

ROYAL COMMISSION INTO VICTORIA'S MENTAL HEALTH SYSTEM

Melbourne Town Hall, Yarra Room,
90-130 Swanston Street,
Melbourne, Victoria

On Friday, 12 July 2019 at 10.00am

(Day 9)

Before: Ms Penny Armytage (Chair)
Professor Allan Fels AO
Dr Alex Cockram
Professor Bernadette McSherry

Counsel Assisting:
Ms Lisa Nichols QC
Ms Fiona Batten
Ms Georgina Coghlan

1 MS COGHLAN: Good morning, Chair, and good morning
2 Commissioners. The topic for today is families and carers.
3

4 Across our state around 60,000 Victorians give their
5 love and support to caring for a family member or a friend
6 who is living with mental health issues. This has
7 incredible value. It would cost Australian governments
8 billions every year to replace the support that carers
9 provide.

10
11 On a societal level the contribution carers make is
12 something the entire Victorian community benefits from.
13 Whilst it is difficult to fully convey the value of carers,
14 Victoria's mental health system and the community more
15 broadly would struggle without their presence and
16 significant contribution.

17
18 These hearings provide an opportunity to listen and
19 learn about what matters to carers, to hear about their
20 different needs, and ultimately to assist you, the
21 Commissioners, to explore what more can be done to
22 acknowledge, recognise and support their contribution.
23

24 Planning for the future will need to be considered.
25 As our population grows and ages, so too does the
26 population age, as do carers. Their diminishing presence
27 in our lives and in our communities is a difficult question
28 for many to consider, and the role of young carers needs to
29 be addressed. How are they identified and best supported?
30 The impact of having a caring role at a young age can be
31 profound: they can miss school and they can fall behind,
32 they can lose hope for their own future.
33

34 Through community consultations and submissions some
35 key themes have emerged. Carers have spoken about the
36 rewards of their caring role, they've described a sense of
37 personal fulfilment that comes from supporting a loved one
38 and the benefits of sharing a deep personal bond. But
39 they've also spoken about how hard it can be, the
40 relentless and ongoing nature of it.
41

42 Many carers have spoken about the need to better
43 recognise, respect and support carers during the
44 assessment, treatment and recovery of their loved ones.
45 Many carers have questioned whether requirements under
46 legislation may be a barrier to sharing information.
47

1 Carers have also spoken about the importance of
2 connected supports and services that respond to the breadth
3 of their loved one's needs. Carers have shared their
4 frustration about needing to repeat the same information to
5 multiple practitioners and professionals across a range of
6 different systems such as education, justice, housing and
7 health services.

8
9 Another issue that arose relates to access to supports
10 for carers to help them in their role as a carer. Others
11 have spoken about feelings of excessive expectations often
12 arising from a pressured system that discharges, in their
13 view, their loved one home too soon without the right
14 treatments and support.

15
16 Today there will be a number of witnesses called with
17 a range of different perspectives. First, you will hear
18 from a witness giving evidence in the name of Rebecca
19 Thomas. She will talk about caring within a family with
20 multi-generational mental health issues. She had a caring
21 role for her mother when she was young, aged between 5 and
22 10, into her teenage years and also into adulthood. She
23 later cared for her two brothers and, tragically, one
24 brother died by suicide earlier this year.

25
26 She doesn't consider the word "carer" appropriate for
27 her role. She was part of the support network for her
28 family and continues to be, along with many other people.
29 She will be giving evidence under a pseudonym, as I've
30 said, "Rebecca Thomas". Her evidence will also be the
31 subject of a restricted publication order which will
32 prohibit identifying information from being published.

33
34 Rose Cuff will give evidence. She is the Statewide
35 Coordinator of Families where a Parent has a Mental
36 Illness, or FaPMI. She will give evidence about how young
37 people come to be carers for their parents and the impact
38 on them of taking on that caring role and what initiatives
39 would best support young carers.

40
41 You will hear for Jesse Morgan and he's the carer for
42 his mum. He's now 25 but he's been caring for her since he
43 was about 14 in a single parent household. He will talk
44 about doing the cooking, the shopping, looking after his
45 younger brother, working part-time and going to school. He
46 didn't have any supports or help. He will talk about the
47 impact on his life, consequences with schooling and setting

1 him back. But for him, although it has been to the
2 detriment of his own life and development, he'll say, his
3 caring role for his mum was always his priority. He will
4 also talk about his own mental health issues.

