ABUSE IN CARE ROYAL COMMISSION OF INQUIRY DISABILITY, DEAF AND MENTAL HEALTH INSTITUTION HEARING

	TRANSCRIPT OF PROCEEDINGS
Date:	11 July 2022
Venue:	Level 2 Abuse in Care Royal Commission of Inquiry 414 Khyber Pass Road AUCKLAND
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Royal Commission:	Judge Coral Shaw (Chair) Paul Gibson Julia Steenson
In the matter of	The Royal Commission of Inquiry into Historical Abuse in State Care and in the Care of Faith-based Institutions
Under	The Inquiries Act 2013

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1		Adjournment from 11.01 am to 11.26 am
2	CHA	AIR: Kia ora anō, Ms Thomas.
3	MS	THOMAS: Thank you, Madam Chair. We will now be hearing evidence from Irene Priest
4		and her sister Margaret Priest who are seated here today, and Irene is also supported by her
5		support worker Anita.
6	CHA	AIR: I can see I think I can see Margaret but I don't think I can see Irene. [Chair
7		adjusted]. That's better. Good, it's good to be able to see you.
8	MS	THOMAS: Just before we begin with Irene and Margaret's evidence, we have got a
9		one-minute scene setting clip which is just some aerial images and pictures of Kimberley.
10		A major focus of the evidence from Margaret about Irene's experiences are at Kimberley.
11	CHA	MR: Yes. Perhaps before we do that, we'll do the affirmation
12	MS	THOMAS: Yes.
13	CHA	AIR: and get that out of the way and then we can move straight to the clip; is that all right?
14	MS	ΓΗΟΜΑS: Yes, thank you.
15	CHA	AIR: First of all, a warm welcome to you both. Thank you for coming, Irene, thank you for
16		coming, Margaret. I'm going to ask if you would like both to take the affirmation. I'll just
17		read it once and just a nod of the head will be fine from Irene.
18		IRENE AND MARGARET PRIEST (Affirmed)
19	MS	THOMAS: Thank you. If we could just have that scene setting clip played now and then
20		we'll start with your evidence.
21		[Video played]
22	QUE	STIONING BY MS THOMAS: Thank you. Good morning, Margaret and Irene. Margaret,
23		can you please start by telling us your full name?
24	A.	Margaret Williamson Priest. [Microphone adjusted].
25	Q.	Thank you. Is it appropriate for me to call you a failed retiree?
26	A.	It is totally appropriate. I was a retired teacher but teaching is in a desperate state so I've
27		been re-registered and back into the workforce.
28	Q.	Thank you. And you are here today seated next to you with your sister Irene?
29	A.	Yes.
30	Q.	And you will be giving evidence about your experiences but primarily about Irene's life that
31		you've shared with her every step of the way for the last 66 years?
32	A.	I will be.
33	Q.	If you could start, please, by telling us when was Irene born?
34	A.	Irene was born in 1956, 13 months after I was.

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- 1 Q. During that birth, did something happen while she was being born?
- A. 13 months prior I had been born by emergency caesarean, so my parents had engaged an eminent specialist but they had shifted so it was a different eminent specialist in a different city to help Irene come into the world. They pleaded with a caesarean but the eminent specialist insisted on forceps, he squeezed Irene's head in the wrong place and this is why Irene's brain injury, why she is so disabled.
- 7 Q. So as a result of that brain injury at birth, does Irene have learning disability?
- A. Irene can't speak, we don't know how much she understands, she needs 24-hour care, she
 cannot dress herself, she cannot toilet herself, she cannot read, write. I would -- I've always
 thought about her as having the mind of a baby really, but she understands a lot more than a
 baby, so it's hard for us to gauge. She surprises us continually.
- 12 **Q.** How does Irene communicate with you and with supporters?

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- A. She will grab my hand or her support -- Anita's hand to say she wants her back rubbed,
 which is very often. She will take our hands to guide us somewhere. We know when she's
 unhappy because she will growl. If she is happy she will click her tongue, she smiles,
 seldom does she laugh, but she has very short moments of concentration sometimes, but she
 has her ways of making her wishes known.
- Q. Can you tell us something about your home life as you were both young children growing up with your parents?
- My father and mother were a very united team, although my mother was very depressed 20 A. 21 and continually felt guilty about not being able to bring Irene safely into the world, and she tried very hard to give us a happy childhood, but -- and it was a happy childhood really. 22 Irene and I were very close. I have felt as though I've communicated for her all her life. 23 But when Irene was five and a half or so my mother had, really she was having a 24 25 break-down, because there was no help for her. There were no social services to help her, there were no respite places, and my mother had tried -- in those days the antidepressants 26 weren't what they are now. They basically wiped her out and she couldn't care for Irene 27 who was very active and, you know, she was found -- she climbed a fence and was in the 28 middle of traffic on the road. So my mother couldn't take antidepressants. 29

There was really nowhere else -- my father was balancing up my mother's health and Irene's welfare, so our family doctor suggested that Irene go into care.

There were two places available. One was Hōhepa which was a private place, but Irene didn't have enough ability to go into Hōhepa, they had to have a certain ability. So Kimberley was our only option.

- 1 **Q.** In terms of Kimberley, was one of the features about Kimberley that interested your parents the fact that it was a training school?
- 3 A. It was touted as a training school, it was called a training centre. I think it was Hospital and
- 4 Training Centre. And I know mum and dad, are as I've always been, were very realistic
- about Irene's capability, but I know that mum and dad to start with, and me latterly, we had
- all hoped that Irene would realise whatever potential she had.
- 7 **Q.** So she was placed in Kimberley in 1962?
- 8 A. Yes, she was five years and eight months.
- 9 **Q.** And lived in Kimberley through until 2004?
- 10 A. Yes.
- 11 **Q.** So 42 years --
- 12 A. Yes.
- Q. -- spent at Kimberley. When your parents delivered Irene to Kimberley, can you tell us
- what they were told by the staff or the managers at Kimberley about contacting Irene?
- 15 A. They were told to leave Irene there for four weeks with no family contact, because that
- would help her to settle, and that would be best for Irene. It was very hard for my parents
- to do that.
- 18 **Q.** And during those first four weeks, did your parents have contact with Irene?
- 19 A. They weren't going to, but they were telephoned during those four weeks to say that Irene
- 20 had contracted hepatitis, and was in isolation, so they went up and collected her
- immediately to take her home to recover. I went with them. I was nearly seven at the time.
- We went in to the isolation ward, she was in a room on her own, she didn't even have her
- 23 teddy bear that she'd taken with her, she didn't have a radio on, she was sitting rocking
- backwards and forwards on a bed, a hospital bed.
- 25 Q. So that was the condition that you found Irene in when you arrived to pick her up --
- 26 A. Yes.
- 27 **Q.** -- because of -- being in isolation? During Irene's time at Kimberley, did she come home
- with you and your parents for weekends?
- 29 A. Yes. So for years she came home every single weekend. In retrospect I don't know
- whether that was a good thing because it made the contrast too much. She has a very good
- sense of direction, we know that, because as soon as we turned left to go towards Levin she
- 32 started to growl.
- 33 **Q.** Right.

