A's] cognitive abilities were deteriorating. However, she was still able to manage phone banking, get her money from the money machine to put on her balcony to pay for ordered takeaways and cat food ... I was subsequently able to assess her personal hygiene when I visited, and subsequently on the occasions that I took her out in my car and we sat and talked ... for up to an hour at a time. I was able to both see her state of dress and smell her (which was never offensive). I also was on the lookout for flies in her apartment and took every opportunity to smell through the open door of the

cat door. On every occasion my judgment was that she was living in a hygienic mess.”

43. Dr C stated that she did not discuss with Mrs A the possible risks of her living in the way she was, such as the possibilities of falling and being unable to get up or being unable to get out of bed. Dr C stated that Mrs A would have known the trajectory of HD because she supported her mother for her mother’s final two or three years.

*Events in 2003*

44. On 27 March 2003, Dr C introduced Mrs A to a field worker from the Huntington’s Disease Association (HDA).<sup>17</sup> The field worker and her successors had some involvement with Mrs A between 2003 and 2010, but records indicate that for the most part, Mrs A did not respond to their attempts to engage with her. The field workers did, however, act as Mrs A’s Work and Income New Zealand (WINZ) agent.
45. On 23 August 2003, Dr D noted that he had discussed the options for Mrs A with Dr C. Dr D noted “GP to persevere”. In a letter to a service provider supporting Ms B, Dr D wrote:

“[Mrs A] needs institutional care, she is deserving of it but refusing it. Whilst there are probably grounds to enforce her hospitalisation that process would also be depriving [Mrs A] of the last semblance of autonomy and individualisation she has, she is aware of the risks of accidents and [Dr C] and I have agreed that we are willing to accept this risk for as long as reasonably possible.”

*2004–2006*

46. Ms B stated that when she moved out of her mother’s home in 2004, her mother had not had a shower in three years, and her mother’s hair was a “matted mess”. Ms B stated that Dr C’s home visits were becoming less frequent “yet still being paid for by [Mrs A] through automatic payments”. Ms B said that Dr C’s visits “were eventually whittled down to a conversation through the curtain at the front door”.
47. Ms B stated that between 2004 and 2006 there were periods of up to five months when her mother would refuse to talk to her and, at those times, Dr C was the only point of contact. Ms B stated that Dr C provided her with little information despite having her contact details. Dr C stated, “I don’t agree that [Ms B] provided me with her contact details”.
48. For a period prior to 2004, Mrs A had a cleaner assisting her. In about 2004 Mrs A refused to allow cleaners into the house. Dr C said that this was because the person doing the cleaning, with whom she was familiar, was no longer able to continue and the bedroom door was broken, so Mrs A was not able to hide from the new cleaner.
49. On 8 December 2004, Dr C recorded that Mrs A’s movements were much more marked and she was almost kicking herself in the face when sitting. Dr C recorded

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<sup>17</sup> Mrs A had had limited contact with the HDA prior to this.

that Mrs A's hair was matted and she had a black mark on her face. Ms B stated that it was dirt, because her mother had not bathed in years.

50. Dr C stated that in 2005, Mrs A's daughters became concerned about the conditions in which their mother was living, and had a meeting with Dr C in their mother's presence.<sup>18</sup> Dr C stated that the daughters wanted their mother in care, and that "it seemed like [they] were just trying to tidy things up nicely for themselves rather than seeing it from their mother's point of view and again there was nothing available as an alternative".
51. Dr C stated that at this time, she gave Mrs A a handwritten letter that Mrs A could produce if she was at risk of being institutionalised or hospitalised. The letter included Dr C's contact details and said she could be contacted day or night. This was "so that [Mrs A] could have me there to see what was going on".
52. Dr C stated that she "physically saw" Mrs A in her home for the last time in January 2005. In April 2005, Dr C recorded that Mrs A had reported panic attacks at the thought of opening the door to anyone, and that even monthly telephone calls were too much. Mrs A agreed to telephone Dr C every six weeks. Dr C noted that Mrs A had a good supply of clonazepam (for anxiety).<sup>19</sup>
53. After Mrs A stopped letting Dr C enter the flat, most of their contact was by telephone and through Dr C's checks on Mrs A's flat. Mrs A telephoned the health centre when she ran out of Ensure, and spoke to either Dr C or one of the practice nurses. Dr C said that the practice nurses were instructed to ask Mrs A how she was, and to try to "draw her out". Mrs A would also contact Dr C when something went wrong, such as when her telephone was not working. On such occasions, Mrs A would contact Dr C either from a telephone box or with the help of a neighbour. In addition, Dr C explained that she would drive or walk past the flat to see whether the television was turned on, and that she would sometimes look through the cat door to check for flies and smells. Dr C said that she was able to have some conversations with Mrs A on the balcony. In response to the provisional opinion Dr C said that Mrs A would "mostly come out" to talk to her.
54. Dr C recorded that she saw Mrs A twice in June 2006, after Mrs A lost her bank card. On the first occasion, Dr C collected Mrs A and took her to the bank. Dr C recorded: "BO moderate (stale) would not allow me in flat." On the second occasion, Dr C arranged for her local branch to open early so that Mrs A could go in unseen by the public. After the second visit, Dr C noted that Mrs A's body odour was less strong.

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<sup>18</sup> The older daughter had moved overseas but was back for a visit.

<sup>19</sup> Mrs A did not take clonazepam on a regular basis, but Dr C had previously suggested that Mrs A take this as required, such as prior to making a telephone call, or being visited by the cleaner or Dr C. Records indicate that the last prescription for clonazepam was in September 2003. Mrs A had stopped taking anti-depressant medication in 2002.

*Hospital admission, September 2006*

55. Ms B said that in September 2006, she was unable to contact her mother and became concerned that she might have suffered some harm. Ms B called the Police, who broke into the flat and took Mrs A to hospital.
56. Mrs A was admitted to hospital at 8.10pm on 22 September 2006. She was reviewed by an ED registrar, who recorded: “felt to be not true suicide intent, more impulse threat”. No acute medical problem was identified. It was recorded that Mrs A felt happy at home and thought she would not cope in a rest home. Progress notes indicate that Mrs A agreed to stay overnight for a review with the social worker and a discussion with her GP the following day. The documented plan was to discuss Mrs A with her GP the next day, and possibly arrange for social work and occupational therapy assessments, to ensure Mrs A’s safety.
57. At 9.50am on 23 September 2006 (the records state 22 September), Mrs A was reviewed by Dr F. Dr C was also present. An entry in the progress notes stated: “GP explained support & cares that are in place and is fully supportive of [Mrs A] returning to own home.” The entry did not indicate whether the extent of the “support and cares” was discussed. Dr F recorded “Pt looks well. Distressed at all the attention”. There is no record of a physical examination.
58. Dr C spoke to a social worker who recorded that Dr C had advised that Mrs A had a suicide plan should she be under threat of removal from her home, and that “[Dr C] is happy to continue to support [Mrs A] in her chosen lifestyle”. The social worker noted that Dr C had agreed that Mrs A did not have a quality lifestyle but said it best met Mrs A’s needs and wishes. Dr C took Mrs A home.
59. No competence assessment was undertaken while Mrs A was in hospital. When asked whether she considered the possibility of organising a formal competence assessment at this time, Dr C stated that “there was no doubt that [Mrs A’s] brain did not work the way it used to work”. However, Dr C considered that although Mrs A was unkempt, she was maintaining a level of personal hygiene. With regard to Mrs A’s suicidal ideation, Dr C said that this was only an issue if Mrs A thought she was at risk of being institutionalised. Dr C stated that she did not think there was anything to be gained by Mrs A remaining in hospital. Dr C thought there was a risk Mrs A could have jumped off the hospital roof, and noted that staff had reported Mrs A spending the night with a curtain wrapped around her, crying. This is not recorded in the hospital notes, but the night medical registrar recorded “[Patient] very teary at present.... Very keen to go home”.
60. Ms B stated that, while her mother was in hospital, she took the opportunity to walk through the flat. Ms B said that, at that time, there were hundreds of Ensure cans in the house, cat fur over everything, and the carpet was not visible except for a trail to the doors. The house smelt like dirt, food and an unbathed person. Ms B advised that there were splashes of brown on the furniture and floors from the chocolate Ensure, the bathroom was blackened and covered with mould, but the toilet was working at that stage. Ms B stated that Dr C said that she would organise for a clean-up of the

property and, as Ms B did not realise how much her mother needed care at that point, she thought that if the house was clean her mother would be better.

61. In response to the provisional opinion, Dr C said that she finds it hard to believe this account of the state of the flat because “the following year [Mrs A] was still able to move very large items around and out of the flat when she left furniture on the balcony for [Ms B]”. However, following the hospital admission, Dr C recorded that Mrs A “admits to mess in house” and that she had eventually agreed to Dr C arranging for some repairs and a clean out, so long as Dr C did not see it. However, in November 2006, Mrs A said she would not be able to accept the help, as the neighbours would see the rubbish being carried out. Dr C noted that Mrs A was still distraught from the hospital episode, which she had found humiliating.
62. Ms B stated that at this point, her mother had not showered for six years, her hair was a clump on her head, she smelled terrible, and the house was uninhabitable. Ms B noted: “During a phone call shortly after mum’s discharge from hospital, [Dr C] told me she disagreed and that mum was fine. She was still being paid for home visits.”
63. Ms B advised that following the hospital admission, her mother was angry with her for having called the Police. On 26 September 2006, Dr C prepared a “Community Care Adult Management Plan”, which she sent to the hospital. This stated: “TREATMENT PLAN: TO STAY AT HOME under [DR C’S] MANAGEMENT. DO NOT ADMIT TO HOSPITAL. IF POSSIBLE, ONLY [DR C] TO VISIT ... [Dr C] has promised not to admit to hospital or institution ([Mrs A] has suicide plans if she should be removed from her flat).” Dr C provided her contact details for any time of the day or night.
64. On 10 November 2006, Dr C wrote to the Police stating that she was to be contacted if any concerns arose regarding Mrs A. The Police report states: “Although [Mrs A] is living in conditions of absolute squalor she is monitored and she is able to function as long as she is left alone.” In an email on 10 November 2006 to the Police Dr C stated: “Remaining at home has been determined to be [Mrs A’s] only option.”

#### 2007–2009

65. Ms B stated that she attempted to persuade Dr C to communicate with her more regularly and to arrange support for her mother. On 27 March 2007, Ms B emailed Dr C to advise that she and her sister were “starting to worry ... whether our mother is alright in that house by herself”. In her email Ms B stated: “It has been months since I have heard from you and since you are the only person she will talk to now I was expecting to hear if she is OK or not.” Ms B also expressed concern about the state of the house, saying she was worried that her mother would have the same issues as her grandmother (who had fallen and remained unconscious on the floor for several hours). Ms B stated that her mother needed to be “somewhere else or have a carer in the home”. She stated: “It is in the best interest of mum and since you have not been inside that house I feel as though you are not able to make the decision for her.” Ms B stated that her email was followed up by a telephone call from Dr C, who said that Mrs A still had the right to choose where she lived.

