

MUCKAMORE ABBEY HOSPITAL INQUIRY
SITTING AT CORN EXCHANGE, CATHEDRAL QUARTER, BELFAST

HEARD BEFORE THE INQUIRY PANEL
ON TUESDAY, 10TH OCTOBER 2023 - DAY 65

65

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1 THE INQUIRY RESUMED ON TUESDAY, 10th OCTOBER 2023 AS
2 FOLLOWS:

3
4 MR. DORAN: Good morning, Chair. Good morning, Panel
5 members.

10:09

6 CHAIRPERSON: Good morning, hold on one second, sorry.
7 Yes.

8 MR. DORAN: Chair, there is a Restriction Order
9 application in respect of this morning's evidence.
10 This morning P117's mother and father will be giving
11 evidence to the Inquiry.

10:10

12 CHAIRPERSON: Do you want me to make a temporary
13 Restriction Order on this application?

14 MR. DORAN: Yes indeed.

15 CHAIRPERSON: so following the usual form I'll
16 temporarily place a Restriction Order just on the
17 application to ensure that if I do make an order it
18 will be effective.

10:10

19
20 THE HEARING WENT INTO RESTRICTED SESSION

10:10

21
22 THE HEARING WENT INTO OPEN SESSION

23
24 CHAIRPERSON: Is there somebody in the room who will
25 communicate to the PPS that the solicitors to the
26 Inquiry will write to them today?

10:28

27 MR. DORAN: Yes, we can ensure that that happens,
28 Chair.

29 CHAIRPERSON: Thank you.

1 **SECRETARY:** Just explaining, Chair, I have put some
2 ticks against the paragraphs what are going to be read
3 in open.

4
5 **P117'S MOTHER AND P117'S FATHER SWORN AND EXAMINED BY** 10:29
6 **MR. DORAN AS FOLLOWS:**

7
8 **CHAIRPERSON:** That was P117s Mother who was sworn
9 first and P117's Father who was just sworn. Can I
10 welcome you both to the Inquiry. You and have I have 10:29
11 met on a number of previous occasions in fact. I just
12 want to welcome you, I'm glad that you have now come
13 through the door of the Inquiry and you can see it all
14 working and you are now going to have the opportunity
15 to give your evidence so thank you. I am going to hand 10:30
16 you over to Mr. Doran.

17 1 **Q.** **MR. DORAN:** P117's Mother, P117's Father, thank you
18 for attending to give evidence. As you know I am Sean
19 Doran, counsel to the Inquiry. We met this morning and
20 we had a chat about the procedures that we would be 10:30
21 following today. Like the chair I have also met you on
22 a number of occasions before, so welcome to the Inquiry
23 this morning. I think we met at one of the very early
24 engagement sessions; is that right?

25 A. We did. 10:30

26 2 **Q.** Now, we are going to be talking about your daughter,
27 P117, and specifically about her time as a patient at
28 Muckamore. We are using first names this morning. As
29 you can see, P117, has been given a cipher, P117 by
 the

1 Inquiry, but thankfully we won't need to use that
2 number during your evidence. P117 was at Muckamore I
3 think from April 1998 to March 2001, isn't that right?
4 And then August 2001 through to March 2018.

5 A. **P117's MOTHER:** Mhm-mhm. 10:31

6 3 Q. If you are answering me, one thing I should say is that
7 it's important that only one of the three of us is
8 speaking at any one time and that's because of the
9 stenographer who has to take a record of everything
10 that is said. So what I am going to do as I go through 10:31
11 the questions later is to address the questions to
12 P117's Mother, because I know, P117's Mother, you have
13 made the main statement. Then once P117's Mother has
14 given an answer, P117's Father, if you want to say
15 something else, just signal to me and we'll make sure 10:31
16 you are able to do what. It is difficult for the three
17 of us. Normally there is just counsel and the witness,
18 but we have to sort of make extra efforts to make sure
19 that we are speaking singly.

20 10:32
21 So, as I have said each of you have made a statement to
22 the Inquiry solicitors; isn't that right?

23 A. **P117's MOTHER:** Yep.

24 4 Q. And the statements are dated the 25th of September
25 2023. P117's Mother, do you have a copy of your 10:32
26 statement with you?

27 A. **P117's MOTHER:** I have. This one here, sorry.

28 5 Q. And P117's Father, have you a copy of P117's
29 mother's statement and your own statement to hand.

1 A. **P117's FATHER:** Yes.

2 6 Q. P117's Mother, is it fair to say that your statement
3 contains all of the detail?

4 A. **P117's MOTHER:** Mhm-mhm, yep.

5 7 Q. And P117's Father, you have essentially adopted 10:32
6 P117's mother's statement?

7 A. **P117's FATHER:** Yes.

8 8 Q. Can I just say something else, P117's Mother, it is
9 very difficult to get used to this but when you are
10 answering me can you make sure you say yes or no or 10:33
11 that you speak?

12 A. **P117's MOTHER:** Yes.

13 9 Q. Thank you for that. And the reason for that is that
14 the stenographer can't really pick up on nods okay?

15 A. **P117's MOTHER:** Okay. 10:33

16 10 Q. It often happens that a witness will nod to a question
17 and then one has to say can you say yes or no because
18 the stenographer needs to take the record. Now, as I
19 have said, the approach that we are going to adopt is
20 that P117's Mother will give the answers and then 10:33
21 P117's Father can add detail if you so wish, P117's
22 Father. Now before I go on to read the statement there
23 are a few other things that I need to explain. You'll
24 see in the statement that a number of staff members are
25 referred to by cipher? 10:33

26 A. **P117's MOTHER:** Yes.

27 11 Q. And I am only going to be referring to them by cipher,
28 is that okay?

29 A. **P117's MOTHER:** Yes.

1 12 Q. And can you also refer to them by cipher as we go
2 through your evidence?

3 A. **P117's MOTHER:** Yes.

4 A. **P117's FATHER:** Yes.

5 13 Q. I think you both have a list in front of you that gives 10:34
6 you the cipher key; is that right?