- 1 A. So she was upset every time she had to go back and my mother cried every time. It never got easier.
- And you said the contrast was so great. What was the main contrast between your caring home versus the life at Kimberley?
- 5 A. Love.
- And I think you've described in your statement that life at Kimberley was just a place of people existing; would that be how you would describe Irene's situation in Kimberley?
- A. Totally. She was a resident to be physically cared for, even though that didn't -- that wasn't done very well. I suppose she was given food, but she couldn't wear her own clothes, my mother knitted lovely jerseys for her, she took a teddy bear up there, everything disappeared, it went into a communal laundry, and she was placed in somebody's clothes that didn't fit. So when she came home we didn't recognise the clothes she was in. She didn't even have that right, to wear her own clothes.
- I'm going to ask you about dental care at Kimberley and can you tell us what happened with Irene's teeth while she was at Kimberley?
- Well, I'm not entirely certain how good the dental hygiene was there. I presume they 16 A. brushed their teeth twice a day. Irene's teeth were quite tightly packed, but maybe she 17 could have had some orthodontic work to make them not quite so tightly packed, if she 18 needed fillings it had to be done under a general anaesthetic because she was frightened. 19 Eventually they said that she should have all her teeth removed. I was very upset about that 20 and pleaded at the time -- I was an adult then -- for her to be given implants, which my 21 parents tried to do, we thought that was a very good alternative. But that wasn't able to be 22 done -- or it was able to be done; it wouldn't be done. 23
- Q. So even though your parents offered to pay and requested implants to be made for Irene, the hospital wouldn't allow that?
- A. No, or I don't know if it was allowed or bothered, but they certainly didn't. And that was a common theme, that my family, who cared very much for Irene and would have given her anything she needed at any time, were not included in the decision-making process, ever, and they tried very hard.
- 30 **Q.** As a result of that decision, I think you mentioned yesterday, Irene's now lost one joyful aspect of daily life, enjoying all the food that one can enjoy?
- 32 A. She loved food, there were very few things that Irene can get great pleasure out of: One is 33 going for a drive in the car, another was eating. And by removing her teeth, they took away 34 one of those huge pleasures, and also a health aspect.

- 1 **Q.** I'm going to ask you about education and training at Kimberley. What did you observe in terms of any education or training that was provided to Irene?
- 3 A. There was none. Irene regressed. So when she went in she was learning to feed herself
- with a spoon, she couldn't feed herself when she came out. She was learning to toilet
- herself, when she came out she couldn't. Even those would have been education for Irene.
- I asked later on if they could try and find some sort of sign language where she could point
- at pictures of what she would like so that she had some choices, that was never followed
- 8 through.
- 9 **Q.** Can you tell us about Irene's weight, and this is around about the 1990s, and what was noticed at that time?
- 11 A. Irene lost a vast amount of weight and at one stage she was 31, 32 kgs. She stayed in
- around the mid-30s, I believe -- Kimberley weighed her, we didn't -- until she left
- 13 Kimberley. Irene came home, my father and mother took her to our family GP, she looked
- so dreadful that he tested her for AIDS, he thought that could be one of the things that was
- wrong with her, that she was in an advanced stage of AIDS. She wasn't. Kimberley's
- answer to that was to get her a restraining chair and force her to sit in it the by buckling her
- into it.
- 18 **Q.** Can you describe for us this restraining chair?
- 19 A. It was a metal chair with a padded seat and back and a strap around her middle. So if she
- was upset and wanted to get away from it, she could actually still move and take the chair
- with her, but injure herself in the process, and she did injure herself trying to get away from
- her chair.
- 23 Q. And at what stages throughout the day did the staff put her in this chair?
- A. Meal times, but I believe they put her in it at other times if she was upset.
- 25 **Q.** Right.
- A. And she might be upset and they would think that would be a good way to settle her down.
- 27 Q. When you and your parents were with Irene at home and eating meal times with her, how
- 28 did you and your parents cope with that?
- 29 A. We gave her the time to feed, and so we were very patient and yes, because of being in this
- restraining chair, so that every time we went near one side she would cower, we still
- persevered, or we'd go to the other side, and sometimes it would take, and I attribute it to
- this restraining chair, sometimes it would take two hours to feed her a meal, but we were
- determined to feed her.
- 34 Q. So you never used that chair at home, but --

- 1 A. No.
- 2 Q. -- just the damage that had been done by the use of that chair at the hospital?
- 3 A. Mmm.
- When you said cower, cowering, can you just tell us a bit more about that? What would happen when you approached?
- A. Well, Irene has ways of making herself known to me, so -- and my parents were the same, so if she was -- if we went near her side she would cower away, it was evident that she was afraid of something, but we have no way of knowing because she has no words.
- 9 **Q.** And was that particularly evident when she was seated for meals when you were feeding her at home?
- 11 A. Yes.
- I'd like to ask you some questions about medication, which we will get to shortly. As I think you've now received the full, well, the files that you have received from Irene?
- 14 A. I believe, when I looked, there are nigh on 30 years of files missing, so we are really -- we
 15 have files from the 1990s until she was deinstitutionalised in 2004, and I think there
 16 are -- there was one record for the 1960s, one for the 1970s, and three for the 1980s. The
- rest are missing.
- 18 **Q.** So three decades -- decades worth of files and records are missing?
- 19 A. Yes.
- Q. Was there any explanation as to how they're missing, why they are missing?
- 21 A. I think Ella may have to answer that question.
- 22 **Q.** That's all right. The files that you have seen, did they show a large number of incident reports and event registers showing that Irene received injuries during her time at
- 24 Kimberley?
- 25 A. Totally.
- Q. I'd like to ask for exhibit ending 015 to be put up on the screen, please. I'm not going to ask you to read that because it's small, I'm just putting this up on the screen as an illustration of one example of an event register from Irene's file that you do have with you, and just for everyone's accessibility, I will just summarise some of the aspects that you can see on this one, this is just one page of her file. It shows the -- in the events section listed there it shows things such as bruises, cuts, scratches, a tear to an eyelid, head injury. In the "Date" column it shows that these incidents occurred in April, in May, another one in May, June,
- July, July, September, November, and November.
- And those are the ones that were written down.

Q. Precisely. In the column where there are sometimes some notes made about causes, there are comments such as "Staff attending to others" when Irene has been injured; "staff not present when other residents hurt Irene"; there's comments such as "found another resident laughing and leaving the scene"; there's a comment of "another resident has attacked Irene"; and there's a comment there which states that "Irene has bruising on her thigh consistent with trying to vacate her restraint chair".

A.

This is just one page of many from the file that you have seen. In your statement that you've provided to the Royal Commission on pages six and seven does your statement there list out just some examples of injuries that Irene received while she was at Kimberley?