66. Dr C stated to HDC that she did not carry out any formal competence assessment of Mrs A at that time.
67. Ms B stated that when she asked why Dr C was still being paid for “home visits”, Dr C replied that she would often drive past to look for flies and “lift the cat flap up to smell inside”. Ms B stated: “I felt as though [Dr C] was not living up to the duty of care that she was being paid to do”. In response to the provisional opinion, Dr C denied this conversation took place and stated that “there should have been no call for [her] to do this as [Ms B] herself could keep an eye on her mother”.
68. Dr C said she visited Mrs A twice in 2007 to discuss the collection of Ms B’s furniture. Records of those visits were not supplied to HDC.
69. Ms B stated that from 2007 until 2009, she had minimal contact from Dr C, with only a few telephone calls. Ms B said that her mother would not answer the door and seldom answered the telephone, and so Ms B was dependent on Dr C to ensure her mother was safe. In response to the provisional opinion, Dr C said that in 2009 Mrs A was in regular contact with Ms B until the death of the cat (discussed below).
70. In 2007, Mrs A’s flat was sold. With Mrs A’s consent, Dr C told the new landlords that Mrs A had HD, and advised them that Dr C and WINZ were to be their sole points of contact for any issues relating to the property. The landlords stated:
- “Over the next few years when we tried to gain access for repairs or inspections, we were told by her doctor in no uncertain terms that going inside the unit could result in [Mrs A’s] death (either by suicide or the shock of it). We were advised by her doctor on several occasions that due to the nature of [Mrs A’s] illness and the threat to her life our intrusion would cause, access to our property was both impossible and unnecessary. We respected the doctor’s instruction ...”
71. In response to the provisional opinion, Dr C said access to the flat was “difficult and risky” rather than “impossible and unnecessary”.
72. Dr C stated that she did not deny the landlords’ access to the property, and said that if they had “insisted on inspecting the property, then arrangements could have been made to have [Mrs A] removed, as we were able to achieve on other occasions”.
73. In response to the provisional opinion Dr C said “[T]here were several occasions of face-to-face contact during the four years [prior to 2010], though not all adequately documented”. She said she visited Mrs A on 7 May 2008 to take her a telephone and returned the following week. The first visit is recorded but the second visit is not recorded in Mrs A’s notes.
74. In 2008, Mrs A’s landlord contacted Dr C to say that there was a leak coming from Mrs A’s bathroom into the garage below. On 28 August 2008, Dr C spoke to Mrs A by telephone, who said she had fixed the toilet and no repairs were necessary. It appears that, in fact, Mrs A had just turned off the water supply to the toilet. The toilet was therefore not able to be flushed, although Mrs A continued to use it.



75. Ms B stated that she contacted her mother again in January 2009, and realised that conditions were worse. She stated: “My mother hid behind the door’s curtain. I managed to catch a glimpse of her body. [...] I could see dirt on her face, arms and feet; her hands obsessively clean. It was very clear to me that she could not possibly be left to carry on like that.”
76. On 31 January 2009, Dr C visited Mrs A after complaints from the landlord about the television being too loud at night. Dr C recorded that she was able to have an hour-long talk with Mrs A, to sort out arrangements for getting a broken door repaired. This discussion was through the curtain, and Dr C was able to see only Mrs A’s feet.
77. In April 2009, Ms B arranged for one of her mother’s cats to be euthanised. Thereafter, Mrs A again refused to speak to Ms B. In response to the provisional opinion Dr C submitted that she believed Mrs A’s relationship with Ms B deteriorated again after the death of the cat.
78. Ms B contacted Dr C on 17 May 2010 saying that contact from Dr C only every few months was insufficient. On 10 June 2010, Dr C emailed in reply: “[Y]our Mum has not been in very regular contact since the cat died — long story.” Dr C told Ms B that Mrs A continued to tell the nurses that she was fine when she rang for her Ensure, and that a couple of months previously she had been to the garage to buy goods.
79. HDC asked Dr C whether she visited Mrs A between February 2009 and August 2010. Dr C stated “it depends on what you call visits”. She stated that she received telephone calls which are not recorded, and that she “tried to make sure [she] checked on [Mrs A’s] apartment once a week” by walking “up to the balcony” and checking whether the letterbox had been emptied.
80. Dr C submitted in response to the provisional opinion that she visited Mrs A twice in June 2009. The clinical records refer to telephone conversations on 4 June 2009, 18 June 2009 and 24 June 2009 and the record for 24 June 2009 states “20<sup>th</sup> June Shopping at supermarket and vets done and delivered with spare cash to tide her over”. There is no record that Dr C saw or spoke to Mrs A at that time and no record of a second visit. Dr C stated: “There were other encounters.”

#### *April 2010*

81. On 9 April 2010, the Police contacted the health centre and told them that the local garage had contacted the Police to report that Mrs A had been in the shop for the last hour and was very confused. The Police report states that Mrs A did not know where she lived, but once the Police ascertained her address they returned her to her home.
82. Dr C advised that after this incident she spoke to the garage manager who said that Mrs A looked fine.

#### *The Rehabilitation Service*

83. This service offers specialist assessments and rehabilitation programmes for people with neurological, musculoskeletal and spinal injuries. On 1 April 2010, Ms E was appointed as the Co-coordinator of clinical services for people with HD. The Clinical

Co-coordinator's role is to co-ordinate services between the client's GP, specialists and allied health providers to provide the best possible support for families living with HD.

84. On 10 June 2010, Dr C spent an hour with Ms E, discussing Mrs A's situation. Ms E said that Dr C told her that "the house must be filthy by now" and that Dr C said she had not been in the house since June 2005. Ms E said that Dr C told her: "If you go around to the flat [Mrs A] will commit suicide." In response to the provisional opinion Dr C denied making these statements to Ms E but said she did warn people that Mrs A had a suicide plan. On 11 June Ms E wrote to Dr C stating: "We will do our best to support [Mrs A] 'from a distance' in the circumstances."
85. Ms E told HDC that soon after she started her new role, she was asked by Dr C to recover \$450 in unpaid GP fees. Ms E advised Dr C that this was not her role.

*August–September 2010*

86. On 21 August 2010, Dr C was contacted by Ms B and Mrs A's father, who was visiting from out of town. Both expressed concern about the conditions in which Mrs A was living. Dr C recorded: "2nd call re flies in window; visited — a few unusual flies, not blow flies in both bedroom windows. Smell through cat flap not of death." Dr C noted visits to Mrs A's flat on 21 and 23 August 2010.<sup>20</sup> Dr C stated that since Mrs A's daughters had either left the area or were estranged, she had undertaken to visit the balcony of the flat on a weekly basis, "to check for flies or smells through the cat flap so that death would not go unnoticed for an undue length of time".
87. On 26 August 2010, Dr C emailed Dr D stating that she had attempted to persuade Ms B and Mrs A's father to contact Dr D. Dr C stated: "It is apparent that [Mrs A's] flat is smelling more like a health hazard."
88. On 2 September 2010, Dr C recorded that she had visited a number of times the previous week, and had knocked on the door but had received no response. She recorded that she had left potted daffodils and a card for Mrs A on her birthday. The card asked Mrs A to call Dr C, but it had not been collected three days later. Dr C noted that on 1 September 2010 she had spoken to Dr D about the current situation, and that the plan was "to continue as is while trying to think of a way to get the place cleaned".
89. A neighbour, concerned about Mrs A, broke into the flat on the landlord's instructions and found Mrs A in bed asleep. The neighbour took photographs of the interior of the flat. Ms B went to her mother's flat that morning and spoke to the neighbour, as did Dr C.
90. Over the following three weeks, there were a number of communications between Ms B, Dr C, Dr D, Ms E, an Environmental Health Officer, and Mrs A's landlords, as efforts were made to determine how to address Mrs A's situation.

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<sup>20</sup> These contacts were recorded by Dr C in an entry dated 25 August 2010.

91. As stated, Dr D had not seen Mrs A since 1999. However, on 8 September 2010, Dr D wrote to Dr C, noting that further to their conversation, he was not sure that “other than the dedicated observation from a distance that you are performing, much else could or can be done for [Mrs A]”. Dr D noted that there may come a time when her flat was a hazard and the Medical Officer of Health would need to be involved, but “presumably not yet”. Dr D noted that he had discussed Mrs A’s situation with his peer group of psycho geriatricians and psychiatrists. Dr D wrote:

“Philosophically the issue concerns paternalism and whether or not we should override her clear intent (if you like her advance directive) for the sake of our belief that she would be safer and more content in institutional care. The consensus of the group was that though there is a place for paternalism this clinical predicament doesn’t at present warrant such a draconian and indeed dangerous intervention.”

92. Dr C was initially of the view that arrangements should be made to move Mrs A out of the flat temporarily while a clean-up was undertaken. Mrs A could then return to her flat.
93. On 13 September 2010, Ms E noted that she had spoken to Dr C and told her that she did not share Dr C’s view. In an email to Dr C the following day, Ms E noted the steps she was taking to arrange for Mrs A to be admitted into care.
94. On 13 September 2010, Dr C emailed Dr D stating: “I am both gutted and ready to fight on [Mrs A’s] behalf. Until [Mrs A] tells me she wants to go into care (and practically, is there anything available?) I will fight for her to hang on to what gives her pleasure in life, as I have previously undertaken to do.”
95. On 17 September 2010, Dr C again emailed Dr D stating that she doubted that Mrs A would be able to “survive resettlement”.
96. On 21 September 2010, Dr D noted the differing views of Dr C and Ms E, and that he had spoken with the DHB’s solicitor. Dr D noted that if there was a question of incompetency, the Medical Officer of Health could intervene, though in view of Mrs A’s history and despite her HD, “it may be that she does retain sufficient competency”. Dr D noted that the solicitor suggested supporting the Environmental Health Officer’s wish to go in and clean up the place rather than pursuing competency issues at that time.
97. On 23 September 2010, Dr C visited the flat. She was unable to speak to Mrs A but said she saw the condition of the flat through the broken door. Dr C stated that she was “pretty horrified” with what she saw at the flat. In response to the provisional opinion Dr C said she had not, at that stage, seen beyond the lounge. Dr C continued her attempts to make arrangements to have the flat cleaned. On 30 September 2010, Dr C arranged for Mrs A to move to a motel, with the intention of having the flat cleaned and then returning Mrs A to it.

98. However, the landlords were not willing to have Mrs A return to the flat. Dr C spoke to Dr D, who said that it had to be assumed that Mrs A would continue this behaviour wherever she went.
99. Dr C subsequently told HDC that the first time she thought Mrs A was not competent was when Mrs A was staying at the motel. Dr C said she took Mrs A back to the flat each evening to visit her cat, and realised that Mrs A had no concept that she was doing damage to the flat. Dr C said it was at this point that she became aware of Mrs A's lack of insight.
100. On 3 October 2010, Dr C certified that she had examined Mrs A on 30 September 2010 and that Mrs A was partially incompetent with regard to her property and totally incompetent with regard to decisions relating to her personal care and welfare. The medical report signed by Dr C states: "She washes her hands. Nothing else has been washed for years...". Ms B applied to the Family Court to be appointed the welfare guardian for her mother. On 4 October 2010, Dr C contacted the Psychiatric Emergency Service (PES)<sup>21</sup> requesting an assessment of Mrs A under the Mental Health (Compulsory Health and Treatment) Act 1992 (MHA). The request was discussed with Dr D, and the steps required to obtain a compulsory treatment order under the MHA were commenced.
101. Dr C arranged for two duly authorised officers to go with her to the motel, accompanied by two Police officers. Dr C stated that when the duly authorised officers advised Mrs A that she was to go to hospital with them, she screamed at Dr C and attempted to attack her physically. Dr C advised that she did not see Mrs A again.
102. Mrs A was admitted to mental health services under section 11 of the MHA for five days, and then under section 13 of the MHA for 14 days.<sup>22</sup> On 30 November 2010, an interim order was made appointing Ms B to be her mother's welfare guardian, in relation to specified aspects of her care and welfare.<sup>23</sup> On 13 December 2010, Mrs A was transferred to an inpatient rehabilitation unit and on 29 December 2011 she was transferred to a specialist facility for people with HD. Mrs A died in 2012.

#### *Condition of the flat*

103. When the flat was being cleared in September 2010, the landlords made a video recording the condition of the flat. That video has been made available to HDC.
104. On the video, an environmental health officer states that in 42 years he had seen only one other place as bad and the smell was unbelievable. In contrast, when interviewed, Dr C asserted that "when [she] went round there was nothing to smell".

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<sup>21</sup> The PES provides 24-hour crisis, urgent and emergency assessments for people of all ages experiencing mental health crises including suicidality.

<sup>22</sup> This provides for the acute psychiatric needs of the adult population (aged between 18 and 65 years). The service is provided on an inpatient basis, and is comprised of individual clinical assessment and treatment delivered in a range of programmes, including intensive care, acute care and acute adolescent care.