7 A. **P117's MOTHER:** Yes, yep.

8 14 Q. That's good. So if ever you want to refer to a member
9 of staff, you'll find their cipher number on that list.
10 I should say don't worry if you do happen to mention a 10:34
11 name, because we have a mechanism that allows us to
12 stop the clock, so to speak, and then we can start
13 again. So, don't be worried about that, it can be
14 tricky sometimes but we'll do our best.
15 10:34

16 Now, there is a final complication that I wanted to
17 talk about and I've mentioned this earlier on, and that
18 is that part of the evidence is going to be in open
19 session and part of it is going to be subject to a
20 Restriction Order. Restriction orders are imposed to 10:34
21 make sure that nothing is reported that might affect
22 the ongoing criminal proceedings in relation to
23 Muckamore. So, as you will understand, there is good
24 reason for restriction. But we're going to be able to
25 do a part of the evidence in open and I'm going to read 10:35
26 those parts in first and then ask you some questions
27 about it?

28 A. **P117's FATHER:** Yes.

29 15 Q. I think I explained earlier on the parts that I will be

1 reading in in open, so I am going to move now to read
2 the statement and I begin with the statement of P117's
3 Mother, which, as I have said, contains all of the
4 detail.

5
6 So the statement is dated the 25th of September 2023
7 and it reads:

8
9 "I P117's Mother, make the following statement for the
10 purpose of the Muckamore Abbey Hospital Inquiry. In 10:35
11 exhibiting any document I will number my documents so
12 my first document will be exhibit 1. My connection
13 with MAH is that my daughter, P117, was a patient of
14 MAH. I attach a photograph of P117 at exhibit 1. The
15 relevant time periods that I can speak about is the 10:36
16 22nd April 1998 to the 27th March 2001 and the 9th of
17 August 2001 to the 26th of March 2018.

18
19 P117 is the daughter of myself and my husband, P117's
20 Father, who is also providing a statement to the 10:36
21 Inquiry. P117 is the younger of our two children.
22 She has an elder sister called P117's Sister. P117
23 has diagnoses of epilepsy, learning disability and
24 behavioural problems.

25 In respect of my pregnancy and birth with P117 all was 10:36
26 relatively normal and straightforward. Whilst P117
27 seemed to be meeting her developmental milestones,
28 when she was about nine months old I began to notice
29 differences between her and her sister. For example

1 P117 never wanted to be cuddled or soothed with
2 affection in the way other babies that age would. At 11
3 months old P117 suffered her first seizure, both my
4 husband and I were present and P117 was on the floor
5 when she started fitting. She had a grand mal seizure. 10:37
6 I am epileptic and therefore immediately recognised what
7 was happening. My older daughter, P117's Sister, is
8 also epileptic. We brought P117 to the Royal Victoria
9 Hospital for Sick Children, Belfast, and she was tested
10 for epilepsy. P117 was diagnosed with epilepsy at 15 10:37
11 months. She has complex epilepsy and is on medication
12 to try and control her seizures. P117's fits are
13 different to those of her sister.
14 P117 has clusters of fits and has different types of
15 seizures ranging from stares and appearing vacant to 10:37
16 full tonic clonic seizures. Both P117 and P117's Sister
17 were prescribed Keppra Levetiracetam for their seizures
18 around 2000. To date this has kept them both seizure
19 free.

20
21 When P117 was about three years old she went to
22 playschool. She did not interact very much about the
23 other children. She sometimes wrecked the table. She
24 was verbal but she would get very agitated, she would
25 shout, she was disruptive, she was very active. By the 10:38
26 time she was five years old the health visitor had an
27 educational psychologist prepare an educational
28 statement. This enabled P117 to go to a school for
29 children with severe learning disabilities. P117
travelled to the school by bus. Both my husband and I

1 considered the school unsuitable as it was for severe
2 learning disabilities and we were concerned it would
3 not challenge P117 or help her to make the best of her
4 abilities. We subsequently decided to home school
5 both P117 and her sister and we engaged tutors to
6 assist, however we faced legal action by the Education
7 Authority for this and we were subsequently find a
8 pound.

10:38

9
10 We then moved house hoping to bring the children within
11 the catchment area for another school which was for
12 children with mild learning disabilities. The girls
13 did start at the school but it was not a successful
14 placement and after a year or so they both went to
15 another school which was also a school for special
16 educational needs.

10:38

10:39

17
18 P117 started at the school between the ages of 9 and 10
19 years old. This continued until she was 19 years old,
20 although there were periods when she did not attend due
21 to being suspended due to behaviour issues. As P117
22 got older her behaviour deteriorated and became more
23 accentuated. She could understand basic things, and
24 could read and write but there was definitely some kind
25 of intellectual disability.

10:39

10:39

26 Despite issues with behaviour, P117 was happy within
27 the family and had a happy childhood. At times the
28 sisters fought, particularly as P117 can be very
29 impulsive and had no sense of danger. However, there
was nothing out

1 of the ordinary for siblings and there is a genuine
2 affection between them.

3
4 P117 was admitted to MAH on 2nd April 1998 when
5 she was 12 years, nine months old for respite. This 10:40
6 admission was suggested by a social worker as it had
7 got to the stage when P117's sister was not getting
8 much attention because P117's needs were so intense.

9 P117 was admitted to Conicar Ward which was the
10 children's unit at MAH and rather old fashioned. She 10:40
11 initially stayed there from Sunday to Thursday every
12 week and spent the rest of the week at home.

13 Subsequently this was extended to Sunday to Friday so
14 essentially she had the weekends at home and we would
15 also visit P117 in MAH during the week. It was the 10:40
16 first time P117 had been separated from us. This
17 arrangement went on for about three years until she was
18 discharged on 27th March 2001.

19
20 Whilst P117 was in Conicar she saw a behavioural 10:40
21 expert... "

22
23 who you name in your statement.

24
25 "When we visited P117 when she was in Conicar she 10:40
26 seemed happy. There were times in Conicar when P117
27 had seizures and had to be admitted to Antrim Area
28 Hospital but we did not consider this unusual given
29 P117's diagnosis.

1 During this period of time we effectively shared care
2 with MAH. We were able to secure help for when P117
3 was at home. Agency care workers would come at the
4 weekends and would sometimes take P117 out to ensure
5 what she had the best possible time.

10:41

6
7 By August 2001 when P117 was 16 years old she had
8 become more aggressive. She would sometimes wreck the
9 house. She hit an agency care worker, myself and my
10 husband. We worried that she might hurt someone.
11 P117's sister was afraid during these episodes also.
12 We looked at different facilities in which to place
13 P117 but were unable to find anything suitable for her
14 specific needs.