- It does: Superficial cut on the crown of her head; sustaining a cut to the back of her head; sustaining a gash to her chin; bleeding, grazed nose; staff found a three-quarter inch cut to the rear of her head which required three sutures -- the requirement for sutures was identified by the doctor two days after the incident when he or she was notified, which seems to be negligent to me; hitting her head on the heater; a three-and-a-half-centimetre laceration down the length of her nose; superficial lacerations on her forehead; small nick to her eyebrow; Irene falling over and knocking her face on a heater; hitting her head on the corner of a table; she hit her head on the bottom of the chair; hitting the side of her head against a door frame; landing on the floor hitting her head; Irene falling while running to the toilet and hitting her head on the toilet seat; Irene falling in the shower causing a cut to the front of her scalp; a cut above her left eyebrow; falling backwards and hitting her head against the metal strip on the toilet door; falling heavily on her back and hitting her head on the floor; Irene falling and causing a gash to her head.
- Q. When you went through the file, when you first saw all of these notes, how did that make you feel?
 - A. I was completely shocked. We were not told of these injuries. We would see that she had injuries when she came home. By this stage she would be coming home once a fortnight or so. We had no idea of these injuries, except the ones that we could see. One I do remember vividly, and that was a large gash that took a long time to heal, it required five sutures underneath her eye and she was not seen by a doctor for that for a couple of days after it happened, and then it was written in her notes "patient uncooperative". They didn't even use her name.
- When you went through the file and counted up the number of injuries to Irene's head during this time, how many did you come to?

- A. We have to remember there are nigh on 30 years missing. I counted 77 head injuries.
- 2 **Q.** Just in the notes that you did have?
- 3 A. Yeah.
- 4 **Q.** That were, as you said, written down?
- 5 A. Yeah.
- 6 Q. I'm now going to move on to a very important part of your evidence about Irene's
- 7 experiences in Kimberley, and that is drug abuse. What would you like to tell the
- 8 Commission about what happened to Irene with medication and drugs while she was at
- 9 Kimberley?
- 10 A. A little bit of background, my father, or our father before he was an optometrist was a
- pharmacist so he knew exactly what he was talking about, and he was very upset by the
- concoction of drugs and the apparently indiscriminate use of drugs, and I would say that
- 13 Irene lost approximately 20 years of her life with this drug use. He tried extremely hard to
- work within what was possible to work with the medical profession there, but it was to no
- avail. He even went as far as saying that if Irene was unsettled or unable to be managed,
- not to give her drugs, to give him a call and we would go and collect her and we would take
- her home. That never happened. So she fell because of her drugs, she had Parkinson's
- because of her drugs.
- She is now drug free and I think it took something like 10 years to get her drug free.
- It had to be done so slowly. She doesn't have Parkinson's now. She doesn't fall.
- Q. So a major side effect for Irene was falling as a result of the drugs that she was on?
- 22 A. To give you some indication of the impact the drugs had on her, at one stage she couldn't
- even walk forwards, she walked around in circles or backwards staring at the ceiling.
- 24 Q. You've said that your father did try to speak with the management of Kimberley, the
- 25 Medical Superintendent and I think you said he also would look after Irene at home. When
- Irene was at home, did your father try and remove some of the drugs out of her regime?
- A. If she was at home for a long time he took her completely off the drugs, and she was as she
- is now, peaceful, sleeping, no need for them.
- 29 Q. And did your father alert the Kimberley staff to that contrast to say --
- 30 A. He did.
- 31 **Q.** And what was the response that he got from the staff?
- 32 A. Well, the staff themselves were really -- they had to go under what the Medical
- Superintendent at that time said, and I think there is a letter on file that actually talks about

- that this Medical Superintendent said something along the lines of that he recognised that drugs were not good to be used but he felt they had no alternative.
- 3 Q. I'd ask for that letter to be brought up on the screen now, please, exhibit 006.
- Margaret, would you be able to read out to us the bottom sentence of the top
 paragraph that's been bolded and the next sentence, so starting with "We all know"?
- A. "We all know that drugs are either unhelpful or poorly tolerated in her case. I also find that drugs are rarely a satisfactory solution to the problem of hyperactivity in our population but are frequently used because there are no alternatives."
- 9 **Q.** Thank you. Just to set this in some context, can we please see the exhibit date, or if that highlight could be taken down so we can see.
- 11 A. 8 June 1995.
- 12 **Q.** Thank you. And who is named as writing this letter?
- 13 A. That was Dr Warwick Bennett.
- 14 **Q.** He was the Medical Superintendent at Kimberley?
- 15 A. He was.
- 16 **Q.** So despite your father having these conversations and an acknowledgment that the drugs 17 were not working, did Irene continue to be medicated or over-medicated at Kimberley, or 18 did things improve?
- 19 A. She continued to be over-medicated.
- 20 **Q.** Why do you think that was, what factors contributed to that?
- I think there was a high turnover of staff, so there were not people who got to know Irene so that they knew how to deal with her. I think it was expedient, there was talk at the time that the night staff liked to party, so they liked to have the drugs so that the residents were quiet.
- 25 **Q.** Be quiet and by that do you also mean subdued effectively?
- 26 A. Subdued.
- 27 **Q.** In the later 2000s when Irene was weaned off the drugs, what did you observe when she came off them?
- A. She stopped falling, she was very happy, she was more alert, she was so alert and she wanted to eat. She was so alert and so interested in food the caregivers at her house had to lock their cars because she would go into their glove boxes to get their lollies.
- 32 **Q.** So her appetite had returned?
- 33 A. Totally.
- Q. In terms of the drugs she was on at the time, can you list out any of those that you know?

- 1 A. There was a concoction, the worst one was Mellaril. So that one was absolutely the worst.
- There was also Carbamazepine, Cisapride, Cogentin, Benztropine, Fergen, Clonazepam,
- Doxepin, and they had all sorts of side effects such as drowsiness, nausea, fatigue,
- 4 coordination disturbance.
- And the one that you said was really not tolerated well by Irene, Mellaril, that's an antipsychotic medication. Has Irene ever received any psychiatric diagnosis?
- 7 A. No.
- 8 Q. I'd now like to move on to another important topic of your evidence which is the physical
- 9 abuse and the assaults on Irene while she was at Kimberley. While Irene was at Kimberley,
- were you or your parents aware that she was being physically assaulted?
- 11 A. Never. Had they known I know my parents would have taken her home, it would have
- been very difficult, they would never, ever have allowed her to be in such a situation.
- 13 Q. The statement that you've provided to the Royal Commission, again on this topic lists a
- number of examples of assaults or attacks on Irene. This is on page 9. I'd ask you to
- highlight some of those to us, please.
- A. Scratched under the left eye by another patient; Irene was kicked by another patient on her
- nose causing it to bleed; another patient pulled Irene's hair and banged her head against the
- wall causing her nose to bleed; another patient pulled Irene's hair on two occasions; pulled
- Irene's head first to the ground and punching her on the face continuously causing grazing
- 20 to Irene's forehead; Irene was attacked by a patient and had a cut lip as a result; she was
- also hit by another patient on the head; Irene was attacked by another resident and again,
- required sutures; she was bitten on the nose by another resident; she was bitten on the chin
- by another patient; quotes from her records say "consistent with injuries caused by,
- 24 assaulter needs full-time supervision, not to be left unattended; two assaulters were known
- for unpredictable and unprovoked behaviour; aggressive peers." A review of an incident
- recommended that staff review Irene's placement within Hawea, or possible transfer to
- another unit to prevent further injury occurring. She wasn't moved.
- 28 Q. So the information you've just shared with us was reviews or audits that were taken,
- 29 undertaken by the hospital but nothing changed?
- A. No, and sometimes the reviews were quite some time after the event. Once it was two
- 31 months.
- 32 **CHAIR:** Could I just ask a question, sorry to interrupt. Did you know about or did your family
- know of the reviews at the time or is this --
- 34 A. No.