<sup>23</sup> These were the "provision of living arrangements including any necessary directions as to the place of residence" and the "provision of medical advice and treatment in accordance with advice given by health professionals responsible for [Mrs A's] treatment".

105. The workers removed the mattress from the bedroom and discovered that both the mattress and the base were wet through and rotten. All the furniture was covered with piles of rubbish, in places up to shoulder height.

*Further information from Dr C*

106. When asked whether she had previously treated patients with HD, Dr C stated that Mrs A had “been [her] first and only experience of patients with Huntington’s disease”. In response to the provisional opinion Dr C referred to the references in the provisional opinion dated 2011 and 2012, and said that knowledge of HD has improved in recent years and that “[her] knowledge of it came from a presentation to GP registrars in 1980, [her] slight awareness of [Mrs A’s] mother’s condition, and communications from [Dr D].”
107. Dr C stated that Dr D had told her that Mrs A could die of an infection but, as she wasn’t going out of the house she was unlikely to be exposed to infection and so, at some stage, “the breathing centre would just shut down” and Mrs A would be found dead. When asked further about this, Dr C said that she anticipated Mrs A would have a respiratory arrest and die suddenly, and that she did not anticipate any gradual deterioration. Dr C believed that “[Mrs A would] at some stage just stop breathing which to me was quite a lovely way to go, quite quickly”. However, Dr C stated that she knew Mrs A’s cognitive function was declining and there were “obviously things going on in her brain”.
108. When asked whether Mrs A would have been able to call for help if she had fallen and been unable to get up or had been unable to get out of her bed, Dr C responded that “she had a cordless phone”. Dr C said that she did not consider arranging a personal alarm for Mrs A. However, Dr C also stated during the interview: “There was one occasion in the notes where I’ve commented that she had a dark mark on her face and I thought that was a bruise and I was concerned that she had fallen, and that was one of my concerns that she would lose her balance at home and hurt herself...”.
109. In contrast, Dr C also stated: “[T]he need for a personal alarm never arose, and there was no need to discuss it with her. She was able to move well right up to the last time I saw her”. In her response to the provisional opinion Dr C said Mrs A had two cordless telephones and arranging an alarm would have required the alarm company staff to enter the flat to install the alarm. Dr C believes Mrs A would not have tolerated that.

*Contact with Dr D*

110. Dr C stated that she spoke to Dr D from time to time to seek his advice, and said that she found his guidance hugely beneficial over the years. She recalled that she was in contact with Dr D a minimum of once a year in order to obtain the special authority for Mrs A’s Ensure, and that she would consult him at other times if she was concerned. However, she frequently made no records of these conversations. She stated that when she could not reach Dr D she would leave a message and he would telephone her at home.

111. Dr D stated in a letter to HDC that a “not uncommon, and extraordinarily problematic, symptom experienced by many Huntington’s Disease patients is their loss of ability to recognise the emotion disgust indicated to them by others”. Dr C stated that she was not aware of this, and that Dr D did not discuss this with her.

*Documentation*

112. Dr C acknowledged to HDC that her records are substandard. She stated: “Most of my contact with [Mrs A] was out of hours and of such frequency that I found it very difficult to ensure that full records were kept of every interaction I had.” In response to the provisional opinion, Dr C stated that from early 2007 she was instructed to record her notes by computer. She said she had “very limited access to the computer and no keyboard skills”. She noted that there has been great change over the years in relation to record keeping, to which she has continuously adapted.
113. Between 24 January 2008 and 3 September 2010, Dr C recorded telephone conversations with Mrs A on 14 days. Records also show several telephone calls to the practice nurses at the health centre, to request a delivery or repeat prescription for her Ensure. Dr C stated that not all of these calls were documented, because at that time the nurses tended to just jot down records on a piece of paper.
114. In response to the provisional opinion, Dr C stated: “I regret that the emphasis is changing to notes that ‘become critical in any future dispute or investigation’ rather than good care for patients. I believe there needs to be a balance in favour of time spent actually caring for patients.”

*Payments*

115. From June 2002 until February 2009, Mrs A was making an automatic payment of \$40 per month to the health centre. Dr C stated that the health centre’s charges for a brief home visit at the time would have been \$40, so “this in no way was covering the costs of the lengthy visits nor the time spent filling out her Ensure Plus order forms, my six-monthly meetings with the field officer [from] the Huntington’s Society to discuss her on-going needs, phone calls with [Dr D], numerous phone calls to my home late at night by [Mrs A], and liaising with family. When asked further about these payments, Dr C said: “[Mrs A] was concerned that I wasn’t getting paid enough for the things I was doing, and particularly when I was doing things like taking her to the bank.” Dr C stated that she saw the payment as a retainer.
116. The health centre records show that payments stopped on 3 February 2009. Ms B advised HDC that her mother stopped the payments. In response to my provisional opinion Dr C stated she believes it was Ms B, not Mrs A, who stopped the payments.
117. Dr C advised that after the payment was stopped, she wrote to Mrs A stating that as she was receiving additional money in her benefit to cover her medical costs, the payments should not have been stopped.

*Further information from Dr D*

118. Dr D stated that over the years, Dr C would contact him intermittently and discuss the “excruciatingly difficult dilemma of how best to care for [Mrs A]”. He noted that on

many occasions Dr C reported to him that Mrs A had verbally communicated that if Dr C or others were to enter the house and see her, she would commit suicide. Dr D stated: “Based on our knowledge of [Mrs A] I reckoned this to be a very serious risk.”

119. Dr D advised HDC that on average he probably spoke to Dr C about once or twice a year. This was not necessarily when he renewed the annual special authority for Ensure, because this may have been done on the basis of a request from the practice nurse on behalf of Dr C. Dr D said that “he would have had” discussions with Dr C about the likely mechanisms of Mrs A’s death and “most likely” discussed the fact that HD patients can have the inability to recognise disgust when this is expressed by others. Dr D advised that he did not regularly keep records of these conversations.
120. Dr D noted the lack of local institutional facilities for patients such as Mrs A, and that the “acute psychiatric services have always been (appropriately) reluctant, if not hostile with respect to receiving persons with [HD], for their problem is finding subsequent long term [placements] ...”.
121. Dr D stated that he was “totally uncomfortable” about giving advice in relation to a patient he did not have access to. He had no direct contact with Mrs A after 1999, and confirmed that all of his information about Mrs A came from Dr C. Dr D stated also that he is not at all comfortable with leaving a person such as Mrs A to live in the circumstances in which she lived, and with the likelihood that she would not be found until some time after her death.
122. Dr D stated: “Clearly, in retrospect, [Mrs A] should have been institutionalised, probably in about 2004. She wasn’t, and for this I apologise, though overriding patients’ wishes and decisions (advance directives) is not something that modern medicine opts to do easily.” Dr D said that “the care provided to [Mrs A] was not perfect”. He stated: “I take some responsibility — I don’t think we managed her well, but it was difficult to know when to intervene.”
123. Dr D advised that it may have been possible for Mrs A to have had a personal alarm, and there was no reason not to have tried an alarm, although there may have been funding difficulties as Mrs A was under the age of 65.

*Further information from Ms B*

124. Ms B stated that her mother “did not have to be living in the squalor she was found in. She was left there by [Dr C] due to a promise that should never have been made in the first place.”
125. Ms B advised that six months after Mrs A was admitted to mental health services, WINZ contacted her and said that Dr C had sent an invoice to WINZ for \$506.00. As Ms B was then the authority on her mother’s WINZ account, she was asked to approve the payment. Ms B advised that she did not authorise payment of the account. Dr C submitted in response to the provisional opinion that WINZ requested an invoice for the time she spent with Mrs A at the motel in 2010 and the account was for a nominal amount as she had spent “up to 14 hours a day” with Mrs A.

*Interview with Mrs A*

126. HDC staff met with Mrs A on 2 May 2012. Although she had difficulty communicating, she stated that she was aware of the complaint and supported it. Mrs A stated that she thought Dr C should have come to see her at home and that she was not happy that Dr C left her alone too much. She stated that Dr C hardly called her at all. Mrs A said that she would telephone Dr C in the early days but, at the end, not at all.
127. That day, Ms B stated that her mother was declining cognitively and her memory was getting worse, however, she was still “onto it” although her speech was difficult.
128. In response to the provisional opinion Dr C stated that Mrs A’s “recollections are clearly wrong, and her reliability is questionable”.

**Responses to provisional opinion**

129. Dr D and Ms B made no comment on the provisional opinion.

*Dr C*

130. A number of Dr C’s comments in response to the provisional opinion have been noted above. In addition, Dr C submitted:
- Ms B’s recollections should be treated with caution.
  - She (Dr C) was concerned about Mrs A’s living conditions and Dr D recognised this concern.
  - Mrs A was found to be in good physical health during her hospital admission in 2006.
  - She only worked limited part time hours and much of what she did for Mrs A fell outside that time.
  - She was satisfied by her “visual examinations” of Mrs A “over the time [she] was seeing [Mrs A] regularly”. When prescribing Ensure she “had adequate knowledge of [Mrs A’s] health and was satisfied the treatment was in her best interests”.
  - That she did not chose to be a gate-keeper but she did not want Mrs A to commit suicide. She tried, over the years, to obtain other supports for Mrs A.
  - That she believes the overall theme of the provisional opinion is “preservation of property” and considers the report “ignores [her] ethical duty to advocate for [her] patient”. Dr C stated: “I don’t believe that should override a doctor’s primary obligation to the patient, and respecting the patient’s wishes.” She said: “I have been placed in an impossible position.”
  - That her actions were intended to ensure that Mrs A enjoyed the best possible quality of life rather than to uphold her promise that Mrs A would not be institutionalised.



## Relevant standards

131. The Medical Council of New Zealand guideline *Good prescribing practice* (April 2010) provides:

“1. You should only prescribe medicines or treatment when you have adequately assessed the patient’s condition, and/or have adequate knowledge of the patient’s needs and are therefore satisfied that the medicines or treatment are in the patient’s best interests. Alternatively you may prescribe on the instructions of a senior colleague or a practice colleague who can satisfy the above criteria, as long as you are confident that the medicines or treatment are safe and appropriate for that patient and the patient has given his or her informed consent. Medicines or treatment must not be prescribed for your own convenience ...”

132. The Medical Council of New Zealand publication *Good medical practice* (June 2008) provides:

### “Good clinical care — a definition

2. Good clinical care includes:

- adequately assessing the patient’s condition, taking account of the patient’s history and his or her views and examining the patient as appropriate
- providing or arranging investigations or treatment when needed
- taking suitable and prompt action when needed
- referring the patient to another practitioner when this is in the patient’s best interests.

...

### Keeping records

4. You must keep clear and accurate patient records that report:

- relevant clinical findings
- decisions made
- information given to patients
- any drugs or other treatment prescribed.

Make these records at the same time as the events you are recording or as soon as possible afterwards.

...

### Prescribing drugs or treatment

5. You may prescribe drugs or treatment, including repeat prescriptions, only when you:

- have adequate knowledge of the patient's health
- are satisfied that the drugs or treatment are in the patient's best interests.

Usually this will require that you have a face-to-face consultation with the patient or discuss the patient's treatment with another registered health practitioner who can verify the patient's physical data and identity.

### **Supporting self-care**

6. Encourage your patients and the public to take an interest in their health and to take action to improve and maintain their health. For example, this may include advising patients on the effects their life choices may have on:

- their health and well being
- the outcome of treatments.

...”

133. The Medical Council of New Zealand publication *The Maintenance and Retention of Patient Records* (August 2008) states:

“Records form an integral part of any medical practice; they help to ensure good care for patients and also become critical in any future dispute or investigation.”

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## **Opinion: Breach — Dr C**

### *Introduction*

134. I acknowledge that Mrs A's circumstances were very distressing for her, and very difficult for Dr C to manage. As advised by my in-house clinical advisor, GP Dr David Maplesden:

“This is an extremely complex case that raises fundamental issues over perceptions of what is a reasonable standard of living, the rights of an individual to live as they want provided they are not an overt threat to themselves or others, the role of the GP and when clinical objectivity might be impeded by personal involvement with a patient, the role of the family in advocating for another family member and the role of community based organisations in attempting to provide support for the choices of a patient.”