5
6 You will hear from Mary Pershall. She cared for her
7 daughter for a number of years. Her daughter, Anna,
8 experienced mental health issues in her teens through to
9 adulthood. They emerged when she was young. She also
10 experienced drug and alcohol issues. The family struggled
11 to get help for Anna and struggled to get the help that she
12 needed, and what ultimately provided her with the stable
13 treatment environment and confinement that she had so long
14 needed was imprisonment. She is currently serving a
15 17-year sentence for causing the death of an older
16 gentleman that she was living with.

17
18 You will also hear from Dr Margaret Leggatt. She is
19 the Founding Director of Wellways Australia, a founder and
20 patron of SANE Australia, and is on the board of Tandem.
21 She will give evidence about the caring roles that family
22 members have for people with schizophrenia and effective
23 care models, although these are difficult to implement.
24 She opines that the system is generally not meeting the
25 needs of families and carers, in particular the mental
26 health workforce is not sufficiently trained to involve
27 families and carers in treatment.

28
29 Finally, you will hear today from John Murray and Kate
30 Dillon, they're not their real names, and they're the
31 parents of a daughter who's experienced an eating disorder.
32 She was hospitalised many times. They speak of their joint
33 experiences as her parents seeking access to the system for
34 children and the transition into mental health services in
35 the adult regime. They will talk about the ongoing caring
36 role they've had.

37
38 As I've said, they're giving evidence using a
39 pseudonym. Their evidence will also be the subject of a
40 non-publication order which prohibits identifying
41 information from being published, but importantly their
42 evidence will be in a closed setting, only permitting
43 Commission staff, lawyers and other authorised people to be
44 present.

45
46 I propose to call Rebecca Thomas shortly. As I've
47 said, there is a restricted publication order in relation

1 to her evidence. Chair, will that order be made now?

2

3 CHAIR: Yes, pursuant to the Inquiries Act 2014, the Royal
4 Commission has made an order prohibiting the publication of
5 any information that might identify the next witness. A
6 copy of that order has been placed next to the door of the
7 hearing room. The witness will be referred to as the
8 pseudonym "Rebecca Thomas" and her brothers as William and
9 Christopher. These are the pseudonyms that will be used
10 throughout the hearing today.

11

12 I would like to remind all persons present, including
13 the media, that any material which will enable the
14 identification of this witness or her brothers cannot be
15 published. The Commission has ordered that the hearing of
16 her oral evidence will be limited to those people attending
17 the hearing today. For those watching on the live stream
18 this portion of the hearings today will not be broadcasted.
19 I ask that the live stream now be cut.

20

21 (Live stream cut.)

22

23 MS COGHLAN: I call Rebecca Thomas.

24

25 <REBECCA THOMAS, affirmed and examined: [10.15am]

26

27 MS COGHLAN: Q. You've made a statement for the
28 Commission in the name of Rebecca Thomas?

29

30 A. Yes.

31

32 Q. I tender that statement. [WIT.0001.0024.0001]
33 Ms Thomas, can you tell us about your family and the family
34 members that over the years have been affected by mental
35 health issues?

36

37 A. Sure. I was born into a family where already there
38 had been some existing mental health issues by both
39 grandparents on either side of my family, and an uncle.
40 And then, both of my parents suffered from mental illness
41 and both of my brothers suffered from mental illness.

42

43 Q. You have experience as a carer when you were a child?

44

45 A. Yes.

46

47 Q. And you also continue to help care for one of your
brothers?

A. For both of them at different times, yeah.

1 Q. The brother you're currently caring for, you also help
2 with the family?

3 A. That's right, quite extensively, yeah.
4

5 Q. We'll come back to that. Can I just ask you what
6 really led you to have such an interest in the Royal
7 Commission and its work at this point in time?