- 1 Q. -- what you've learned subsequently? So were you ever told of the outcome of the reviews?
- 2 A. No.
- 3 **Q.** Thank you.
- 4 **QUESTIONING BY MS THOMAS CONTINUED:** Is there anything else that you've learned through reading the files around safety measures or safeguarding or any plans or strategies
- that the staff put in place to try and prevent these assaults happening?
- 7 A. We knew this one. The answer was, and I think it was 1997, Irene was provided with
- padded rugby headgear and she wore that continually, all day, every day, and it was even
- 9 written on her files that it was suggested she wear it in bed to keep her safe in bed. Her
- injuries continued despite the headgear.
- 11 **Q.** So the solution from the hospital's perspective was to provide the victim of the assault with
- a headgear?
- 13 A. The aggressive peers that they describe seemed to have nothing happen to them. Irene had
- to wear the headgear. I wouldn't like that, I can assure you. We got used to seeing this
- frail, determined little poppet going around with this huge headgear -- and to wear it in
- bed?
- 17 Q. When you visited Irene at Kimberley, did you ever see physical violence occurring
- vourself?
- 19 A. I did. So usually the door of the wards were, or the villas were locked and we had to knock
- or ring a bell, and someone would let us in. I went up, I was in my teens, I drove up to get
- Irene and the door was open, so with the insouciance of a teenager I went straight in and
- I went into the day room and lying on the floor, naked, was a resident and a caregiver,
- 23 nurse, I have no idea which, but a very big man with boots on was kicking her as hard as he
- could in the side. I was extremely upset about that. I collected Irene, took her home, asked
- 25 my parents to make a complaint. And that's when I found out about the climate of fear
- about complaining about anything because it would be taken out on your child. They didn't
- complain. I'm complaining now.
- 28 Q. So at that time you asked your parents to complain about what you'd witnessed, but they
- were reluctant to do that because of the fear of repercussions?
- A. Mmm. I wasn't privy to the discussions, but I do know that one of their friends who had,
- one couple, they had a child in Kimberley and I believe there were repercussions on that
- 32 child when they made a complaint, but I don't know the details of that.
- 33 Q. I'm going to ask you now about seclusion.

A. I did not know about seclusion until I read the files. I might add at this point that when
I read the files I had been so shocked that I have actually -- I was diagnosed with vicarious
trauma. Irene is more precious in a way than one of your own children, and I have
children. You always know that your children are going to become independent and grow
up, and you absolutely love them to bits, but this is a lot stronger because you know they
are never going to grow independent so the love is fiercer, you're far more protective.

You know with your children that if you die you can trust other people to look after them. With Irene I can't. And she has - she's like a toddler and to put somebody who is claustrophobic, or was, in seclusion where it wasn't even a safe environment, is reprehensible. Once she was in seclusion for eight hours. Another time she came out with an injury. She was secluded -for - 13- times that are written down for getting up early in the morning. So if we recall that people in institutions are in bed early, and I would suspect 7 o'clock would be a late evening for Irene, 13 times she was put in seclusion for getting up between 5.00am and 10 to 7.00am in the morning.

- 15 **Q.** So she was an early riser and --
- 16 A. I'm an early riser, it runs in our family, but she'd already been in bed for 10 hours.
- 17 Q. And was put in seclusion when she woke up early, according to the rules of the --
- 18 A. Yeah.

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- 19 **Q.** -- hospital?
- 20 A. And that would be so frightening for her.
- 21 **Q.** And I think you've also mentioned on at least one occasions that's noted in the notes she came out of seclusion with an injury to her chin?
- 23 A. Yes. So it wasn't even a safe environment.
- Q. And on another occasion she was in seclusion for a very lengthy period?
- 25 A. Eight hours. And that was written down. I can't bear to think what hasn't been written down.

 26 down.
- 27 **Q.** In your statement you've summed up your thoughts on Kimberley. Can you tell us what they are?
- 29 A. It's just one word, hellhole.
- Q. In terms of Irene's behaviour and skills for her 42 years at Kimberley, what do you say about those in terms of opportunities to thrive, living a good life?
- 32 A. She went backwards.
- 33 **Q.** So she regressed during her time there?

- A. Completely. And she was unhappy. If she'd regressed and she was happy, it would have been fine, but she had nothing, not even happiness, not a joy of food, no love, no decent medical care, and abused.
- 4 **Q.** You've said that later, so closer to the time when Irene was moved out of Kimberley, some things gave some small pleasures?
- A. Yes, it seemed to happen when they were starting the deinstitutionalising process. I could be being cynical, but you have to forgive me for being very cynical. When they started that process my parents had to become Irene's welfare guardians, and that meant finally the parents could have some say. So she would be taken on van rides or there would be some activities. I think they were tarting Kimberley up for the move into the community. But that's me being cynical I think, I don't know that.
- 12 **Q.** So in 2004 Irene was resettled or moved into a home in the community, an NZ Care home?
- 13 A. Yeah.
- 14 **Q.** What were your first impressions when she moved into that home?
- 15 A. We were thrilled. Lovely caregivers, lovely environment, a six bedroom home, three 16 acres- of land, she was free to walk out in the garden, have homecooked meals, sit around 17 in a lounge with carpet on the floor, it was really lovely-. And, you know, we had -- we 18 could talk to these caregivers who were -- they loved -- we really, some of them, a couple 19 of them, loved Irene, mmm.
- Q. So that was 2004. From March 2006 onwards, what did you notice when you would come and pick up Irene?
- A. So during this time my mother was dying of cancer and I would take Irene out, we always 22 took her out every week, I would take her out, and -- with my mother, we would take her 23 for a drive, she loves a drive, and as I was going out, a caregiver whispered to me "Lift up 24 25 her jersey". I don't normally think to lift her jersey when you take your sister out you don't automatically lift up her jersey, it was such a strange request, of course I complied, and 26 when I lifted it up I saw what were evidently carpet burns all over her front and back, and 27 when I investigated further, there were bruises around her wrist and ankles. So it wasn't an 28 isolated incident, it looked as though she had been dragged on a number of occasions, 29 which is incredibly dehumanising. 30
- And around about this time did you also observe -- were there some other injuries, head injury?
- 33 A. Well, I wanted to know what other injuries were because I hadn't been told of any injuries, 34 and I asked the middle manager if I could have Irene's records. They -- I was not able to

have those. She was extremely uncooperative and I found did not tell the truth, because her stories changed from time to time.