135. Mrs A had been diagnosed with HD, which is a neurodegenerative disorder that will, in most cases, eventually result in the person being unable to care for himself or herself. Both Dr C and Ms B stated that Mrs A had a strong wish to remain in her own home.

136. I accept that Dr C continued to attempt to honour this wish. However, given the usual progression and complications of HD, it is clear that Mrs A was likely (if she lived long enough) to become cognitively impaired and also to be prone to falls and progressive weight loss in spite of nutritional supplements, and to develop various psychiatric symptoms, including loss of insight into her condition.
137. In my view, Dr C failed to assess Mrs A's competence, to satisfy herself that Mrs A remained competent to refuse services. In addition, Dr C assumed responsibility for Mrs A but failed to ensure the provision of adequate care and support. In these circumstances, I consider that Dr C failed to provide services with reasonable care and skill, and breached Right 4(1) of the Code.
138. Dr C prescribed for a patient she had not reviewed for an extended period and formed a relationship that went well beyond the normal doctor–patient relationship and involved Dr C acting as the gate-keeper for any contact by support services. In this respect, I find that Dr C did not comply with professional standards and so breached Right 4(2) of the Code. By failing to keep adequate records Dr C also breached Right 4(2) of the Code.
139. Dr C consulted Dr D from time to time, and he supported her actions. Although this does mitigate the seriousness of her actions to some extent, in my view, this infrequent contact does not excuse Dr C's poor management of Mrs A.

#### *Competence*

140. It is undisputed that, during 2002 to 2010, Mrs A's ability to care for herself adequately reduced and that, by 2010, she was living in squalid and unsanitary conditions.
141. In accordance with Right 7(2) of the Code, a consumer is presumed competent to make an informed choice and give informed consent to treatment and/or services (including refusing consent to treatment and/or services). If a consumer is not competent, treatment decisions may be made by a person who is legally entitled to consent on behalf of that consumer. Where appropriate, the courts may appoint a Welfare Guardian under the Protection of Personal and Property Rights Act 1988 for that purpose.
142. The Protection of Personal Property and Rights Act 1988 provides that the Act applies to a person who—
- (a) lacks, wholly or partly, the capacity to understand the nature, and to foresee the consequences, of decisions in respect of matters relating to his or her personal care and welfare; or
  - (b) has the capacity to understand the nature, and to foresee the consequences, of decisions in respect of matters relating to his or her personal care and welfare, but wholly lacks the capacity to communicate decisions in respect of such matters.
143. A welfare guardian can be appointed if a court is satisfied—

(a) that the person in respect of whom the application is made wholly lacks the capacity to make or to communicate decisions relating to any particular aspect or particular aspects of the personal care and welfare of that person; and

(b) that the appointment of a welfare guardian is the only satisfactory way to ensure that appropriate decisions are made relating to that particular aspect or those particular aspects of the personal care and welfare of that person.

144. The primary objectives of the court are to make the least restrictive intervention possible in the life of the person in respect of whom the application is made, having regard to the degree of that person's incapacity.

145. However, the Protection of Personal Property and Rights Act 1988 has limited efficacy if the subject person refuses to comply with a court order.

146. If compulsory assessment or treatment is required, the relevant legislation is the Mental Health (Compulsory Assessment and Treatment) Act 1992 (MHA). Section 2 of the MHA provides that:

*mental disorder*, in relation to any person, means an abnormal state of mind (whether of a continuous or an intermittent nature), characterised by delusions, or by disorders of mood or perception or volition or cognition, of such a degree that it—

(a) poses a serious danger to the health or safety of that person or of others; or

(b) seriously diminishes the capacity of that person to take care of himself or herself;—

*Advance directive*

147. Mrs A had the right to make an advance directive regarding her future treatment should she become incompetent. Right 7(5) of the Code provides: "Every consumer may use an advance directive in accordance with the common law."

148. In English law, competent patients have an absolute right to refuse medical treatment, including life-saving treatment. This principle extends to advance treatment refusals that are made for the time of potential future incompetence. The administration of life-sustaining medical treatment to a competent patient without consent, or to an incompetent patient in disregard of a valid advance refusal, amounts to a battery. However, a treatment refusal is valid only if the patient, when making the decision, was:

(1) competent;

(2) informed in broad terms of the nature and purpose of the procedure;

(3) free from controlling outside influences; and

(4) intended his/her refusal to apply to the circumstances that subsequently arose.<sup>24</sup>

149. Consequently, in order to make a valid advance directive regarding possible institutionalisation should she become incompetent in the future, Mrs A had to be competent, and had to understand and anticipate the future trajectory of her illness, including an appreciation of the risks that might arise.
150. When HDC staff asked Dr C whether she discussed this with Mrs A, Dr C stated that Mrs A would have known the trajectory of Huntington's disease because she had supported her mother during her mother's final two or three years. However, Dr C said that she knew little about Mrs A's mother and how she was affected by HD.
151. Dr C also said she did not discuss with Mrs A the possible risks in her living in the way she was, such as falling and being unable to get up or being unable to get out of bed. In contrast, Dr D indicated that Dr C told him that Mrs A was aware of the risks of accidents.
152. I do not accept that in 2002 Dr C had a sufficient basis to be confident that Mrs A was aware of the likely course of her illness or of the risks she would be running in the future if she remained alone in her home. As such, I do not accept that Mrs A's comments during the conversation in 2002 amounted to a valid advance directive. Additionally, as Mrs A was not assessed as incompetent until late 2010, even if she had made a valid advance directive, it would not have been in force prior to that assessment.

*Duty to assess competence*

153. Dr C asserted that Mrs A would have refused any supports or cares offered to her. New Zealand law is clear that every competent person has the right to refuse medical treatment. This right is set out in the New Zealand Bill of Rights Act 1990. Right 7(7) of the Code also provides the right to refuse services and withdraw consent to services.
154. As stated, in 2002 Dr C had a conversation with Mrs A about the possibility of Mrs A's future institutionalisation. Dr C said that Mrs A was adamant she did not wish ever to be institutionalised. When asked whether she took steps to assess whether Mrs A had the capacity to make such a decision at that time, Dr C indicated that she considered that Mrs A's reasons were well thought out and well reasoned.
155. The question is whether, in light of the likely progression of HD, there was a point prior to October 2010 at which Mrs A's competence should have been assessed.

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<sup>24</sup> *Re T (Adult: Refusal of Treatment)* [1993] Fam 95 (CA) 103 per Lord Donaldson MR; and *W Healthcare NHS Trust v KH* [2005] 1WLR834, at [15] per Brooke LJ. For a decision in which an advance refusal of life-saving treatment was regarded as valid by an English court see *Re AK (Medical Treatment: Consent)* [2001] 1 FLR129.

156. When Dr C was asked whether she conducted a formal competence assessment of Mrs A at any stage, Dr C stated: “I don’t know what you mean by formal. I would have thought that every time I visited her I was assessing her.”
157. The last time Dr C visited Mrs A in her home was in January 2005. Thereafter, Dr C had few opportunities to review Mrs A’s living conditions, and her physical and mental health. Despite this, in March 2007, Dr C told Ms B that Mrs A still had the right to choose where she lived. In response to the provisional opinion Dr C referred to approximately six meetings she said she had with Mrs A after September 2006 and prior to July 2009.
158. In order to refuse treatment, a person must first have the capacity to consent to it. As Lord Donaldson stated: “The right to decide one’s fate presupposes a capacity to do so. Every adult is presumed to have that capacity, but it is a presumption which can be rebutted.”<sup>25</sup> Lord Donaldson also stated: “Doctors faced with a refusal of consent have to give very careful and detailed consideration to the patient’s capacity to decide at the time when the decision was made.”<sup>26</sup>
159. The English Court of Appeal has established a set of guidelines with regard to the duty to assess a patient whose competence is in question.<sup>27</sup> The Court stated that a health authority should identify “as soon as possible” whether “there is concern” about a patient’s competence to give or refuse consent to treatment. It stated that “if the capacity of the patient is seriously in doubt it should be assessed as a matter of priority”.<sup>28</sup>
160. The guidelines state that in “serious or complex cases involving difficult issues about the future health and wellbeing or even the life of the patient” the issue of capacity should be examined by an independent psychiatrist.<sup>29</sup> If, following this assessment, there remains “a serious doubt about the patient’s competence” the guidelines indicate that “the seriousness or complexity of the issues in the particular case may require the involvement of the Court”.<sup>30</sup>
161. The Court considered that a presumption of competence is of little consequence where there are serious doubts about a patient’s capacity to make an important decision. The judgment concluded that “where delay may itself cause serious damage to the patient’s health or put her life at risk the formulaic compliance with these guidelines would be inappropriate”.<sup>31</sup>

*Dr C’s assessments of Mrs A’s competence*

162. Dr C advised that after 2002 she was aware that Mrs A’s cognitive abilities were deteriorating, but Mrs A was still able to manage telephone banking and get money

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<sup>25</sup> *In re T (Adult: Refusal of Treatment)* [1993] Fam 95, 112g (Eng CA).

<sup>26</sup> *Ibid*, 113A.

<sup>27</sup> *St Georges Healthcare NHS Trust v. S* [1999] Fam 26.

<sup>28</sup> *Ibid* 63H.

<sup>29</sup> *Ibid* 64A.

<sup>30</sup> *Ibid* 64A-B.

<sup>31</sup> *Ibid* 65B.

from the money machine. Dr C said she was able to assess Mrs A's personal hygiene when she visited her and, later, when she took Mrs A out in her car. Dr C stated: "[O]n every occasion my judgment was that she was living in a hygienic mess."

163. As stated, in the period after January 2005, Dr C's opportunities to observe Mrs A were very limited. Most of the contact was by telephone. Dr C saw Mrs A twice in June 2006, after Mrs A lost her bankcard. On the first occasion, Dr C collected Mrs A and took her to the bank. Dr C recorded: "BO moderate (stale) would not allow me in flat." On the second occasion, Dr C arranged for the local bank to open early so that Mrs A could go into the bank without being seen by the public. After the second visit, Dr C noted that Mrs A's body odour was less strong than on the previous occasion.
164. On 22 September 2006, Mrs A was admitted to hospital overnight. The following morning, Dr C was present when Dr F reviewed Mrs A. An entry in the progress notes in relation to the ward round states: "GP explained support & cares that are in place and is fully supportive of [Mrs A] returning to own home."
165. Dr C spoke to a social worker who recorded: "[Dr C] is happy to continue to support [Mrs A] in her chosen lifestyle."
166. No competence assessment was undertaken while Mrs A was in hospital in 2006. When asked whether she considered the possibility of organising a formal competence assessment at that time, Dr C stated that "there was no doubt that [Mrs A's] brain did not work the way it used to work". In my view this was a lost opportunity to assess Mrs A. In response to the provisional opinion Dr C stated: "If I am to be criticised for this then why not the hospital staff?" As stated, the record notes that Dr C told the hospital clinicians that Mrs A had support and cares in place.
167. Dr C stated in her response to my provisional opinion that she spoke to Mrs A in person on up to six occasions over four years between 2006 and 2010.<sup>32</sup> There are no contacts by telephone or in person recorded between 20 June 2009 and 23 September 2010. However, Dr C stated in response to the provisional opinion that "[t]here were other undocumented meetings outside on the balcony, where it was possible to review [Mrs A's] physical and mental health". Dr C indicated that an incident in April 2010 reassured her about Mrs A's condition. The local garage manager had contacted the Police to report that Mrs A had been in the shop for the last hour and was very confused. The Police returned Mrs A to her home. Dr C said she was reassured because the garage manager told Dr C that Mrs A looked fine. In contrast, the Police report states that Mrs A initially did not know where she lived and was very confused.
168. As Dr Maplesden advised:

"Taking into account the overall situation I feel that [Dr C] failed, probably from late September 2006, to ensure [Mrs A] was reviewed in a manner that would

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<sup>32</sup> The records show two visits in 2006, the contact while Mrs A was in hospital in 2006, visits on 7 May 2008, 31 January 2009 and 20 June 2009. There are no further visits or telephone conversations with Mrs A recorded prior to 23 September 2010.

reasonably reassure a health provider as to the ongoing physical and mental health status of the patient and their suitability to maintain an independent existence.”