10:41

15
16 On the 9th of August 2001 myself and P117's Father
17 telephoned our GP for advice on what to do. A social
18 worker came out to our home and documents were signed
19 to have P117 detained at MAH. The social worker took
20 P117 in a car and P117's Father and I followed behind
21 in our car. P117 was just 16 years old when she was
22 readmitted to MAH and detained under the Mental Health
23 Order. She was admitted to Fintona North Ward in which
24 the children did not have their own room but rather
25 they all slept in a large dormitory. We did not have
26 any experience of detention before this. We were told
27 that P117 would remain in MAH for a period of six weeks
28 for assessment. We were also told that we could not
29 visit P117 during this time which we found that very

10:41

10:42

10:42

1 difficult. I would telephone MAH to ask how P117 was
2 and to try and speak to her but the staff we spoke to
3 would not let P117 talk to us on the telephone.
4 After the six week assessment period had ended myself
5 and P117's Father visited P117. We felt what P117 was 10:42
6 okay but we thought what she had to remain in MAH as we
7 were told that it was the best place for her to receive
8 the proper treatment she required and to have her
9 medications adjusted appropriately. At no stage were
10 we told that P117's detention in MAH would be long- 10:43
11 term. We believed after treatment she would come home
12 again full-time.

13
14 We were able to bring P117 home most weekends from
15 Friday afternoon until Sunday evening after her initial 10:43
16 six week period, despite her remaining a detained
17 patient. There were no restrictions on what
18 activities we as a family could do with P117 during
19 this time at home.

20
21 P117 also attended a school for children with special 10:43
22 educational needs from MAH for a few days every week
23 between the ages of 16 years to 19 years old whilst she
24 was a detained patient. P117 was brought in a taxi
25 from MAH to the school. However, P117 did not settle 10:43
26 well in the school and this was when she was suspended
27 for bad behaviour which meant that her attendance at
28 school was on and off.

29

1 When P117 was 19 or 20 years old she was given a trial
2 period in a supported living facility for a few months.
3 This trial was unsuccessful because the other residents
4 seemed more subdued than P117 who could be very active
5 and so she did not fit in. Also, there were very few 10:44
6 activities for P117 there and staff did not seem to be
7 able to arrange any for her. During this time we
8 continued bringing P117 home at the weekend and would
9 have brought her to Newcastle for visits. When this
10 trial placement ended P117 was readmitted to MAH." 10:44

11
12 Now, P117's Mother and P117's Father, I am now going
13 to go forward then and start at paragraph 60 and read
14 in 60 to 70 and these paragraphs deal with the issues
15 of medication and discharge resettlement. I am also 10:45
16 going to read in 74 and 75.

17
18 "During P117's time in Donegore she was put on
19 Clozapine which we were told was part of an attempt to
20 reduce the cocktail of medication that P117 was taking. 10:45
21 We were told that there was a risk to her heart from
22 the Clozapine and that she would therefore need blood
23 tests every month to manage this risk. We were also
24 told there would be side effects at the beginning of
25 the treatment and so she was started on a dosage of 25 10:45
26 milligrams a day. As part of the adjustments to P117's
27 medication her Clozapine dosage was increased
28 frequently. She was at times over medicated as she
29 would be jerky and drooling which would not behaviour

1 that she would usually have. I contacted the
2 consultant Dr. H614 directly about the medication P117
3 was on and the effect it was having on her. At this
4 stage P117 was on over 200 milligram of Clozapine. We
5 were worried that P117 was going to have a seizure 10:46
6 because of the high medication level. I knew her
7 medication levels as we had to give her medication to
8 her when she came home at the weekends and so this
9 information had to be shared with us.

10 P117 had a grand mal tonic clonic seizure when her 10:46
11 Clozapine medication was at 400 milligrams. I cannot
12 recall the exact date this occurred but I was so
13 worried that I contacted doctor H614 directly. She was
14 on holiday at the time but assured us she would contact
15 MAH about the level of Clozapine being given to P117. 10:46
16 We can only assume that in response to this the
17 prescription was slightly reduced.

18
19 I remained worried about the possibility of P117's
20 Clozapine medication being increased again and so I 10:46
21 contacted everyone I could think of for help. On the
22 9th March 2015 I was due to attend a meeting at MAH
23 about P117's Clozapine. Prior to that meeting, I had
24 telephoned the Public Health Agency for assistance and
25 spoke to someone at the PHA." 10:47
26

27 who you name in your statement.

28
29 "I explained my concerns about the level of P117's

1 medication, including that P117 had a grand mal
2 seizure following the increase of her Clozapine to 400
3 milligrams. The person from the PHA I spoke to agreed
4 to contact MAH about this issue.

5
6 Both myself and P117's Father attended the meeting and
7 were told that P117 had been re-graded from a detained
8 patient to a voluntary patient. I was provided with a
9 letter dated the 10th March 2015 from the Chief
10 Executive of the Belfast Health and Social Care Trust,
11 BHSCT, which stated: "I wish to inform you that from
12 9th March 2015 the above named has been assessed as no
13 longer needing to be detained in hospital and is now a
14 voluntary patient." I attach a copy of Mental Health
15 Order discharge of 9th March 2015 at exhibit 15 and a
16 copy of the letter dated 10th March 2015 at exhibit 16.
17 We are suspicious of the motives of BHSCT sending such
18 a letter at the time.

19
20 After this meeting P117's Clozapine medication was not
21 increased again. I do remember that there were Mental
22 Health Review Tribunals before this meeting when P117
23 was reviewed to a voluntary patient but I do not recall
24 the detail of these or when the last one before this
25 one was held. Although P117 became a voluntary
26 patient in March 2015 no facility was provided to her
27 by BHSCT.

28
29 P117 was resettled on 26th March 2018 at a supported
living facility."

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which you mention in your statement.

"We had requested a home for P117 close to our home in Belfast. We had meetings with the resettlement team at MAH before she was moved to the supported living facility. P117 went for a trial in the facility which was supposed to be for one or two nights but P117 stayed on at this facility and refused to return to MAH once she started to stay there. P117 is happy with how she is now, certainly by comparison with MAH. Since P117 has been discharged the curvature of her back has improved. Her back was poor while she was in MAH but it was not an issue before she went to MAH. She is walking every day now which she was not able to do in MAH and is living a more independent life. After P117 left MAH between September, December 2018 she was treated for an extreme fungal infection in her ears at the RVH. This had never been diagnosed in MAH even though she had repeated infections in MAH."