A caregiver, who was very brave, went into the house in the middle of the night when somebody he knew was on nightshift and copied the records for me. They were: Irene had a fall hitting her right cheek; Irene had abrasions on her right thigh; Irene had grazes under her right forearm; on 5 June, Irene suffered a head injury, a cracked chin and bruised eye, which -- for which she had to go to hospital and of course I was suspicious because she fell against a dresser but she had injuries on both sides of her head, which is almost -- I can't imagine how that could happen and neither could her doctor.

On another occasion Irene had a suspected broken arm by it being twisted up behind her back; she was also overdosed on drugs requiring her stomach to be pumped.

- Q. So this information was on the files that had been photocopied to give to you? 12
- 13 A. [Nods].

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- When Irene was sent to hospital with a serious head injury, did anyone contact you to let 14 Q. you know? 15
- No. 16 A.
- So you weren't able to be there with her? 17 Q.
- No, she went to hospital alone. I was not contacted. That broke my heart. A. 18
- Once you'd become aware of all of these things going on, did you make a complaint to NZ 19 Q. Care? 20
- A. Well, it was very difficult because I was not her welfare guardian, my father had died and my mother was the only welfare guardian, they were only allowed one welfare guardian at 22 the time. I went, first of all, to her doctor who explained that he couldn't speak to me because I was not her welfare guardian. I explained that my mother was dying of cancer 24 25 and he said I could talk to him but he could not talk to me.

I then decided I had to tell my mother what was going on, I was trying to shield her in order to get joint welfare guardianship, which is an unusual thing, but my lawyer petitioned the court to get joint welfare guardianship because we didn't want to take my sister away from my mother again.

In the meantime I contacted New Zealand Care and they were -- I can only describe the managing director as tardy in his response.

When that managing director finally did respond to you, what did he offer, what was his 32 Q. solution? 33

- A. Eventually, and this did take quite some time, he offered that Irene should be removed to a safe house, meaning that the other five people resident in her home would be in an unsafe house. So I refused that obviously and said they had to get this house right.
- 4 Q. Did the Police become involved in this complaint?
- Yes, I had left her doctor with asking him that every time Irene arrived into his rooms that he wouldn't just treat her for what she was there for, that he was to examine her thoroughly.

 And he found evidence of harm to Irene and he contacted New Zealand Care and said that either they called the Police or he did. New Zealand Care chose to.
- 9 Q. So once the Police were involved did they investigate the abuse that Irene had been --
- 10 A. They were fantastic. They had covert cameras in her room and the problem with this is that
 11 the abuse would have had to have happened in Irene's room. When he interviewed the staff
 12 the ones who had caused the harm were hardly going to tell the truth. At nights when
 13 injuries sometimes happened there was only one person on nightshift, so there would be no
 14 witnesses, and Irene has no voice. She made her wishes known of how she disliked certain
 15 caregivers though.
 - **Q.** So what was the outcome of that Police investigation?

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17 A. They couldn't provide evidence of anything, but we certainly furthered the cause of
18 New Zealand Care getting it right, and they have got it right now. It's no longer
19 New Zealand Care, it's under a new name, but they certainly got it right, I was involved in
20 choosing staff for the house. They finally got procedures in place. Prior to that there had
21 been no audits, so I think it was two years after Irene was deinstitutionalised that the first
22 audit was in place.

So if I can just go back to when Irene was at her most vulnerable in this New Zealand Care house when I was not her welfare guardian, my mother was dying with cancer, she also, her court-appointed lawyer had become -- gone to Whangārei to become a judge so she had no lawyer. So I then went to the court where there was supposed to have been a report sent each year from NASC I think it is, it's called, and they were to have provided this report and that hadn't been done.

So there were a whole lot of things, the policy -- the procedures had not been put in place, and Irene was left without anybody to advocate for her, which should never happen. Irene's got me to look after her. The other residents did not and they don't in other houses either, and we must never leave these people without an advocate. So many have no families to speak of. Who cares for them?

1	We have a collective responsibility to care for them and make certain they ha	ıve
2	someone to look after them.	

- The Police investigation did not result in a prosecution, but can you tell us what happened to the particular staff members involved with NZ Care?
- 5 A. There were three people who lost their jobs at this house, one was the middle manager.
- I know that person was moved to another place to manage houses. She was in charge of
- three houses and I believe she was moved to another area still to work for New Zealand
- 8 Care. And I think the others were moved sideways as well. I'm not certain of that.
- 9 **Q.** So this was -- these were incidents that happened in 2006. Were there some further incidents in the NZ Care home in 2013 and 2014?
- 11 A. Yes, there were.
- 12 **Q.** Can you tell us what happened in 2013?
- I was advised in 2013 by a caregiver that Irene's nose was bruised and swollen. The

 caregiver said that Irene went to bed with no injury but had a broken nose in the morning,

 which I did not believe. And I was later proven correctly and the manager of the house had

 lied about that.

And again, you might think that you hear that your sister has a broken nose, you accept that, but I now don't take anything at face value and haven't done for a very long time. I investigate. And I was particularly lucky because Irene had had her hair done by her hairdresser and she had to rest her hand on Irene's nose in order to cut her fringe and we established when her nose had been broken. So Irene went for several days with no painkillers.

- 23 **Q.** So went for several days with a broken nose and no painkillers?
- A. And I was lied to about when it happened. So I don't know, but I may well have been lied to about how it happened.
- Q. Did you complain to NZ Care about this situation, did they address this?
- 27 A. I did complain and they took it very seriously so I took it no further.
- 28 **Q.** Right.

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- 29 A. Then in 2014 I received an anonymous letter from a staff member at Irene's house.
- Q. I might just ask if it's all right for that letter to be put up on the screen?
- 31 A. Yes, by all means.
- 32 **Q.** Is that large enough for you to read?
- 33 A. Yes.
- Q. Could you read that full letter out with the date?

A. 21 October 2014. "Dear Margaret, as both an employee at the care home and an advocate for Irene, I feel it is important that you are made aware that the caregiver has returned to work full-time hours at the house.

The caregiver was previously employed at another New Zealand Care house, namely -- another one in the area. She was removed from this house after a very serious complaint of alleged abuse was laid against her. There were many staff members who signed statements advising they had witnessed verbal, physical, mental abuse against a particular client who the caregiver had taken a dislike to several years before. Having worked with this caregiver when she first came to our house and again just recently following her long absence due to illness, I have major concerns for the safety of our clients. These concerns have been voiced by several other employees, but we have been told to get on with it, and that her return is an order that has come from top management.