169. Dr Maplesden stated further:

“I cannot see that any such review was undertaken after September 2006, and very occasional conversations [through] a window, without physically viewing the patient, were no proxy for competent clinical assessments (of physical as well as cognitive status). It was inappropriate for [Dr C] to continue to assume the patient was ‘OK’ just because there were no blowflies in the windows or no ‘smell of death’ coming from the flat.”

170. Dr C should have been aware of the strong likelihood that Mrs A would develop progressive cognitive decline, but would lack insight into this. As a result, reasonable vigilance was required to detect this decline, including discussing with her mentor what a minimum “formal” assessment of cognitive competence might involve, if she was not aware herself of such a process. I remain of the view that the nature of the interactions between Dr C and Mrs A from September 2006 was insufficient for Dr C to assess whether Mrs A remained competent to refuse consent to treatment. In my view, it was unreasonable for Dr C to assume that Mrs A would be most likely to die from respiratory failure, when she was at increased risk of falls and malnourishment, both of which could have led to a prolonged and particularly unpleasant death.

171. In my view, given the known trajectory of patients with HD and the probability that Mrs A would at some stage lose competence, Dr C’s failure to assess Mrs A’s competence to make the relevant decisions was suboptimal care and unacceptable.

*Assumption of responsibility*

172. I consider that in light of the expected trajectory of HD it was inappropriate for Dr C to make assurances to Mrs A in 2002 that she would not be institutionalised.

173. Dr C said that she did not consider it was in Mrs A’s interests to discuss with her the circumstances in which she would not be able to remain at home. Dr C said: “I was aware obviously that if she got to a state that required committal then I had to do that.” Dr C also submitted in response to the provisional opinion that the steps she took “were to ensure that [Mrs A] enjoyed the best quality of life that was available to her, given her condition and what was available to assist her to achieve this; not to ensure that any promise was upheld”.

174. Dr C told HDC that she “never said never” in September 2006. Nevertheless, Dr C prepared a “Community Care Adult Management Plan” which she sent to the hospital. The plan included the statement: “[Dr C] has promised not to admit to hospital or institution.” In addition, on 13 September 2010, Dr C emailed Dr D stating: “[U]ntil [Mrs A] tells me she wants to go into care (and practically, is there anything available?) I will fight for her to hang on to what gives her pleasure in life, as I have previously undertaken to do.”



175. I find it is more likely than not that Dr C did promise to ensure that Mrs A was never institutionalised and took steps to ensure that this promise was upheld. In my view, it was unwise for Dr C to give such undertaking and persist with her attempts to honour it, despite being no longer able to assure herself that Mrs A was safe and able to care for herself. Over the years a number of people attempted to raise concerns about Mrs A, but Dr C took steps to ensure that she remained solely responsible for decisions about Mrs A's care.
176. I accept that Dr C was concerned that Mrs A might commit suicide if contacted by anyone other than herself; however, such concerns should have indicated the need for a psychiatric evaluation of Mrs A. In response to the provisional opinion Dr C submitted Mrs A had refused to allow Dr D to visit her. I note that this refusal was in 1999 and there is no record of any subsequent discussion of this issue.

#### Family concerns

177. In September 2006, Ms B became concerned about her mother and called the Police. Mrs A was admitted to hospital overnight, and the documented plan was to discuss her condition with her GP the next day and possibly arrange for social work and occupational therapy assessments to ensure Mrs A's safety. Ms B stated that, at this point, her mother had not showered for six years, her hair was a clump on her head, she smelled terrible and the house was uninhabitable. However, despite Ms B raising these concerns with Dr C, Dr C disagreed and said that Mrs A was fine. In response to the provisional opinion Dr C said Mrs A did wash her body. However in her medical report in 2010 she stated that Mrs A washed her hands but "[n]othing else has been washed for years".
178. Between 2007 and 2009, Ms B wrote a number of emails to Dr C expressing concerns about the need for Dr C to communicate with her more regularly and to arrange better support for her mother. Ms B stated that she thought her mother needed to be somewhere else or have a carer in the home and, as Dr C had not been inside the house, Ms B felt that Dr C was not able to make decisions for Mrs A.
179. Ms B stated that from 2007 until 2009 she had minimal contact from Dr C, with only a few telephone calls. As her mother would not answer the door and seldom answered the telephone, Ms B was dependent on Dr C to ensure her mother was safe.
180. In August 2010, Ms B and Mrs A's father contacted Dr C expressing concerns about the conditions in which Mrs A was living. It was clear by this stage that Dr C was aware Mrs A's flat smelt like a health hazard.

#### Clinicians and Police

181. Following the incident in September 2006, Dr C wrote a "Community Care Adult Management Plan" which stated, "TREATMENT PLAN: TO STAY AT HOME under [Dr C's] management, DO NOT ADMIT TO HOSPITAL. IF POSSIBLE ONLY [DR C] TO VISIT."
182. In November 2006 Dr C also wrote to the Police stating that she was to be contacted if any concerns arose regarding Mrs A.

### Landlords

183. In 2007, when Mrs A's flat was sold, Dr C told the new landlords that going inside the flat could result in Mrs A's death. The landlords stated: "[W]e were advised by her doctor on several occasions that due to the nature of [Mrs A's] illness, and the threat to her life, our intrusion would cause, access to our property was both impossible and unnecessary. We respected the doctor's instruction ...". In response to the provisional opinion Dr C stated that her view was that it would be "difficult and risky" rather than impossible and unnecessary for the landlords to enter the flat.

### Clinical services co-ordinator

184. In 2010, Ms E, the co-ordinator of clinical services for people with HD, discussed Mrs A's situation with Dr C. Dr C said that she had not been in the house since June 2005 but that if Ms E went to the flat, Mrs A would commit suicide.
185. In September 2010, when Ms E advised Dr C that she was taking steps to arrange for Mrs A to be admitted to care, Dr C emailed Dr D stating: "I will fight for her to hang on to what gives her pleasure in life, as I have previously undertaken to do."
186. In her response to the provisional opinion, Dr C referred to her "ethical duty to advocate for [her] patient". I note the views of Dr Maplesden:

"It is apparent [Dr C] went well beyond the expectations of a 'normal' doctor/patient relationship in terms of the services she provided for [Mrs A] and her level of advocacy for [Mrs A] and these actions were perceived by [Dr C] to be in [Mrs A's] best interests ... while it seems [Dr C's] intentions were for [Mrs A's] rights and wishes to be honoured at all cost, I wonder if her clinical objectivity was lost, particularly after early 2005 when [Mrs A] would no longer allow [Dr C] into the flat and particularly after September 2006 when [Dr C] became aware (from [Ms B]) as to the state of the flat but [Mrs A] was unwilling to co-operate with attempts to clean it. [Dr C] increasingly became the 'gate-keeper' for any support service attempting to access [Mrs A] or her surroundings and was also instrumental in denying the landlord access to maintaining the property as was his right."

187. In my view, given that Dr C's actions had the effect of preventing other concerned parties from being involved in Mrs A's welfare, it was essential that Dr C act proactively, to ensure that Mrs A was still competent to make the relevant decisions. If Mrs A was to remain in her own home, Dr C should have ensured that appropriate steps were taken to review Mrs A in order to be reassured that Mrs A remained able to live independently.

### *Care and support*

188. The Medical Council of New Zealand publication *Good medical practice* provides that good clinical care includes adequately assessing the patient's condition, taking account of the patient's history and his or her views, examining the patient as appropriate, providing or arranging investigations or treatment when needed, and taking suitable and prompt action when needed.

189. In my view, Dr C had a duty to assess Mrs A's condition, particularly after 2006, when Dr C was aware that Mrs A was receiving little support or assistance and Mrs A's family was expressing concerns about her.
190. As stated, in September 2006 Dr C was present when Mrs A was reviewed by Dr F, and it is recorded that Dr C stated that support and cares were in place. At this stage, the support and cares Dr C was providing to Mrs A were minimal. It is not possible to verify the frequency with which they occurred, because Dr C kept very limited records. However, Dr C said that Mrs A telephoned the health centre when she ran out of Ensure, and spoke to either her or one of the practice nurses. Dr C said that the practice nurses were instructed to ask Mrs A how she was, and to try to "draw her out". Mrs A would also contact Dr C when something went wrong, such as when her telephone was not working. On such occasions, Mrs A would contact Dr C either from a telephone box or with the help of a neighbour.
191. In addition, Dr C explained that she would drive or walk past the flat to see whether the television was turned on, and she would sometimes look through the cat door to check for flies and smells. Dr C said she was able to have some conversations with Mrs A on the balcony. In my view, these opportunistic contacts were not sufficient to amount to providing "support and cares".
192. From June 2002 until February 2009, Mrs A was making an automatic payment of \$40 per month to the health centre. Dr C stated that this covered her home visits to Mrs A, plus other expenses. Dr C said that the health centre's charges for a brief home visit at the time would have been \$40, so "this in no way was covering the costs of the lengthy visits". I accept that the payment was modest in light of the time involved from time to time in supporting Mrs A.
193. However, after 2005, there were no home visits beyond viewing the exterior of the flat and raising the cat door, but the payment was unchanged, although Dr C submitted there were further unrecorded contacts. After the payment was stopped, Dr C wrote to Mrs A stating that as she was receiving additional money in her benefit to cover her medical costs, the payments should not have been stopped. In addition, Dr C attempted to have other parties take steps to recover the unpaid "retainer". In response to my provisional opinion Dr C stated that it was not Mrs A who stopped the payment. Despite this, I consider that Dr C should have considered whether the payment, having been stopped, signalled either that Mrs A's previous consent to services no longer applied or that there were concerns about her condition.
194. Dr C said she believed that at some stage Mrs A's "breathing centre" would just shut down and Mrs A would be found dead. Dr C anticipated that Mrs A would have a respiratory arrest and die suddenly, and did not anticipate any gradual deterioration. I accept that Dr D had advised Dr C that a respiratory arrest was a possibility.
195. During her interview with HDC staff, Dr C stated that one of her concerns was that Mrs A would lose her balance at home and hurt herself. When asked whether Mrs A would have been able to call for help if she fell and was unable to get up or became unable to get out of her bed, Dr C responded that "she had a cordless phone". In

response to the provisional opinion Dr C said Mrs A had two cordless telephones. Dr C said that she did not consider arranging a personal alarm for Mrs A. However, in response to the provisional opinion she also stated that Mrs A would not have permitted the installation of an alarm.

196. I accept that Mrs A would have resisted any arrangements that necessitated her being seen by others. Despite this, in my view it was not adequate care to make no provision for the possibility of Mrs A becoming incapacitated through illness, falling and being unable to get up, or being unable to get out of bed, other than the possibility that Mrs A might be able to access her telephones. There was a real possibility that, in such a case, Mrs A would die slowly, for example, from dehydration. I do not consider it was sufficient to open the cat door from time to time and check for the odour of death.
197. Dr C should have had a frank conversation with Mrs A in 2002, when Dr C was satisfied that Mrs A was still able to make decisions for herself. However, Dr C did not do so because she assumed Mrs A knew about HD and did not consider it was in Mrs A's interests to discuss with her the circumstances in which she would not be able to remain at home. In my view, Dr C should have made her professional responsibilities clear to Mrs A and established a framework for providing services that complied with her ethical and professional obligations.