Moving on to paragraph 74:

"Neither myself nor my husband have any confidence in the way that P117's medication was managed by the clinician at MAH. We believe there was an overuse of medication because it was easy when other methods should and could have been explored. In or around February or March 2022, I wrote to Sarah Meekin, a

1 *consultant clinical psychologist at BHSCT about getting*
2 *help for P117 who I believed was going downhill. Since*
3 *April 2022, P117 has had assistance from Caroline*
4 *Cafferty under the guidance of Sarah Meekin to help her*
5 *manage her emotional state. This is a service that I* 10:50
6 *had to work at to ensure that it is regularly provided*
7 *to P117. Also at the request of myself,*
8 *Dr. Dors is helping to wean P117 off the Clozapine that*
9 *had been prescribed and administered to her at MAH. All*
10 *of these changes have made a considerable difference and* 10:50
11 *I wonder about the difference for P117 if MAH had been*
12 *prepared to adopt this approach, especially the*
13 *provision of behavioural psychology."*

14
15 I'll just read in then the final paragraph which is 10:51
16 paragraph 84:

17
18 *"Every few years the Trust through social workers tried*
19 *to put P117 under the Mental Capacity Act (MCA) and*
20 *deprive her of her liberties. This has recently arisen* 10:51
21 *again and I had to e-mail Catherine Jack again. We met*
22 *with Peter Sloan, Director of Learning Disability, and*
23 *Tracey Reid on Monday the 4th September 2023 at the non-*
24 *clinical service building at the RVH. We stated our*
25 *concerns and we are awaiting the outcome. We also* 10:51
26 *raised our concerns about how social workers treat us."*

27
28 A. **P117's MOTHER:** Yes.

29 16 Q. So, P117's Mother and P117's Father, that's a part of

1 your statement. It's difficult obviously to do it it
2 in this way, we read part and then we ask questions and
3 then we move on to another part later, but insofar as
4 that part of your statement is concerned, P117's
5 Mother, are you content with those paragraphs? 10:52

6 A. **P117'S MOTHER:** Yes.

7 17 Q. Is there anything that you want to add to them or
8 change in those particular paragraphs?

9 A. **P117'S MOTHER:** well especially the last one there.
10 P117 at the moment is still ongoing reducing on the 10:52
11 Clozapine.

12 18 Q. Yes?

13 A. **P117'S MOTHER:** And P117 is down at the moment to 50
14 milligrams twice a day. Very soon she will be down to
15 25 milligrams in the morning and 50 at night and over 10:52
16 this last lot of months there has been a big difference
17 in P117. Before the increase you couldn't get P117 up
18 in the morning, you were lucky you got her up at 11.30.
19 Now P117 is up at 9 o'clock in the morning, as bright as
20 a button, more alert, very few incidents compared to 10:52
21 when she was on a high dose. So that has made a
22 considerable big difference to P117, the reduction, and
23 it is still ongoing and she is coming off the Clozapine,
24 I have been speaking to Dr. Dors. I feel for the best
25 for P117 and, as I say, the reduction so far has been 10:53
26 positive in every way.

27 19 Q. So it's an ongoing process?

28 A. **P117'S MOTHER:** Yes.

29 20 Q. But things are moving positively?

1 A. **P117's MOTHER:** Yes, but you have to fight for all
2 these things. That was numerous phone calls to Dr.
3 Dors, he wasn't sort of too keen on doing it and I says
4 well as a mum I owe it to P117 to help her in every way
5 I can. That's why I also got Psychology on as well and 10:53
6 that has helped also because it is not just medication,
7 psychology has helped P117 in lots of ways.

8 21 Q. Yes?

9 A. **P117's MOTHER:** I am going to continue to do that.

10 22 Q. So is it fair to say then in recent times at least you 10:53
11 had a dialogue with the professionals responsible for
12 P117?

13 A. **P117's MOTHER:** Yes, always been even in Muckamore I
14 still was on the phone, if I wasn't happy about
15 medication. I was always on the phone and speaking to 10:53
16 them, not that I always got anywhere, you know, but I
17 always made sure I was always involved. Even now in
18 supported living we are even more involved in every
19 sense.

20 23 Q. So you engage with the professionals and you are 10:54
21 satisfied now that they are taking your views on Board?

22 A. **P117's MOTHER:** Yeah, you have to make them listen, it
23 is the only way you get results.

24 24 Q. P117's Father, would you like to add anything to that
25 at this point? Don't forget, we are dealing only with 10:54
26 the parts of the statement that we've covered.

27 A. **P117's FATHER:** with the medications, they are quick to
28 put them on tablets, the medication, but trying to get
29 them off them. They put them on them, they are on them

1 for life, they don't reduce them unless you insist,
2 that's what the problem is. Even today, you're still
3 arguing with the doctor to try and get them reduced.
4 But we've done that and we are afraid of taking her
5 down, her behaviour might start. P117's Mother has 10:54
6 proved them wrong by getting them to bring them down
7 and there has been no issues with her behaviour, if
8 you know what I mean.

9 25 Q. So I suppose from a lay person's point of view the
10 challenge is to find the right balance? 10:55

11 A. **P117'S MOTHER:** It is, yeah.

12 A. **P117'S FATHER:** Sometimes the doctors just overmedicate.

13 26 Q. I'm going to come back actually to the subject of
14 medication in a moment but, I am going to go way back now
15 to the early phases of P117's admission and she was 10:55
16 admitted in April 1998 to Muckamore, isn't that right?

17 A. **P117'S MOTHER:** She was, yes.

18 27 Q. She was 12 years nine months at the time?

19 A. **P117'S MOTHER:** Yes.

20 28 Q. I think you say she spent three years in Conicar ward? 10:55

21 A. **P117'S MOTHER:** Yes.

22 29 Q. And at that time you say there was a sharing of care,
23 so essentially P117 would have been in Muckamore during
24 the week and then at home at the weekends?

25 A. **P117'S MOTHER:** She was yes, yeah. 10:55

26 30 Q. In your statement you make the point that Conicar was a
27 bit old fashioned. By that do you mean the building
28 itself or the way things were run?

29 A. **P117'S MOTHER:** The way it was laid out too, it wasn't

1 like really very homely, it was just like a bed, you
2 know, it wasn't very cosy, you know. It was just like
3 a room.