I do intend to bring my concerns to the attention of the Ministry of Health and other interested parties, but out of respect I wanted to include you in this matter.

I do not feel able to include my name, sorry Margaret. After seeing the treatment dealt out by the caregiver to the staff members who laid the first complaint, I would actually feel genuine fear for my safety. I trust you understand. Thank you."

- **Q.** Thank you, Margaret. How did you react when you received this letter?
- A. I contacted one of the middle managers of New Zealand Care who really laughed it off and said a lot of people had received letters. I didn't feel it was taken seriously. Then I spoke to a caregiver in the house that I did trust, and I always make it a point of having caregivers in the house that I trust, and happily now I trust them all -- it's been hard won. And that caregiver explained that the contents of the letter were true but that this caregiver of concern was working in a monitored situation and was never alone with residents. And this caregiver promised to advise me if there were any incidents. So I decided to leave it until I had reason to complain and I didn't. But I was extremely unsettled by that letter.
- **Q.** You mentioned earlier that you now have some input into the care home and staff that are appointed there. How did that come about?
- A. The managing director of New Zealand Care, the original one that I didn't take to and didn't think -- and was tardy in his response, employed a person, a woman who is now, I think, the managing director of this new group. And this person has a very good heart, she is very competent and she was trying, I think, to make me feel included. She knew where we should be going and I think she felt that she was giving me back some input into my sister's life and that was the right thing to do, yeah.

- 1 Q. In terms of Irene's caregiving situation today, how do you feel about that?
- 2 A. Oh, we're so blessed. Anita has travelled to Auckland with us, we had to drive up from the
- 3 Kapiti Coast. New Zealand Care released her, thank you. The caregivers are fantastic, and
- 4 it doesn't matter how fantastic they are though, I'm still on high alert in case there is a
- reliever there, people get sick, and I go at different times, when I pick up Irene, I'm always
- looking to see if there's anything that's not being done correctly, I don't want to be like that,
- but I feel I have to be no matter how good it is. I have to rebuild my trust, and Irene's life is
- only as good as the caregivers who are looking after her. And if Irene isn't cared for
- 9 properly, then my life isn't too good either.
- Q. Can I ask you about an incident that happened recently in 2020 in terms of medical care
- that was being sought for Irene?
- 12 A. Yes, I had a call from Irene's GP who said that her iron levels had dropped very suddenly
- and were critically low and that he was, from past experience he was absolutely convinced
- that she was showing signs of upper gastrointestinal cancer and that we needed to have her
- assessed urgently. And I said that this could be difficult assessing Irene and that we would
- pay for a scan if necessary, whatever was the easiest way and he said there was no need,
- when he made something urgent the patient was seen by the public hospital within a week
- and this was urgent, and that's what he would do.
- 19 **Q.** So that letter was then sent as a referral?
- 20 A. Yes.
- 21 Q. At the top of your page 15 of your statement is there a paragraph --
- 22 A. Yes.
- 23 **Q.** --from the letter that you then received about that referral?
- 24 A. Yes. This was to her GP: "You have not provided a good reason to further investigate this
- 25 finding in this patient and provided no indication how this might be humanely achieved.
- We have limited clinic space and it is not a good use of that space to be assessing patients
- for suitability for endoscopic exams. If there is a physician more familiar with her care
- 28 then you might wish to consult that person."
- 29 **Q.** How did your GP and yourself react to this letter?
- A. My GP who is also a lawyer and an incredibly humane man with a huge social conscience
- who never rocks the boat, he was completely shocked and his advice was that I go to the
- 32 press.
- 33 **Q.** About this response?
- 34 A. Yes.

- Q. Is that the step that you took at that point, or did you choose something else?
- A. No, I prefer not to go to the press. Because I -- pardon, sorry, press, but I have found you very useful to keep in the background. That's, you know, Parliament or the press are my backstops, I try to change things first. And I decided to make a complaint.
- **Q.** How did that go, making that complaint?

A.

Q.

It's really interesting, because the head of department tried to get me not to take it any further. I wanted to speak to the specialist concerned, because I wanted to have some sort of restorative session where he could see the error of his ways and how upset he'd made us and change it so that it didn't happen to someone else again. And his head of department spent a considerable amount of time on the phone to me, and then it transpired she hadn't even told him about this complaint. I suspect it was because she didn't want to lose this person, they're short-staffed. And I said I was really sorry, she needed to put her brave shoes on, tell him about it, because if I didn't get this restorative session I would definitely be taking it further.

So she did put her brave shoes on. I did talk to the specialist, a very long talk, and it was -- he completely apologised for that. He assured me he hadn't meant it in the way that it read. I took that at face value. And, more importantly, protocols were changed so that now one person doesn't have that form of control, they have a group of people making those decisions at [GRO-C].

So the restorative thing that made me feel better was that things changed.

Miraculously -- so sometime during that Irene had become acute, and that is another story of how Irene and I were left in a side ward with not even a glass of water, we couldn't go to get it, there was very little understanding of how to treat a person with Irene's disability in that public sector at that time for me on that day. So, miraculously, we had meetings about palliative care and how we were going to treat Irene in her own home because the specialist I saw was convinced it was the same thing. We decided not to investigate further because it would be too invasive for her and if they found out it was upper GI tract cancer, the treatment was so awful it would have taken away her quality of life. So I decided to let nature run its course. And here she is. After a blood transfusion and something to help her stomach that her doctor has given her.

Can I ask you to talk to us now about the impacts of her experiences at Kimberley and those at NZ Care, the impacts that they've had on Irene? And I might ask for -- there's a photograph I think that was taken that you took of Irene. Was this in the late 1990s?

A. Yeah, I'm not entirely certain. We have very few times of Irene when she was at -- looking her worst. This was a good day. And it would be late 1990s, maybe early 2000s and we destroyed -- Anita destroyed one photo that wasn't as good as this one, and we just didn't take photos because she looked so dreadful. But this photo, she was in the car, when she came home her only safe place to be I think was in the car because she had control over that environment, so she was only settled when she was in a car. And she could see who was in the car, she was in control of that environment.

When I look at that, she doesn't look as thin as she was, but I look at the hopelessness in her eyes, and the spaced-outness, the drugs. It makes me feel very sad.

- **Q.** And you've mentioned the drugs. In terms of significant impacts on Irene's life, how would you describe the drugging?
- 12 A. She lost around 20 years of her life. There was no quality of life for her at that time.

Α.

- **Q.** Any other significant impacts that you would like to describe about Irene, the impacts of this care?
 - A. I think the neglect and the lack of love which I keep coming back to has made her less trusting of people. I think that is building up again now, thanks to the stability of her caregiving, the workforce in that house, which I would say now is a model house and that every care home should be looking at that home as an ideal. But Irene used to be very warm and cuddly, and that's going to take time. We've been working on it now since 2004, we're getting there, but it's not where it was.

I think, like me, I think she lost her trust in people. I think she had -- she existed, and how she existed I have no idea. How she survived, I have no idea. She has a resilience that is remarkable.