#### *Medication*

198. From 2000 Mrs A was prescribed "Ensure", a nutritional supplement often used by people unable to eat or experiencing undesirable weight loss through age, infirmity or disease. However, there is no record that Dr C took any steps to assess her weight or otherwise check her nutritional status for a period of 10 years. In many cases the repeat prescriptions were requested by Mrs A speaking to the practice nurses. In response to my provisional opinion Dr C said she was satisfied by her "visual examinations" of Mrs A "over the time [she] was seeing [Mrs A] regularly". When prescribing Ensure she "had adequate knowledge of [Mrs A's] health and was satisfied the treatment was in her best interests".
199. The Medical Council of New Zealand guideline *Good Prescribing Practice* states that doctors should prescribe medicines or treatment only when they have adequately assessed the patient's condition, and/or have adequate knowledge of the patient's needs and are therefore satisfied that the medicines or treatment are in the patient's best interests.
200. In my view it was inappropriate for Dr C to prescribe Ensure over a prolonged period with no follow-up or check as to the efficacy of the treatment other than the few occasions on which she states she saw Mrs A. As stated, no meetings with Mrs A are recorded between February 2009 and August 2010.

#### *Record-keeping*

201. Dr C has acknowledged that her records are poor. She stated that many of her conversations with Mrs A and Dr D took place while she was at home outside of working hours, and that she failed to make records subsequently. In response to the provisional opinion Dr C stated: "I regret that the emphasis is changing to notes that

‘become critical in any future dispute or investigation’ rather than good care for patients. I believe there needs to be a balance in favour of time spent actually caring for patients.”

202. A full and accurate clinical record is vitally important for continuity of care and the delivery of a seamless service. HDC has made numerous comments in previous reports stressing the importance of good record-keeping and the accuracy of the medical record.<sup>33</sup> In *Patient A v Nelson Marlborough District Health Board*<sup>34</sup> Judge Baragwanath noted that it is through the medical record that doctors have the power to produce definitive proof of a particular matter.
203. I also note that the Medical Council of New Zealand’s publication *The Maintenance and Retention of Patient Records*<sup>35</sup> states that “records form an integral part of any medical practice; they help to ensure good care for patients and also become critical in any future dispute or investigation”. The publication requires a doctor to keep clear and accurate patient records. I would therefore have expected that Dr C document her interactions with Mrs A and, in particular, her assessment of Mrs A’s mental state and her justification for the approach taken. Dr C has submitted that she had limited access to computers and no keyboard skills. However, I remain of the view that, in this case, documentation was particularly important because Dr C was the only clinician with full knowledge of, and involvement with, Mrs A. In my view, Dr C failed to maintain records to the expected standard.

#### *Conclusions*

204. I accept that Dr C was attempting to support and advocate for Mrs A, and that from around 2005 Mrs A refused the limited external support that was offered to her, such as a cleaner.
205. However, Dr C failed to assess Mrs A’s competence in order to satisfy herself that Mrs A remained competent to refuse services. In addition, Dr C assumed responsibility for Mrs A but failed to ensure the provision of adequate care and support. Accordingly, in my view, Dr C failed to provide services with reasonable care and skill, and breached Right 4(1) of the Code.
206. By prescribing for a patient she had not reviewed for an extended period, and forming a relationship that went well beyond the normal doctor–patient relationship and involved her acting as the gate-keeper for any contact by support services, Dr C did not comply with professional standards and so breached Right 4(2) of the Code.
207. By failing to keep adequate records, Dr C also breached Right 4(2) of the Code.

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<sup>33</sup> For example, 10HDC00610, 09HDC01765, 08HDC10236, 06HDC12164, 04HDC17230.

<sup>34</sup> (HC BLE CIV-2003-204-14, 15 March 2005).

<sup>35</sup> August 2008.

### **Opinion: Dr D — adverse comment**

208. Dr D first met Mrs A in December 1992, and in 1995 he arranged for Mrs A to undergo pre-symptomatic testing for HD. From September 1999, Mrs A declined any further appointments with Dr D.
  209. Thereafter, Dr D's involvement with Mrs A was confined to having conversations with Dr C about Mrs A once or twice per year and completing an annual "special authority" application for Ensure. Dr D stated that Dr C told him on many occasions that Mrs A had said that if Dr C, or others, entered the house and saw her, she would commit suicide. Dr D stated that "based on our knowledge of [Mrs A] I reckoned this to be a very serious risk".
  210. Dr D agreed that he "would have" discussed with Dr C the likely mechanism of Mrs A's death and that she might die suddenly. He advised that he "most likely" discussed the fact that HD patients can have the inability to recognise disgust when this is expressed by others. However, Dr D did not regularly keep records of the conversations he had with Dr C about Mrs A.
  211. When asked, Dr D stated that he was "totally uncomfortable about giving advice relating to a patient he did not have access to" and confirmed that all his information about Mrs A came from Dr C. Dr D also stated that he is not at all comfortable with leaving a person such as Mrs A to live in the circumstances in which she was living, with the likelihood she would not be found until sometime after her death.
  212. Dr D stated that one of the factors in his decision-making was that the local psychiatric institution was reluctant, if not hostile, with respect to admitting people with HD. Dr D acknowledged that the care provided to Mrs A was not perfect and said: "I take some responsibility — I don't think we managed her well, but it was difficult to know when to intervene."
  213. I agree with Dr D's assessment. Given the known likelihood that Mrs A would, at some stage, lose competence and be unable to care for herself appropriately, it was not acceptable for Dr D to continue to support Dr C in her actions. However, I accept the difficulties he faced in finding an appropriate placement for Mrs A, and that he was totally reliant on the information Dr C provided to him.
  214. In my view, Dr D should reflect on the contribution his actions had to the outcome in this case.
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## Recommendations

215. I recommend that Dr C:

- apologise to Mrs A's family. The apology is to be sent to HDC by **21 June 2013** for forwarding to the family; and
  - arrange for regular mentoring from a senior colleague four times per year to be organised by RNZCGP for the next two years, until 30 May 2015, and for the mentor to provide written information to the RNZCGP (by 30 June 2014 for year one and 30 June 2015 for year two) that the mentoring has occurred and that Dr C appears to be continuing to maintain adequate records and an appropriate standard of professional conduct.
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## Follow-up actions

- A copy of my final report with details identifying the parties removed, apart from the expert who advised on this case, will be sent to the Medical Council of New Zealand, the District Health Board and the Royal New Zealand College of General Practitioners, and they will be advised of Dr C's name.
- A copy of my final report, with details identifying the parties removed, apart from the expert who advised on this case, will be sent to the Director-General of Health and placed on the Health and Disability Commissioner website, [www.hdc.org.nz](http://www.hdc.org.nz), for educational purposes.

## Appendix A — Expert clinical advice to the Commissioner

The following expert advice was obtained from Dr David Maplesden:

“1. My name is David Vaughan Maplesden. I am a vocationally registered general practitioner having graduated from Auckland Medical School in 1983. I hold the qualifications MB ChB, Dip Obst and FRNZCGP. I was in full time urban general practice from 1986–2005 and have been in part-time practice from 2005 to current, currently doing 4/10ths urban practice.

Thank you for the request that I provide clinical advice in relation to the complaint from [Ms B] about the care provided to her mother, [Mrs A], by [Dr C]. In preparing the advice on this case to the best of my knowledge I have no personal or professional conflict of interest. I have examined the available documentation: complaint from [Ms B]; complaint from [Mrs A’s] landlords; response from [Dr C]; brief GP documentation; records from support agencies Huntington’s Disease Association and [the NASC]; response from [the DHB and Hospital] notes.

### 2. Complaint summary

(i) [Ms B] complains that [Dr C] has provided insufficient care for her mother, [Mrs A]. The complaint relates primarily to the unhygienic conditions [Mrs A] was found to be living in [in September 2010]. The conditions are detailed on file (photographs and DVD) and include tins of Ensure Plus and empty pizza containers piled sufficiently high to obscure most furniture in [Mrs A’s] flat, a toilet that has been non-functioning for at least two years [...] and a rotten wet mattress on the bed. [...] [Ms B] had not been in the flat since 2006, and [Dr C] had not entered the flat since 2005. [Ms B] states that when she moved out of the flat in 2004, [Mrs A] *had not had a shower in 3 years; her hair was becoming a matted mess...the house wasn’t tidy but you could still see the furnishings...* There were prolonged periods when [Mrs A] would not communicate with her daughter, and [Dr C] was the only point of contact. [Ms B] feels she was not kept sufficiently informed by [Dr C] as to her mother’s progress over this period. However, during 2006 *it would appear...that mum was still managing herself considerably well. She was organising groceries and sorting her own finances.* [Ms B] recounts arranging for her mother’s admission to hospital in later 2006, and then inspecting the flat in her mother’s absence. She describes ankle deep rubbish through the house with dirt and grime in the bathroom. *I felt frustrated that mum was allowed to live in such a mess.*

(ii) [Ms B] has enclosed an e-mail sent to [Dr C] on 27 March 2007, noting telephone contact details and voicing her concerns at her mother remaining alone in the flat in the state she had observed it previously. [Dr C] telephoned [Ms B] back explaining [Mrs A] had a right to choose where and how she lived, and that she had already passed her expected life span. [Ms B] saw her mother again in January 2009 (albeit from behind a curtain) but ascertained her mother was filthy apart from obsessively clean hands. [Ms B] complains about inadequate contact from [Dr C] over the next two years with only occasional phone calls and e-mails. [Ms B] describes herself and her father meeting with [Dr C] in August 2010 to discuss [Mrs A’s] situation. *We*



*make it clear that we want mum to be in an institution, [Dr C] blatantly told us it will never happen.*

### 3. [The] DHB response and [Hospital] clinical notes

(i) *[The DHB] has had little direct involvement in [Mrs A's] care since 2004. There was an overnight admission on 21 September 2006 following [Ms B's] contact with the police. [Mrs A] was noted to be unkept [sic] but there is no direct reference to the state of her living conditions. [Mrs A] was seen by a social worker and the close involvement of the GP, [Dr C], is recorded. It appears [Mrs A] left hospital with the GP, and was certainly discharged back into the GP's care with no further plan to follow-up by [the DHB].*

(ii) Front page for admission 21 September 2006 notes GP as [Dr C] *to be contacted any time, night or day, if patient presents. ED nursing notes record Pt has Huntington's for many years — now unable to care for herself at home. Pt very fearful of going into a rest home, said she would kill herself if she had to...Medical registrar notes include the comments has been entirely self caring, no home help, increasing concern from daughter re ability to cope...unkempt appearance...examination otherwise normal. Discharge summary noted borderline thyroid function results, bloods otherwise normal. Pt's GP attended the hospital the next morning [following admission] and is supporting pt in her own home and was happy to take her home.*

(iii) Social worker notes for this admission, reflecting discussion with [Dr C], refer to [Mrs A's] reclusive behaviour, only going out occasionally at night to access a money machine, *occasionally she will go shopping with GP to stock up on food...she has allowed no-one in the house since her last cleaner left about 12 months ago...she has a suicide plan in place which she will carry out should she be under threat of removal from her home...[Dr C's] willingness to continue to support [Mrs A] in her own home is noted.*

(iv) There is a report from [a] neuropsychiatrist dated 8 August 2011. He notes [Mrs A] was initially referred by [Dr C] for psychiatric assessment on 12 November 1992. He explains that HD sufferers often neglect personal hygiene and often fail to recognise dirt and filth and the disgust this might engender in observers. Attempts to assist patients such as [Mrs A] to maintain an accepted degree of personal and general hygiene are *often very forcefully resisted by the patient whom of course doesn't recognise or accept the problem.* [Dr D] outlines [Mrs A's] assessments and progress from the time of her diagnosis of HD was confirmed in 1993 (life expectancy generally 10–15 years from time symptoms apparent) until she refused any further contact with him in 1999. *Over the subsequent years intermittently [Dr C] would contact me by phone and discuss the excruciatingly difficult dilemma of how to best care for [Mrs A].* He was aware of the strong relationship between [Dr C] and [Mrs A], but that [Mrs A] was increasingly reclusive to the point that the only contact she allowed with [Dr C] would consist of [Dr C] attending the house to ensure there were signs of life. [Dr C] continued to provide [Mrs A] with food supplements (Ensure) and had discussed with [Dr D] regarding [Mrs A's] assertion she would kill herself if any

attempt was made to remove her from her home. [Dr D] sympathises with [Dr C's] dilemma — aware that [Mrs A] was living in a degree of squalor but her refusing any attempts to alleviate this, [Mrs A] still able to communicate effectively when required (on the odd occasion she ventured out at night to purchase food), [Mrs A] not being suicidal unless provoked and not an obvious risk to others, and [Mrs A] having already passed her predicted life expectancy. [Dr D] states *The local institutional facilities for such patients are lacking...placement... requires experienced and attentive nursing care. Enacting a committal order, even if there were clinical grounds, which was arguable, would have risked provoking a suicide attempt...The only person committed and willing to try to support [Mrs A] was her GP...*[Dr D] states he discussed [Mrs A's] case with his peers [...] and it was not felt appropriate for the state to intervene at that point. However, when the truly appalling nature of her surroundings was discovered [...], *her autonomy had to be overridden.*

(v) [Dr D] states that, in hindsight, [Mrs A] should probably have been institutionalised in about 2004 *though overriding patients' wishes and decisions (advance care directives) is not something that modern medicine opts to do easily. Whilst I have no doubt that in institutional care [Mrs A] will suffer psychologically, her physical care will be greatly improved.*

(vi) Additional clinical notes record that [Mrs A] reluctantly went into a motel following the discovery of her living conditions and the need for the house to be cleaned and repaired. Her exit from the house was on the understanding she would go back, and when it became obvious she could not (time required to clean and repair the premises and landlord declining her return), [Dr C] requested [Mrs A] be committed to [mental health services] because of the risk of suicide, no suitable alternative placement, and lack of insight into the undesirability of her former situation.