4 31 Q. Was it a dormitory type arrangement?
5 A. **P117'S MOTHER:** No it wasn't a dormitory, she had a room 10:56
6 didn't she?
7 A. **P117'S FATHER:** No, she didn't.
8 A. **P117'S MOTHER:** I can't remember, Conicar, it is a
9 long time.

10 32 Q. I am going to stop you now. 10:56
11 A. **P117'S MOTHER:** Sorry.

12 33 Q. No, no, it's okay, it's really difficult to do this.
13 But again, P117's Father, if you can let P117's Mother,
14 just one moment, if you can let P117's Mother finish
15 and I will invite you to come in after that. You were 10:56
16 talking about Conicar?
17 A. **P117'S MOTHER:** It's that long ago, over all the years,
18 it was very old fashioned, do you know what I mean, it
19 was just like a bed, it wasn't very homely, it was very
20 sort of dull. 10:56

21 34 Q. P117's Father, you were going to say something about it.
22 A. **P117'S FATHER:** It was a ward because one night when
23 P117 was taking fits in it, we went up to the room and
24 there were other patients.

25 35 Q. It was a dormitory type arrangement at that stage. P117 10:57
26 was discharged at that time in March 2001, it was quite
27 a while ago, looking back would you say that that
28 particular arrangement at that time worked reasonably
29 successfully?

1 A. **P117'S MOTHER:** Yes, it did, she was a child but she was
2 very happy, at times we went up and she was playing out
3 in the courtyard, she was playing with a ball. P117 was
4 happy like she had a ball throwing into a net, she was
5 happy then, we never had any kind of concern, you know. 10:57

6 36 Q. And then after that she had a six month period at home,
7 isn't what right?

8 A. **P117'S MOTHER:** She did, yes.

9 37 Q. And you say in your statement that her behavioural
10 issues became more difficult? 10:57

11 A. **P117'S MOTHER:** As she got older she got stronger, you
12 know, and just got very aggressive and we tried
13 everything. As I said in the statement, we got agency
14 workers who came in at the weekend and she got out
15 sometimes, I even out with the agency workers just to 10:58
16 get out of the house, went out with them for a bit of
17 lunch or something along with P117, you know, and it
18 did work for a while but it just got to the stage what
19 she was just too unsettled to keep at home.

20 38 Q. And in August, in or around August 2001 she was then 10:58
21 readmitted and detained under the Mental Health Order?

22 A. **P117'S MOTHER:** Yes, she was, yes.

23 39 Q. And you say that the ward that she was admitted to was
24 Fintona North ward?

25 A. **P117'S MOTHER:** Fintona North, yes, it was like a big 10:58
26 dormitory.

27 40 Q. Did that seem different to you from the time that P117
28 was first admitted?

29 A. **P117'S MOTHER:** I didn't see the dormitory ward at the

1 start, it was only later on I got to see the ward, we
2 didn't get to see it for a long while. As I say she
3 was in there for six weeks and we weren't allowed to
4 contact her or see her or anything, and it was hard.

5 41 Q. That I assume was the first time she would have been 10:59
6 completely away from the family for such a long time?
7 A. **P117'S MOTHER:** Yes, yes, it was hard, yeah.

8 42 Q. And is it right to say that at that stage you thought
9 this was going to be a relatively short-term
10 arrangement? 10:59
11 A. **P117'S MOTHER:** well I just thought she needed
12 treatment, as I say we didn't want to put her into
13 Muckamore, we tried other venues, they weren't
14 appropriate and I always knew Muckamore was a bad place
15 and it was the worst day of my worst day of my life 10:59
16 putting her in there and Jennifer at home and Jennifer
17 didn't have a life, we didn't have time for her because
18 everything focused around P117 to do the best we could.
19 I didn't want to put her into Muckamore but there was
20 nowhere else and it was hard. 10:59

21 43 Q. On this occasion she was a bit older and she was a
22 detained patient?
23 A. **P117'S MOTHER:** we didn't actually realise at the start
24 that she was being detained, we didn't actually because
25 we didn't know all the ins and outs, we didn't realise 11:00
26 at that time that she was a detained patient. We just
27 thought she went up for six weeks for treatment.

28 44 Q. Was that not explained to you at that time?
29 A. **P117'S MOTHER:** No, because you weren't told anything,

1 no, you were very much just the mummy and daddy, you
2 weren't told anything.

3 45 Q. So at the time that she was admitted in 2001 you
4 weren't aware that she was admitted specifically under
5 the Mental Health Order as such? 11:00

6 A. **P117'S MOTHER:** No, I wasn't aware of that, no.

7 46 Q. And you talk about the initial six week period which
8 you say was very difficult?

9 A. **P117'S MOTHER:** It was very difficult, I phoned at
10 times, I phoned about her every day and I tried to get 11:00
11 speaking to her but they wouldn't let you speak to her,
12 I'm sure it must have been difficult for P117 also.

13 47 Q. Then after that you got back to the arrangement whereby
14 P117 would be in the hospital during the week and with
15 you at the weekends again? 11:00

16 A. **P117'S MOTHER:** Yes, we brought her home at the
17 weekends, yes.

18 48 Q. It is interesting you say in your statement there were
19 no restrictions on what activities we as family could
20 do with P117 during the time at home? 11:01

21 A. **P117'S MOTHER:** There wasn't, no, no restrictions,
22 no, we went away for the weekends, went on day trips
23 like normal families do.

24 49 Q. At that stage would the arrangements have been fairly
25 similar to the earlier time in Conicar? 11:01

26 A. **P117'S MOTHER:** Yes, yes.

27 50 Q. I want to ask you very briefly about a couple of things
28 you mention in your statement about this early phase in
29 the hospital. You say that P117 attended a school for

1 children with special educational needs whilst she was
2 at the hospital?

3 A. **P117's MOTHER:** Yes, she did, yeah.

4 51 Q. Was she collected by a taxi then?

5 A. **P117's MOTHER:** She went by a taxi to school. 11:01

6 52 Q. And can you remember how long that arrangement worked
7 for?

8 A. **P117's MOTHER:** P117 didn't really settle very well in
9 school, you know, I mean she was very disruptive, even
10 when we had her at home. She was brought home and the 11:01
11 principal phoned me to say she was being suspended for
12 a couple of weeks, she just didn't take very well to
13 school.