Q. Can I ask you to also tell us a little about some of the impacts on you?

Well, when I read the files the vicarious trauma was a surprise and not a particularly welcome one. I think when you love someone so acutely and feel so responsible for them, you cannot live your life happily at all. So I have always felt I have had to be thinking about Irene, it underpins every single thing. And yes, it stressed me out. Anybody who's had psoriasis will know that comes on from stress. I've had that. Anybody who has had shingles will understand that's brought on by stress often, and I've had 14 doses. So I think the stress of being on high alert and looking after Irene and never being able to relax or enjoy my life fully unless she is, has had a huge impact on me.

This is Irene's story, but I can only say that I'm very happy my parents weren't alive to hear the extent of what I've had to face with knowing what's happened to Irene.

1		I'm almost certain that she remembers some of it because when I talk to her
2		caregivers about it in front of her, I don't talk about it behind her back, her whole
3		demeanour changed, and I could see her well-being reducing when I talked about it at first.
4		We have no way of knowing that's true, but I've been interpreting her wishes and feelings
5		for a long time, and I would lay odds.
6	Q.	Has this left you angry?
7	A.	Yes. And my anger will not go until I'm able to forgive. And I won't be able to forgive
8		until there's an acknowledgment of the inhumanity towards Irene and others in her
9		situation.
10		I was doing so well until then.
11	Q.	You're doing extremely well. Would you like to tell us something about the things you've
12		mentioned in your statement here in terms of looking forward, the training of staff and what
13		thoughts you've got on those topics?
14	A.	Yes. Well, interestingly enough, the training, it seems to be up to the caregiving
15		organisation to organise the training. There is a national certificate and I believe for people
16		like Irene, the training will go there's level 3, level 4, but no level 5. For example, Anita
17		has asked each time in her review for more training. To get a level 5 qualification that had
18		to be found and done by correspondence from Ireland. New Zealand doesn't have the level
19		5 training for people like Irene. So the training needs to be there. And I think this is an
20		area where the Government has to take more control over the training and the salaries,
21		because too much has been devolved to private enterprise.
22		New Zealand Care is now very good. I don't know about all the houses, but
23		I suspect they're pretty good now. We need to make them all like that. How can we do that
24		without monitoring by the Government? So going back to the caregivers, I've digressed. In
25		order to have happy residents, we need to have a stable workforce. In order to have a stable
26		workforce, we need to have a career path. We need to recognise that somebody has been
27		there and give them an increment for how long they've been there, like they do with
28		teachers. If they get an extra qualification, they need to get a salary rise. I don't think that
29		happens in a lot of places at the moment.
30		I'll just check to see if there's anything that I have missed there, if you'll excuse me.
31		Yes, I did.
32		I've had experience with caregivers and at one stage seven out of Irene's eight

caregivers resigned in a period of seven to eight months, I can't remember exactly. That

was because of a very poor middle manager. So it's not enough to have caregiver training, you must have middle management training as well.

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We need to professionalise the sector. We need to put money into it. They are professionals. They will be qualified eventually, they need to be recognised for their service and also for their qualifications.

- Thank you. Also in terms of, there's some comments in your statement around audits and oversight. From your experience with the NZ Care home and auditing, do you have any comments on that?
- Yeah, I think the entire process of deinstitutionalising was done too quickly and things 9 A. weren't put in place, most notably the checks and audits. They're there now, but it's like, 10 you know, I was -- I am a teacher, I keep forgetting that, we know that ERO, the old 11 inspectors, are arriving and what do you do? You tart the place up, you will get prepared, 12 you know exactly what they're looking for. And it's the same for the houses. They're 13 audited, they're inspected, but they know they're happening, I presume they know what 14 they're looking for. And I think these homes should be open at any time to somebody 15 wandering in and checking them. We're protecting vulnerable people and we have to have 16 the systems -- you have to have the systems there. It is an utter place, I think, for 17 government control, setting the wages, setting the salary scales, setting the qualifications. 18
- 19 **Q.** Finally, just on your last page of your statement under the "conclusion" paragraph, if you could read to us your two final sentences, please.
- 21 A. "Irene never deserved to be hurt or frightened. She deserved to have the best life that was 22 available to her, but this has not happened for most of her life. I've spent my life fighting 23 for Irene and I'm tired. I can only hope that this Royal Commission will lead to change in 24 the disability care system."
- 25 **Q.** Thank you. I understand in preparing for your evidence today you have actually prepared a final few paragraphs that you would like to read out to the Commissioners now.
- I have spoken not only for Irene but for all those who do not have a voice or family to
 speak for them. Irene's disability was caused by an eminent specialist applying forceps in
 the wrong place during her birth. The medical profession then appeared to close ranks, as it
 didn't diagnose Irene's disability, although it was immediately obvious to an overseas
 physician. There was no other place for Irene to go except Kimberley. For that, she had to
 be made a ward of the State.

My parents trusted the State to care for Irene. It did not. I know she was abused in many ways. I also know she would have been abused in ways I do not know. Medical staff

knew of the abuse. This did not stop the abuse. When she was deinstitutionalised she was abused by caregivers in her own home. In her current home where she receives the level of care that is her right, she is very happy.

I weep for the fact that for 44 years she did not enjoy this right. And the pain it has caused her, my parents and me. I would have expected that at some stage in Irene's life, someone at sometime or maybe a lot of people many times should have said "sorry".

In my experience emotionally mature people are able to apologise and then all parties are able to begin the process of healing. That has not happened at any stage of Irene's life, or of mine. It has been inordinately difficult for our family to heal without an apology. As Gandhi held to be true, the true measure of any society can be found in how it treats its most vulnerable members.

I would ask everyone listening to reflect upon how poorly our society should be rated on how it allowed Irene and her fellow survivors to be treated. Nothing will ever change what has happened to Irene. The only acceptable form of apology will be the changes that must be established, monitored and continually improved so that such abuse never occurs again.

- **Q.** Thank you, Margaret. I'll just see if any of the Commissioners have any questions that they may have for you.
- **CHAIR:** Are you up to that, Margaret?
- A. Give me a minute.