#### 4. Huntington's Disease Association (HDA) fieldworker files

(i) The HDA file front page comments that [Dr C] *coordinates all care.* Additional community supports are listed as the HDA fieldworker (who acts as an agent for WINZ) and a social worker. Contact details are also included for [someone to do] (cleaning/shopping) and [the NASC].

(ii) Notes for 25 March 2003 refer to difficulties with [Mrs A's] daughter, [Ms B], and assistance required for her. [Mrs A's] reclusive lifestyle is noted and *[Dr C] feels it would be very traumatic for [Mrs A] to move. She does not want to be in residential care...* The field worker keeps in contact with [Dr C] and there is occasional telephone contact with [Mrs A], usually regarding WINZ issues. On 21 August 2003 *[Mrs A] declined to have a needs assessment ...very paranoid — caregiver is leaving & will need to be replaced, [Mrs A's] sister refused entry to flat when she comes...[Dr C] will inform [Dr D]. Possible need to do a PPP [Protection of Personal and Property Rights].* By March 2005 it is noted [Mrs A] is now living alone ([Ms B] having shifted out) and in June 2006 it is evident the telephone has been cut off (not clear when or if it is reinstated).

(iii) Notes for 16 June 2006 include *[Mrs A] still living in reclusive style...reference to [Dr C] taking [Mrs A] to the bank, paying off her Telecom bill and buying [Mrs A] stocks of food. On 22 June 2006 there is a message per [Dr C] that [Ms B] will no longer go inside her mother's house because of bad hygiene. On 12 February 2007 it is recorded that [Dr C] is still getting telephone contact [from Mrs A] from time to time & actually bought her a vacuum cleaner (at [Mrs A's] request)...*

(iv) Notes for 14 March 2007 read *Meeting with [Dr C] — contact with [Mrs A] at w/e. Drama as flats have been sold & she was to move. [Dr C] has contacted landlord & managed reprieve...Discussed risk factors with [Dr C]. She is sure she has covered every eventuality & has promised to care for [Mrs A] until death...On 23 June 2007 No change in [Mrs A's] circumstances. Daughters want her in care as scared she will fall and not be found. [Dr C] has regular discussion with [Dr D] re [Mrs A] and does not make decisions unilaterally. In October 2007 the field worker receives a call from an 'old friend of [Mrs A's] irate at [Mrs A's] lifestyle. I explained that [Mrs A] had rights...Discussed with [Dr C] but she is not concerned about criticism of [Mrs A's] lifestyle. She discusses with [Dr D] regularly. Also discussed with [the NASC] who are also powerless to intervene when all aid has been rejected...*

(v) There is a handwritten summary dated April 2010 noting the only person having contact with [Mrs A] is [Dr C] who *troubleshoots in times of crisis — eg new landlord, phone difficulties, money difficulties, cat problems etc. She also rescued her from hospital after police put her there...[Dr C] has arranged major clean-ups of flat — which [Mrs A] always reneges on...*Notes for September 2010 refer to contact from [Dr C] requesting assistance to get [Mrs A's] flat cleaned, and [Mrs A's] subsequent hospital admission. Positive direct interaction between the field worker and [Mrs A] is documented on 13 July 2011 although difficulties remain with attending to [Mrs A's] personal hygiene.

(vi) WINZ documentation in the HDA file indicates [Dr C] has provided documentation to support [Mrs A's] ongoing disability and a Special Situation Benefit (application 12 December 2002). A letter from [Dr C] to WINZ dated 20 September 2006 indicates a regular monthly payment is directed to [Dr C's] practice from WINZ to cover [Mrs A's] medical fees. An e-mail from [Dr C] to HDA dated 3 April 2007 refers to [Mrs A's] rent payment arrangements with a change in landlord.

5. The [NASC] running file has been viewed. Excerpts include:

(i) Records have been reviewed from 3 December 2002. On 21 August 2003 [Dr C] has explained that *[Mrs A] has deteriorated mentally and physically in the last 6 months with increasing paranoia and panic attacks. She has become paranoid about her looks and will not allow anyone to see her not even her own family members.*

(ii) 30 March 2004 a meeting with the allied health team and [the NASC] is held to discuss ongoing support for [Mrs A]. Options discussed included committal to *appropriate residential care. [Dr C] pointed out that both her and...psychologist agree that this is not an option for [Mrs A] as she would most definitely attempt to*

*take her own life if put into this situation...* Support care was to continue with a cleaner attending at least once a fortnight but *No attempt is to be made by the cleaner to enter [Mrs A's] room.* At this stage it appears [Mrs A's] daughter, [Ms B], is still living with her, at least intermittently. Notes for 30 October 2005 indicate [Ms B] has shifted back after a period of absence.

(iii) Notes for 19 March 2007 — *Conversation with [Dr C]. [Mrs A] was admitted to [Hospital]...some months ago when her daughter was unable to contact her and the Police were called. [Dr C] went to hospital and took [Mrs A] back home. Meeting was held with police etc to explain the situation...[Mrs A's] paranoia is extreme now — no-one is able to get in the house at all...[Dr C] continues to speak with her but is not able to enter her house now...[Dr C] agrees that a reassessment would be impossible and must not be attempted. She will liaise with [...]* ... [Mrs A's] file is apparently closed at this point.

#### 6. [Dr C's] response and GP records

(i) [Dr C] has provided a detailed synopsis of her involvement with [Mrs A] since she first saw her in 1986. This record is on file and will not be repeated in detail. Some relevant points are summarised below.

(ii) [Mrs A] was referred to psychiatrist [Dr D] in 1992 (see [the DHB] response). In 1999 she was referred to [the NASC] for assistance with meal preparation, and her flat was completely redecorated in March of that year. Visits with [Dr D] stopped in February 1999 because of [Mrs A's] acute embarrassment regarding the symptoms of her condition and her increasing unwillingness to be seen in public. Antidepressants were used during 2001 on the advice of [Dr D], who had offered to visit [Mrs A] but she did not consent. [Dr C] was visiting [Mrs A] weekly to monthly over this time.

(iii) In October 2002 [Dr D] *alerted [the NASC] that [Mrs A] would need a place in care.* [Dr C] also attempted to persuade [Mrs A] to accept more help and consider institutional care. At this stage [Mrs A] voiced concrete suicide plans should she ever be made to shift from her flat, as her hermetic existence was what she wanted and she could not consider being in a more public situation. In fact, no suitable long term care facility, with expertise in the special needs of patients with HD, was available at this time even had [Mrs A] consented to leave her flat. [Dr C] felt that [Mrs A] was likely to die from her condition within the next three or four years given the average lifespan of such patients, and she could provide her with the support required to maintain independence over that period.

(iv) Through 2003, [Mrs A's] paranoia and anxiety at contact with outside people increased, to the extent she required anti-anxiety medication before such visits to enable them to take place. Monthly GP visits were maintained through this period and 2004, although at times [Mrs A] was not answering the door. When her regular cleaner (organised by [the NASC]) was no longer available, [Mrs A] refused a new cleaner and [Mrs A's] daughter ([Ms B]) said she would clean the flat. The dietary supplement, Ensure, was provided from 2003. [Mrs A's older daughter] emigrated [overseas] in mid 2003.

(v) [Dr C] last entered [Mrs A's] flat in January 2005. [Mrs A] deferred subsequent scheduled visits and also expressed concern at receiving phone calls from [Dr C]. It was agreed [Mrs A] would telephone [Dr C] every six weeks. In June 2006 [Mrs A] spent time with [Dr C] on two occasions as [Dr C] attempted to facilitate resolving a problem with [Mrs A's] bank card that required her to attend the bank. Her extreme paranoia was evident on these occasions.

(vi) In September 2006 [Mrs A] was taken to hospital after her daughter had called the police because she could not contact her mother (See [the DHB] notes). [Dr C] was not allowed to enter the flat but a degree of disarray was acknowledged (and had been the concern of daughter [Ms B]) and [arrangements were made to clean the flat] and make any required internal repairs. However, [Mrs A] declined this arrangement at the last minute, asking [Dr C] to supply rubbish bags, a vacuum cleaner and rubber gloves.

(vii) Over 2007/2008 *most of the contacts were when [Mrs A] ran out of Ensure Plus, which was deliberately arranged to happen at monthly intervals.* A toilet leak was discovered in August 2008 and the need for a plumber to enter the flat was discussed with [Mrs A] by [Dr C]. [Mrs A] stated the toilet had overflowed but she had fixed it and it was now working properly. External evidence of a leak disappeared, in hindsight because [Mrs A] had turned off the cistern.

(viii) In February 2009 [Dr C] visited [Mrs A] at the request of the landlady who had received complaints about the television being on at night. [Dr C] spoke to [Mrs A] through her broken balcony door for an hour but could see only her feet. Arrangements were made to repair the broken door without entering the flat. *At this time [Mrs A] reunited with [Ms B] and met her new grandson.* However the mother/daughter relationship broke down again a short time later. *Subsequent contacts through 2009 were over the telephone and included arrangements for a new bankcard.*

(ix) In April 2010 the local BP service station called police because [Mrs A] had been at the premises for some time, *looked strange and obviously had a lot of cash on her.* Police returned [Mrs A] to her flat and contacted [Dr C] who spoke with the service station manager who stated she had had a *nice chat* with [Mrs A] who *appeared clean and did not smell.*

(x) Through 2010 [Dr C] would visit [Mrs A's] flat weekly to ensure there were no signs she had died. In August 2010 [Mrs A's] father discussed with [Dr C] placing [Mrs A] in care. [Dr C] made repeated attempts to contact [Mrs A] to arrange cleaning of the flat. [In] September 2010 [Dr C] visited [Mrs A] and, together with a report and photographs supplied by a neighbour, it was realised the flat was unhygienic and required cleaning. [Dr C] spoke with the Medical Officer of Health and after met with the Environmental Health Officer to try and facilitate cleaning of the flat so [Mrs A] could stay. She managed to persuade [Mrs A] to leave the flat for what [Dr C] thought would be a day, to allow for cleaning. However, the true extent of the condition of the flat became apparent once cleaning commenced and, after a few days when it seemed

unlikely [Mrs A] could return to the flat, and there were no suitable community facilities available, [Dr C] reluctantly committed [Mrs A] to secondary care.