14 53 Q. But there was an attempt at least to put in place
15 school? 11:02

16 A. **P117's MOTHER:** Yeah.

17 54 Q. Alongside the hospital and of course alongside your care
18 for P117 at the weekends. Now the other thing that you
19 mention about this phase in the hospital was the
20 placement in another supported living facility when P117 11:02
21 was about 19 or 20?

22 A. **P117's MOTHER:** Yes, yes.

23 55 Q. Was that hoped at the time to be a long term
24 resettlement?

25 A. **P117's MOTHER:** well I think they tried it and hopefully 11:02
26 it would work but, they weren't very understanding with
27 her, you know what I mean. They just didn't seem to be
28 bothered because P117 was young and P117 is lively,
29 even now she is very active and a lot of the residents
were

1 very sort of quiet, maybe older and autism, more
2 quiet, subdued, whereas P117 would have needed to be
3 taken out. They didn't really take her out. They took
4 her out on the bus and bought an ice cream on to the
5 bus. They didn't want to be bothered taking her out 11:03
6 anywhere, you know, it didn't work.

7 56 Q. It just didn't work out for her?
8 A. **P117'S MOTHER:** It didn't work for her at all.

9 57 Q. At the time. Now you refer to P117 being lively and it
10 is very remiss of me because I haven't yet introduced 11:03
11 the photograph of P117 which you have provided at page
12 25, I wonder if we can have that on the screen, please.
13 Is that a fairly recent photograph?
14 A. **P117'S MOTHER:** No it's not, no.

15 58 Q. When would that have been taken? 11:03
16 A. **P117'S MOTHER:** That's new, that one, that's not an old
17 one. P117 before she went into the Muckamore was thin
18 now, now she's like overweight.

19 59 Q. So you think that's a fairly recent photograph?
20 A. **P117'S MOTHER:** That's a fairly recent, yes, very 11:03
21 recent.

22 60 Q. I see there is dribble cake on the table, must have
23 been the occasion of a party of some kind.
24 A. **P117'S FATHER:** That photograph was taken at my other
25 daughter's house, bungalow. 11:04
26 A. **P117'S MOTHER:** Jennifer's bungalow. She lives in the
27 same grounds with different services. That is her back
28 garden.
29 A. **P117'S FATHER:** They both have a learning disability, so

1 the whole thing is we have to get both our children set
2 up in supported living because when we're not here
3 there is nobody else to do it for us. So we couldn't
4 just leave them to their own devices because we care
5 for the kids, we had to get them set up before we 11:04
6 depart.

7 61 Q. Yes. So that's taken at P117's sister's facility?
8 A. **P117's MOTHER:** Yes.

9 62 Q. Now, again, I apologise for skipping around but I am
10 going to go back to the issue of medication which you 11:04
11 dealt with in some detail in your statement. You talk
12 about the medication that P117 was on and you have also
13 given us some further detail about the current
14 initiatives to reduce the medication. You also make
15 the point in your statement that you were aware of the 11:05
16 appropriate medication levels because you had P117 at
17 home at the weekend. Now, at paragraph 61 you say she
18 was at times overmedicated as she would be jerky and
19 drooling which was not behaviour that she would usually
20 have. If you want to go back and have a look at 11:05
21 paragraph 61 there. Now, you're talking in those
22 paragraphs about P117's later years in the Donegore
23 ward?

24 A. **P117's MOTHER:** Yes.

25 63 Q. Within the hospital? 11:05
26 A. **P117's MOTHER:** Yes.

27 64 Q. And when you say at times do you mean in Donegore or do
28 you mean throughout her stay in the hospital?
29 A. **P117's MOTHER:** When P117 was in Donegore that was when

1 she was first put on the Clozapine. Laura was on a lot
2 of different drugs, what they call a family of drugs.
3 So we were told by the psychiatrist then they were
4 putting her on the Clozapine and they were telling us
5 about the risk about her heart, you have to get blood 11:06
6 tests every four weeks and I wasn't too happy about it.
7 She went on it, and we had her home a lot as well, and
8 P117 was doing a lot of jerking like this here and I
9 used to rub her arm to try and comfort her and she used
10 to drool an awful a lot. Even when you brought her 11:06
11 home she was falling asleep, P117 are you not going to
12 talk to us, she used to fall asleep all the time. I
13 was very worried about the jerks and then the jerks got
14 worse and I phoned up the ward and I asked them to keep
15 a record of this, and they did for a while. They were 11:06
16 saying to me yes, she had been jerking a lot. I had
17 been saying to the psychiatrist what I am not happy
18 about her being on this. Before P117 went on the
19 Clozapine, P117 was able to walk about on her own. We
20 used to take her around Castle gardens out in Antrim, 11:07
21 we used to bring her out there for walks. She used to
22 walk on her own, she would chase after us before she
23 went on the Clozapine. She walked independently, no
24 issues. When she was put on the Clozapine, even to
25 now P117 won't walk on her own, she has to hold on to 11:07
26 somebody, sometimes two people. She never had what
27 problem before. But these drugs are like controlling,
28 like they take, they don't just do the behaviour they
29 damage them in other ways. I mean P117 has lost

1 confidence. So, as I say, the psychiatrist kept
2 putting it up, putting it up. I kept telling her I'm
3 not happy about it. We went to meetings and P117
4 even like, she just couldn't focus. So then --

5 65 Q. But again, just sorry to interrupt you, P117's 11:08
6 Mother, you were engaging in meetings and you were
7 getting the review?

8 A. **P117'S MOTHER:** We were up there all the time, whether
9 it was medication, whether it was incidents. All the
10 time, we were up there all the time, we kept saying to 11:08
11 them about the medication, you know.

12 66 Q. P117's Father has got something to say.

13 A. **P117'S FATHER:** These meetings were called by us, it
14 wasn't the hospital arranging the meetings, P117's
15 Mother was on the phone insisting on having meetings 11:08
16 because of the drugs, that is where it came from.

17 67 Q. I just want to ask you about something, it appears in
18 one of the reports and I don't want this to be brought
19 up on screen, this was a social work report with the
20 Mental Health Review Tribunal back in 2010 and it's at 11:08
21 Exhibit 8, do you want to just have a look at Exhibit 8
22 in your papers and if you go to page 44. You see those
23 page numbers at the top?