- Take a breath, take a breath. If you don't want to take questions we would quite understand. We can always give them in writing to you and you can do them later; would you prefer that?
- A. No, I can do it, it's part -- I believe this is part of the healing process.
- I do hope so. It seems to be a painful way to heal if I might say so, but we really appreciate what you're doing for us. I've got a question, and it just relates, because part of this forward-looking view, it relates to your quite adamant and forceful advocacy for the Government to take control. And I heard why, to do with training, career paths, oversight. And we hear that message. Can you, and very shortly, tell us why that is so important, what is going wrong now that it needs that in your view to be taken over by the Government?
- A. Because I trust the Government. They are answerable to the people. The care agencies, no matter how good they are, they are still profit-making enterprises. The Government is a constant, the people in private companies are not. The standards have to be set by the State

- I believe. I cannot trust, any longer, private organisations. I know there will be some good ones, but I cannot trust them to provide the constancy that is needed here.
- 3 **Q.** And the consistency?
- 4 A. Totally. It must be consistent. What has been done for Irene must now be done, or ensured that it's done for everyone.
- Thank you. Thank you for that response. I'm just going to check with Commissioner Steenson, do you have any questions?
- COMMISSIONER STEENSON: I do have a couple, tēnā koutou, tēnā koe, Margaret, tēnā koe,

 Irene. Thank you for your fulsome evidence, extremely helpful. So my question is -- I

 have two questions. My first question is around, you mentioning that medical staff knew

 about the abuse but that didn't stop the abuse. Do you have views on why that's the case?
- I think that often -- I know what happened in the New Zealand Care home, that the staff didn't have an avenue to complain or to make comments. Often medical staff are scared to complain. In Irene's case, the Medical Superintendent at the time, Warwick Bennett, and others, I can't remember their names, but I know my father used the word "arrogant" many times. He knew best and if that was happening that was just how it happened, that's what these people were like. And I think -- I think a lot of things would have been excused by them being under-staffed, amongst each other. I don't know.
- 19 **Q.** Okay.
- A. It's inexcusable to me.
- 21 **Q.** Right.
- 22 A. But they knew and they didn't stop it.
- Q. Okay. So a combination of perhaps an arrogance and also a lack of a whistleblowing safety process?
- 25 A. Yeah. Yeah, maybe a lack of passion for -- maybe it was just a job, maybe they switched
 26 off when they went home. I know they probably needed the job, it was slightly better paid
 27 in psychiatric care, I believe. You know, the over drugging for example, I consider that a
 28 form of abuse, maybe it gave them peace to party at night, as the rumour said. I don't
 29 know.
- Thank you. Then my second question just relates to forward-looking as well, because you talk about Irene's current home as being ideal?
- 32 A. Mmm.
- 33 Q. It would be good to hear, in your view, what are the factors that make it that way?
- 34 A. She's loved.

- 1 **Q.** By the -- it's all to do with the caregivers?
- 2 A. Absolutely. All to do with the caregivers. They love her. They cook lovely meals for
- them. It's a home atmosphere, they feel safe. Their wishes are acknowledged. They bring
- in -- like, we organise Irene can get her hair done now, and I want to point out there that
- Irene's pension isn't quite \$70 a fortnight, she can get her hair done, and manicures,
- pedicures, whatever, because we have the money to pay for it, others don't have that. And I
- 7 think they deserve a bit more of a pension.
- 8 **Q.** Okay.
- 9 A. So having those things, it makes -- the caregivers are the main thing, but she can live as
- near a normal life as she ever possibly can. Her potential is being realised, Anita takes
- Irene, she recognised that she likes art and will focus longer if she is looking at a painting,
- so Anita takes her to look at sculptures, to the museum, she takes her to concerts.
- 13 Q. So the way that the staff are treating her, what is it that makes them better, is it that
- the -- their -- the way the house is run, the governance, or what is it about that that
- makes -- have you attracted better staff?
- 16 A. They have a wonderful team spirit in that house, the caregivers have been together for a
- long time. I know that after I kicked up quite a fuss the staff in that house were paid
- slightly more, or the manager certainly was, they got in the best manager that they had from
- Hawke's Bay to get the systems right. I believe they have avenues for complaints,
- 20 they -- the staff enjoy their job because they're working for an enlightened organisation.
- 21 Q. Right. Great, that's great, thank you. Tēnā koe.
- 22 **CHAIR:** And I'll just ask Commissioner Gibson for his questions and to thank you.
- 23 **COMMISSIONER GIBSON:** Yes. Thank you, Margaret, Irene. I've got a few questions. First,
- just how much money is available to Irene? Is she eligible for National Superannuation at
- 25 the moment?
- A. Yes, but her wage didn't go up because a lot of that is taken out for her care. It's written
- down, can anybody find how much it is? I think it's \$68 a fortnight, was it? Yeah, she
- 28 gets.
- 29 Q. So not as much as available to her as others, non-disabled people under that scheme; is that
- right?
- A. No, the rest I sign over to New Zealand Care for her, well, her housing, her board. So her
- pocket money is that \$68, I think.
- 33 Q. You talked about problems with guardianship advocacy. Irene is very lucky to have a sister
- like you. What are the changes do you think need to be made with that system, with those

systems, and in particular how can disabled people without strong advocates as family members be better supported, kept safe?

A. Everybody, every resident should have a welfare guardian. My thought is if possible they should have joint welfare guardianship, guardians, because of what happened when my mother was dying. There was no-one to take her place. Or every person, disabled person should have a court-appointed lawyer. And it should be somebody I think that the person, if they are able, should be able to choose.

The court-appointed lawyer that Irene has, and he was only appointed because I made changes by applying for that welfare guardianship, his first words to me were in a sentence, he said, "I don't know why you want this job, you'll get nothing for it." Why would I want a lawyer like that representing my sister? I would have liked to have chosen my family lawyer, or someone I knew and trusted and liked, to represent Irene. And if residents or people like -- disabled people are able, they should be able to have a trusted lawyer if they haven't got a family member to help them, or advocate for them.

Q. That part of the system needs to change as well?

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- A. Absolutely, you cannot leave someone like Irene who is unbelievably vulnerable, she's as vulnerable as a baby. You cannot, you would not leave a baby without someone to look after them. Irene, through the fault of the system, was left with no-one to advocate for her. I would expect that there are a large number of people at this moment who don't have advocates. That's why I'm speaking, it's not just for Irene, it's for all those others.
- Q. A final question. You talked about the role of Government and trust in that, which seems to be very generous given what you've experienced over the years, but also, as I understand it, NZ Care is a private organisation, which itself seems to have reformed or transformed especially around the house that you and Irene are familiar with. But you still think that there's not a role for private providers?
- A. I think there's a role for private providers, but they have to abide by national standards.

 You know, it's the Government qualification, the Government sets the standards and the
 private organisations measure up to them because they're audited. The final arbiter of the
 standards must be, I think, the Government.
- Yeah. It's just left to me to thank you now. First, can I acknowledge what both you and Irene, what looks like half a century of more of inhumanity, I can't say sorry, apologise on behalf of the Government, but you are so deservant of that apology and more. Thank you, your evidence is so important, so much a lost story of so many years. Thank you, Irene, for teaching us about resilience, about hope, about how survivors can be survivors.

Lunch adjournment from 1.10 pm to 2.23 pm

1		And thank you, Margaret, for teaching us about being a sister and a supporter.
2		Thank you, and we look forward to that day where you actually will receive that apology.
3		Kia ora.
4	CHAI	R: Thank you, all, very much, that brings us to the end of the morning's proceedings. You
5		can go and have a well-deserved break. Do take advantage of any well-being that we can
6		offer you, there's plenty there and we want you to use it for both you and Irene. So please
7		take advantage of that.
8	A.	Thank you.
9	Q.	We will adjourn.