(xi) In a supplementary response, [Dr C] notes regular contact with the Huntington's Disease Association Field officers from 2003 (visits every six months to discuss [Mrs A's] progress once [Mrs A] refused face to face visits from them in later 2003). Involvement with [the NASC] has been discussed above. In 2010 [the rehabilitation service] were to take over WINZ liaison when the HD field officer resigned. However, [Dr C] feels they offered inadequate assistance overall.

(xii) There is an e-mail from [Dr C] to WINZ case worker dated 23 September 2010 which outlines the discovery of [Mrs A's] poor living conditions and requests financial or other assistance to help clean up the flat so [Mrs A] can remain there. [Dr C's] comments include:

a. *I have been aware that [Mrs A] has been unable to put out any rubbish for some years...despite my providing her with disposable gloves...[Mrs A]...assured us she had 'fixed' the leaking toilet, and it appeared this was so...However...did she just turn off the flush 2 years ago...*

b. *[Mrs A] has lived past her predicted life expectancy with symptomatic Huntington's Disease. This expectancy is what has let me leave her to live as best she was able and desired...Any time we attempt to take [Mrs A] out may well precipitate a suicide attempt — she has been quite clear about her intentions should she believe someone is trying to shift her...*

(xiii) There is e-mail correspondence on file between [Dr C] and various agencies and individuals (including [Ms E] from [the rehabilitation service] and [Dr D]) regarding her attempts to get [Mrs A's] flat cleaned and [Mrs A] back into it rather than forcing [Mrs A] against her wishes, and with the real threat of suicide, into sheltered accommodation. Ms E is strongly of the opinion that [Mrs A] must now go into sheltered accommodation but states in an e-mail dated 14 September 2010 that [Dr C] *can and should celebrate all the work you have put in over the years that has enabled [Mrs A] to remain in the flat for so long.*

(xiv) Computerised notes have been provided from July 2009. These consist mainly of repeat Ensure prescription records until the record of 25 August 2010 that documents telephone discussions between [Dr C], [Ms B] and [Mrs A's] father as per the response above. Subsequent records indicated frequent attempts at contact between [Dr C] and [Mrs A], with [Mrs A] resisting although [Dr C] has observed signs of activity within the flat. [Dr C] has noted in her response that over the past 16 years she has only worked at the surgery two half days per week, and most of her contact with [Mrs A] was outside of her surgery time. Subsequently there has not been much note-keeping. While this standard of documentation is not consistent with expected standards, I feel there is no particular need to request further GP notes as [Dr C's] response is largely corroborated by the supporting documentation on file, and it seems unlikely the notes, if sparse, will contribute usefully to the assessment of this case.

## 7. Comments

(i) This is an extremely complex case that raises fundamental issues over perceptions of what is a reasonable standard of living, the rights of an individual to live as they want provided they are not an overt threat to themselves or others, the role of the GP and when clinical objectivity might be impeded by personal involvement with a patient, the role of the family in advocating for another family member and the role of community based organisations in attempting to provide support for the choices of a patient.

(ii) From a clinical perspective, and with reference to [Dr D's] comments in 3(iv), there appears to be some doubt over whether [Mrs A] could have been forced into an institution against her will prior to the true nature of her living conditions being established in September 2010. The Mental Health (Compulsory Assessment and Treatment) Act 1992 requires that the mental disorder suffered by the patient pose *a serious danger to the health or safety of that person or of others* or *seriously diminishes the capacity of that person to take care of himself or herself* before the person can be committed to an institution. [Dr C] had not noticed any overt problems with [Mrs A's] nutritional status, personal hygiene or appearance during their brief encounters as late as June 2006, although she was noted by hospital staff to be unkempt during the brief admission there in September 2006. The flat was last entered by [Ms B] in September 2006 and was noted to be untidy and unhygienic. Attempts to persuade [Mrs A] to accept external assistance cleaning it up and maintaining it were unsuccessful and [Dr C] appears to have made several assumptions over the ensuing years that the living conditions had not deteriorated to the stage of being a threat to [Mrs A's] health. There is no indication [Mrs A] sought, or required, intervention for any acute illness (including gastroenteritis) over this period. There was no complaint recorded from tenants in the same block of flats regarding signs of poor hygiene such as malodour or flies. Apparently [Mrs A] did not appear unduly malodorous or unkempt when she interacted with a garage attendant in April 2010. I cannot see therefore, without the benefit of hindsight, that [Mrs A] could have been deemed as committable (and the flat entered against her expressed wishes) before the discovery in September 2010 of her atrocious living conditions. However, given the natural history of HD and propensity for advanced sufferers to have problems with personal hygiene as described by [Dr D] (3 (iv)) there is an issue over whether [Dr C] did enough to confirm [Mrs A] was living in reasonable conditions rather than assuming she was.

(iii) It is apparent [Dr C] went well beyond the expectations of a 'normal' doctor-patient relationship in terms of the services she provided for [Mrs A] and her level of advocacy for [Mrs A], and these actions were perceived by [Dr C] to be in [Mrs A's] best interest. Any financial compensation appears to have been minimal when related to the time put in by [Dr C] to ensuring [Mrs A's] relative independence and health. While it seems [Dr C's] intentions were for [Mrs A's] rights and wishes to be honoured at all cost, I wonder if her clinical objectivity was lost, possibly after early 2005 when [Mrs A] would no longer allow [Dr C] into the flat and particularly after September 2006 when [Dr C] became aware (from [Ms B]) as to the state of the flat, but [Mrs A] was unwilling to cooperate with attempts to clean it. [Dr C] increasingly

became the ‘gatekeeper’ for any support service attempting to access [Mrs A] or her surroundings, and was also instrumental in denying the landlord access to maintain the property as was his right. Again in hindsight, allowing the landlord access when first requested would have identified earlier the need for the flat to have a thorough clean and on-site support reinstated, and minimised the eventual significant damage done to the flat through [Mrs A’s] inattention to hygiene. Intervention at this time may have resulted in [Mrs A] staying at the flat, with appropriate support, until her death, although equally possible was the threat of eviction given the state of the flat even at that time. [Dr C’s] reason for the gatekeeper role was [Mrs A’s] desire to remain in the flat, and her voiced intent to kill herself (with a plan outlined) should there be an attempt to remove her. It is not so clear that more firmly negotiating regular cleaning of the flat, while perhaps causing physical unease, would have precipitated a suicide attempt given the fact such support had been in place until at least 2005.

(iv) There was an ongoing deterioration in [Mrs A’s] condition, as expected, during the time she was under [Dr C’s] care. [Dr C] sought regular specialist advice from [Dr D], although [Dr D] was dependent on [Dr C’s] perception of [Mrs A’s] condition and her surroundings on which to base his recommendations. [Dr C] was aware [Mrs A’s] ability to care for herself would be increasingly impaired, but was attempting to balance [Mrs A’s] clearly and strongly expressed desire and right to be left to lead her solitary existence (with which she was evidently quite contented) and the assumption that [Mrs A] was likely to be nearing the end of her expected lifespan and it might be possible to honour her wishes, against the wishes of family members to have better support for her, the lack of a suitable facility to provide the specialist support required, and [Mrs A’s] refusal to allow what might have been determined as reasonable surveillance under the circumstances. I think the circumstances prevailing from at least September 2006 (when [Mrs A] had been released from hospital back to the flat, the flat was known to be in an unhygienic state and [Mrs A] declined assistance with cleaning) prevented [Dr C] from making an appropriate and clinically sound assessment of [Mrs A’s] ability to continue her independent existence. Her decision to continue to support [Mrs A’s] independence from this point, while made with the best of intentions, I feel was flawed because of the inability of [Dr C] to adequately and regularly assess [Mrs A’s] physical and psychological status or the condition of her surroundings. However, it is difficult to determine what options might have been effective at this point without increasing [Mrs A’s] risk of self harm. [Mrs A’s] choice to decline any sort of physical surveillance from 2006 was a consequence of deterioration in her paranoid state (secondary to the HD) and marked lack of insight into the state of her current living conditions (again secondary to her HD). However, I cannot confirm that she would have been deemed sufficiently mentally unwell at this point (and without evidence of her unsavoury surroundings) to warrant committal to an institution against her will.

(v) In summary, with the benefit of hindsight it is apparent [Dr C] did not recognise in a timely fashion the degree to which [Mrs A’s] ability to self care had become compromised to the point that removal of her from her flat and into supported care, against her will, was a necessity. Unfortunately, while [Mrs A] herself did not apparently suffer any physical consequence of the situation, the damage to her flat was considerable as was the distress of family members and neighbours on seeing her



living in squalid conditions. It is difficult to quantify a degree of departure from expected standards of care in this situation. It is quite apparent [Dr C] was attempting to support, and advocate for, [Mrs A] at significant personal financial and time cost. Until the time [Mrs A] refused external support, [Dr C] had organised the appropriate involvement of community support agencies, and attempted to do this again in 2006 and 2010 with respect to cleaning [Mrs A's] flat. [Dr C] continued to maintain contact with [Mrs A] through a variety of means in order to reduce the risk of her expected death going undetected. In a perverse way, [Dr C] was trying to ensure [Mrs A] maintained her own perception of personal comfort (solitary nocturnal existence with TV and cat in an environment she felt secure within) which one would expect of a supportive practitioner in a palliative care situation which, in effect, this was. While it is difficult to comprehend, the distress suffered by [Mrs A] at the thought of leaving her flat (sufficient to make her threaten suicide), despite the state it was in, probably exceeded the distress of her friends and family at seeing how she was living. All of this must be taken into consideration when determining whether there were shortcomings in the care offered by [Dr C]. Taking into account the overall situation, I feel that [Dr C] failed, probably from late September 2006, to ensure [Mrs A] was reviewed in a manner that would reasonably reassure a health provider as to the ongoing physical and mental health status of the patient and their suitability to maintain an independent existence. This was in spite of concerns raised by family members, and resulted in [Dr C] adopting a 'gatekeeper' role that prevented an opportunistic assessment of [Mrs A's] surroundings by the landlord or his agents. However, as discussed above, there were extenuating circumstances in a complex situation, and I feel [Dr C's] management probably departed from expected standards to a mild degree under these circumstances. It is apparent [Dr C's] compassion for [Mrs A] and her situation may have clouded to some degree her clinical objectivity."

**Following receipt of additional information, Dr Maplesden provided the following further expert advice:**

"I think [Dr C's] departure was probably closer to moderate when one considers she took ultimate responsibility for this lady's care (and additional support systems, including family, were virtually non-existent after September 2007) but really failed to discharge that responsibility in a professional and clinically sound manner. Had she been a lay person with misplaced good intentions I think the behaviour may have been less open to criticism. However, [Dr C] should have foreseen that the natural history of HD meant her patient would inevitably become more dependent (but would likely have no insight of this) and would need regular reviews to ascertain her suitability for independent living or additional supports required for her to stay safely in her own home.

I cannot see that any such review was undertaken after September 2006, and very occasional conversations through a window, without physically viewing the patient, were no proxy for competent clinical assessments (of physical as well as cognitive status). It was inappropriate for [Dr C] to continue to assume the patient was 'OK' just because there were no blowflies in the windows or no 'smell of death' coming from the flat.

Mitigating factors were: the fact there was some ongoing contact between doctor and patient, albeit very limited; the patient's expressed wish to stay in her own home (advance directive) made at a time when she was presumably mentally competent; the patient's threats to suicide should she be removed from her home (although these threats may have indicated a need for more professional psychological evaluation); and the ongoing intermittent contact [Dr C] had with [Dr D] regarding the patient.

As far as [Dr D] is concerned, I am not aware that [Dr C] ever formally referred the patient for management advice, or whether, if she had previously been in the hospital mental health service, she was ever formally discharged from that service. The 'advice' arrangement does seem to have been very informal to the extent I am not aware either party consistently documented the interactions.

It appears [Dr C] was keeping [Dr D] informed of the situation and he was therefore reliant on the information given to him to reflect his thoughts back to [Dr C]. Had she been asking him for specific management advice eg, how do I assess whether the patient is still mentally competent or safe to stay in her home, then I would have expected [Dr D] to satisfy himself he had all the information required to give such advice."