24 A. **P117'S MOTHER:** 44, yes.

25 68 Q. So it's at the very top of the page. It is a social 11:09
26 work report for the Mental Health Review Tribunal. I
27 just wanted to ask you about one of the entries in that
28 report and again I don't want it brought up on screen.
29 If you go on to page 50?

1 **CHAIRPERSON:** We are in December 2010.

2 69 Q. Yes, this report was compiled in December 2010, and
3 this is an entry in relation to March 2010, it's
4 towards the bottom of the page at page 50 and it says:

5
6 *"In April 2010 there was a change of medication with*
7 *the introduction of Clozapine and over a period of time*
8 *it became evident that the number of episodes of*
9 *aggressive behaviour, their intensity and the duration*
10 *of physical intervention had decreased. The number of*
11 *incidents recorded from April and May 2010 were for*
12 *five each month with only one incident per month in*
13 *June, July and August of 2010."*

11:09

11:10

14
15 Now just to ask you about that, did it seem in the
16 earlier stages that Clozapine was in fact having a
17 positive effect?

11:10

18 A. **P117'S MOTHER:** That had a massive effect big time in
19 every way. To the day now P117 has very few incidents
20 with getting the reduction. P117 had, even in her
21 supported living, had a lot more incidents when she was
22 on a higher dose of clozapine.

11:10

23 70 Q. So is it fair to say that the pattern was the initial
24 introduction of clozapine seemed to have a positive
25 effect but then as the dosage increased behavioural
26 difficulties increased?

11:10

27 A. **P117'S MOTHER:** No, it used to make P117 very, very
28 tired. I mean P117 was like a zombie. As I say,
29 compared to what three or four months ago, P117 has
 like

1 woke up if you like. She is more alert, I mean she's
2 up at 9 o'clock in the morning, she is ready to go out
3 at 12.30. Before three or four months ago you were
4 lucky if you got P117 out of the bed at 11.30. She
5 also used to have a lot of urine infections when she 11:11
6 was on a higher dose and that is another one of the
7 symptoms that as a result got better.

8 71 Q. P117's Father, you wanted to add to that?

9 A. **P117's FATHER:** P117's behaviour on Clozapine would
10 have helped her behaviour the reason being she was like 11:11
11 a zombie, anybody with that much drugs in them,
12 obviously your behaviour is going to be better, because
13 you are lying there like a zombie, doped up.

14 72 Q. So it had a clear effect on her in the sense of
15 affecting her personality in that way if you like? 11:11

16 **P117's FATHER:** Exactly.

17 73 Q. I just wonder about this, going back to Donegore, to
18 what extent did what remain an issue throughout the
19 remainder of her stay at the hospital, was it a
20 constant source of worry or were there long periods when 11:12
21 P117 appeared to be reasonably settled and it appeared
22 to be helping her or was it a constant source of concern
23 to you?

24 A. **P117's MOTHER:** Just constant.

25 A. **P117's FATHER:** A constant battle. 11:12

26 A. **P117's MOTHER:** It was just a constant battle, obviously
27 we were still involved in P117's life, even more so in
28 every aspect of her life, even though they probably
29 don't like it, but we still are, that's what we have do

1 for her. It was just an ongoing battle with the
2 medication, you know what I mean, she was still on the
3 clozapine when she left along with other drugs.

4 74 Q. I think you say also that you spoke with the Public
5 Health Agency about this issue and they said they would 11:12
6 raise it with the hospital?

7 A. **P117'S MOTHER:** I mean, whenever P117 was in Muckamore
8 I didn't sleep very well, I was up to high dough and I
9 used to sit in the house and cry and I got the
10 telephone book out and I said to myself what am I going 11:12
11 to do here. I rang up Mencap, everywhere I could think
12 of. Somebody said to me phone up the Public Health
13 Agency and I says but who do you ask for, and they said
14 well you ask for the learning disability. Then I
15 phoned up that day, I got this very nice man, I can't 11:13
16 say his name. He is a very very nice man, there is
17 nice people out there but you have to look for them. I
18 spoke to him and he was very understanding and I told
19 him the position we were in and I said I'm worried
20 about my daughter, she's on a very high dose of 11:13
21 clozapine, she had a grand mal fit when she was on 400
22 milligrams and I am going to go up and see them today
23 and I am worried about this. So he says I am going to
24 ring who it was we were saying, H50 I think, yeah, H50
25 and what's her number. 11:13

26 75 Q. Are you saying that the Public Health Agency said they
27 would ring the hospital?

28 A. They would get in touch with Muckamore and they said
29 they want to find out what's happening. Yep, H614

1 along with H50 and we went up to see them and we walked
2 in and H50 said to me Mrs [surname] you got in touch
3 with the Board and I said yes, I did.
4 **CHAIRPERSON:** Sorry, you just used the surname so we
5 are going to pause. 11:14
6 A. **P117'S MOTHER:** Sorry, did I use surnames.
7 76 Q. **MR. DORNAN:** You used your own surname?
8 A. Sorry.
9 **CHAIRPERSON:** Almost every single witness has done it.
10 We are just going to pause. 11:14
11 77 Q. **MR. DONAN:** Thanks, Chair. You can go ahead.
12 A. **P117'S MOTHER:** Anyway H50 says you got in touch with
13 the Board and I said yes, I did. I knew what they were
14 up to but to cover themselves they made her a voluntary
15 patient. That was to cover up because I had got in 11:15
16 touch with the Public Health Agency, I knew they were
17 going to increase the Clozapine but because they got, I
18 got in touch with the Board and they got in touch with
19 them, to cover it up they made her a voluntary patient.
20 78 Q. Were you told this at a meeting then at the hospital? 11:15
21 A. **P117'S MOTHER:** Yes, H50 said just make P117 a voluntary
22 patient as from today. But then whenever you do these
23 things, it probably doesn't sound appropriate to say it
24 like this, but when you try to stand up for P117 and you
25 try to get one over, that's probably the wrong way of 11:15
26 saying it, but when you are trying to do the best for
27 P117, you know, when this happens, they come back with
28 a big blow and they go and do something like, the only
29 way I can describe it, and it is not appropriate, is

1 what I call dirty tricks, I know that's probably not
2 appropriate to say. But they come back and do
3 something else in another area, if you know what I
4 mean, that's what they do.

5 79 Q. I did want to ask you about this in your statement 11:16
6 because you talk about the meeting that occurred in
7 paragraph 64 of your statement and this was a meeting,
8 am I right in saying, to discuss medication?

9 A. **P117'S MOTHER:** Yes, we've always had things with
10 medication, we always had problems. 11:16

11 80 Q. You say: *"Both myself and P117's Father attended the*
12 *meeting and were told that P117 had been re-graded from*
13 *a detained patient to a voluntary patient. I was*
14 *provided with a letter dated the 10th March from the*
15 *Chief Executive of the Belfast Health and Social Care 11:16*
16 *Trust which stated "I wish to inform you that from 9th*
17 *March 2015 the above named has been assessed as no*
18 *longer needing to be detained in hospital and is now a*
19 *voluntary patient"."*

20 A. **P117'S MOTHER:** Yes. 11:16

21 81 Q. And you provide the Inquiry with a copy of the order of
22 discharge of the 9th of March and a copy of the letter
23 from the Trust as well. So, are you saying that this
24 was the first time that you were informed that P117 was
25 re-graded or to be re-graded to a voluntary patient? 11:17

26 A. **P117'S FATHER:** Yes.

27 82 Q. Was at that meeting?

28 A. **P117'S FATHER:** why would they do that? P117's behaviour
29 didn't change from one day to the next day, P117 has

1 A. P117's FATHER: Yes.

2 A. P117's MOTHER: Yes, 100%, yes.

3 87 Q. Now this meeting, at this time as you say P117 became a
4 voluntary patient and that was March 2015 and you say
5 that no facility was provided for her by the Trust. 11:19
6 Are you making the point that formally she was ready to
7 leave Muckamore in March 2015 but there was no suitable
8 placement available for her at that time?

9 A. P117's FATHER: That's right.

10 A. P117's MOTHER: None. 11:19

11 88 Q. Can I ask you just to provide the Panel with a bit of
12 detail about how the resettlement process worked, if
13 you can fill in the gap between March 2015 and March
14 2018?

15 A. P117's FATHER: Every few months we would go up to 11:19
16 multidisciplinary meetings and then they offered us in
17 early '18 a facility, but it wouldn't be suitable for
18 P117, it was a wee bit out of the way. So we heard
19 about this other place being built beside us so we were
20 happy with that. But from 2015 to 2018 you still had 11:20
21 ongoing issues with arguing over medication and just
22 different things, [REDACTED]
23 [REDACTED], I probably can't mention that maybe in this open
24 session.

25 89 Q. I think we should pause, chair, because I am going to 11:20
26 broach issues of that kind within the restricted
27 session.

28 CHAIRPERSON: Are you now going to deal with the rest
29 of the statement after we have taken a break?

1 **MR. DORAN:** In a moment, yes, I do have -- what I am
2 saying is I would like to pause the feed and go back a
3 few minutes because the witness has encroached on some
4 of the restricted territory.
5 **CHAIRPERSON:** Oh, I see. 11:21
6 **MR. DORAN:** If that can be --
7 **P117's FATHER:** Sorry.
8 **MR. DORAN:** There is absolutely no difficulty about
9 this at all and we will be able to return to those
10 matters in due course. 11:21
11 **CHAIRPERSON:** Stop for a second because we have only
12 got a three minute delay, if you want the feed stopped
13 we need to do it now.
14 90 Q. **MR. DORAN:** That's perfect, Chair. You've mentioned,
15 P117's Father, the process of issues arising over 11:22
16 medication and other matters.
17 A. **P117's FATHER:** Yes.
18 91 Q. Were you content with your involvement in the
19 resettlement process, do you feel that you were
20 properly involved in the process whereby P117 moved from 11:22
21 Muckamore to the facility that she is in now?
22 A. **P117's FATHER:** Yes, but we had to do an awful lot of
23 arguing with the Trust because I probably can't mention
24 this either.
25 92 Q. Well, I think what we can do actually -- 11:22
26 A. **P117's FATHER:** Can I mention risk
27 93 Q. assessment. You can, yes.
28 A. **P117's FATHER:** We weren't happy with that.
29 94 Q. Actually, P117's Father, what I am going to do just
 to

1 err on the safe side?

2 A. **P117's FATHER:** I can't talk about this, you can't talk
3 about it openly, it's like walking a tightrope.

4 95 Q. It's far better for us to end the open session now and
5 then we can come back to talk about these issues during 11:23
6 the restricted session, it is a sensible time to take a
7 break I think?

8 **CHAIRPERSON:** It is. Can I ask a member of the Inquiry
9 staff to remind those in Room B, because the feed is
10 now being cut, I was going to do this publicly, the 11:23
11 name must not be published in any way. We will now
12 take a break. We have got quite a long way to go I
13 think because we've dealt with about half of the
14 statement but we will break now, you need a break,
15 everybody needs a break. We'll take 15 minutes but I 11:23
16 would like to start promptly, if we can and then we'll
17 deal with the rest of the statement in restricted
18 session.

19

20 **THE HEARING ADJOURNED FOR A SHORT PERIOD.** 11:23

21

22 **THE HEARING RESUMED AS FOLLOWS:**

23

24 **THE HEARING WENT INTO A RESTRICTED SESSION**

25 11:41

26

27

28 **LUNCH ADJOURNMENT**

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THE INQUIRY RESUMED AS FOLLOWS:

THE HEARING WENT INTO OPEN SESSION

CHAIRPERSON: Mr. McEvoy.

13:58

MR. MCEVOY: Chair, members of the Panel, good afternoon. Chair, Panel members, in this session you'll be hearing evidence from the father and mother of P36. I have been asked to apply for a Restriction Order so, if I could, in order to make that application, ask for the application.

13:59

CHAIRPERSON: we'll make a temporary Restriction Order to cover the application for the usual reasons.

THE HEARING WENT INTO RESTRICTED SESSION

13:59

THE HEARING WENT INTO OPEN SESSION

CHAIRPERSON: we will be sitting -- it's another long day tomorrow I'm afraid, and apologies to the stenographer, who's been working probably harder than all of us, thank you very much. But we will take breaks tomorrow. we won't be able to get through the whole morning with just one break okay 9 o'clock tomorrow morning. Thank you very much.

17:02

17:02

THE INQUIRY WAS THEN ADJOURNED UNTIL WEDNESDAY, 11TH OCTOBER 2023 AT 9:00 A.M.