8 A. When I heard there was going to be a Royal Commission
9 I immediately began to think of my family's experience and
10 my experience in relation to my family and felt that it was
11 really important that, if I could participate in some way,
12 that I would really like to, and so, began exploring ways
13 that I could do that. I think I registered for one of the
14 community consultations and then, not long after that, my
15 brother took his life and ...
16

17 Q. Just take your time.

18 A. It became even more important to me to participate and
19 potentially tell my family's story, because I felt that my
20 brother, even though he'd suffered from a mental illness
21 for a significant amount of time, should not have lost his
22 life in the way that he did, and I really wanted to be able
23 to talk about the experiences of my family in a way that
24 contributes to changing the way we deal with mental health,
25 particularly the mental health system, and I suppose try
26 and make it better if there's anything that I can say or my
27 experience can contribute in a way that provides the
28 Commissioners with information to help them understand the
29 difficulty that the system is currently in, and under, so
30 that what happened to my brother never happens again -
31 sorry.
32

33 Q. That's okay. And I'll ask you about that in the
34 course of asking you questions. As a result of what
35 happened with your brother, William, your other brother
36 experienced a psychotic episode?

37 A. That's right, yeah.
38

39 Q. I'm going to take you back, first of all, to your
40 childhood and caring for your mother and just ask you then
41 about both of your brothers.

42 A. Yeah.
43

44 Q. You've said that you were a carer for your mother when
45 you were a child?

46 A. Yes.

47 Q. At that time in the household there was you and your

1 father, and your mother, and your two brothers?

2 A. That's right.

3

4 Q. You remember your mother suffering from what you
5 thought was depression?

6 A. As I look back, that's how I would describe it. I
7 think she probably had postnatal depression and, when I was
8 very young, sort of from the ages of about 5 to 10, I
9 remember taking a lot of responsibility in looking after
10 both of my brothers and supporting my mum when she was
11 unwell.

12

13 Q. In terms of your father's condition, what was the
14 situation with him?

15 A. So, he had suffered from depression. It was referred
16 to at that time as, he had a nervous breakdown. I don't
17 know how that would be - the terminology for that now.
18 That was the way we talked about it. He was hospitalised
19 for a period of time, I think I was in my teenage years,
20 and he actually left the hospital unauthorised, and I
21 remember there being a very intense conversation when he
22 arrived home unexpectedly, yeah.

23

24 Q. In terms of the period of time you've talked about,
25 being aged 5 to 10, and also as a teenager and having
26 caring responsibilities, were there any supports available
27 for you?

28 A. Not that I was aware of. Certainly, when I was in
29 that 5 to 10 year age group there was nothing happening. I
30 don't think anybody in my mum's family - we were living
31 where her family were living - that they were aware of what
32 was going on, and certainly I wasn't aware that there was
33 mental illness at that age; I just knew that my mum needed
34 my help and support and that's what I did.

35

36 Q. And so, as a teenager you effectively ran the house?

37 A. Yeah. My mum went out to work full-time. In order to
38 send us to a school that both my parents wanted us to go
39 to, and during that time I ran the house day-to-day. I
40 remember helping mum with her breakfast every morning. I
41 used to cook dinner most nights. I cleaned the house every
42 week. I was responsible for overseeing and keeping an eye
43 on my brothers in many different forms.

44

45 Q. In your adult years, if I can ask you about 2003, you
46 say in your statement that your mum had another manic
47 episode, and so, can you just explain what happened for her

1 after that time.
2 A. Sure. So, she was interstate visiting family and we
3 got a phone call to say that she needed to come home
4 because she wasn't well. She was put on a plane, and I
5 think one of my brothers met her at the airport. I'm not
6 exactly sure the details of exactly what happened straight
7 after that, but I know she went into a mental health
8 facility, and at that time she was formally diagnosed with
9 bipolar.
10
11 Q. And, she was aged 65 years?
12 A. Yes.
13
14 Q. Over the next 10 years your mother's mental health was
15 monitored by a GP?
16 A. Yes, so she - yeah.
17
18 Q. And your father by then had passed away in a car
19 accident?
20 A. That's right.
21
22 Q. While you were living in Newcastle, you were involved
23 in her care in Melbourne as much as you could be?
24 A. Yeah, that's right, quite extensively really. Even
25 though I was living interstate, I was involved in
26 supporting her, we spoke on the phone often and we
27 generally talked about her mental health and how she was
28 going and things that she needed or just, I suppose,
29 encouragement and support. She relied on that. I think
30 there was a lot of reliance on the emotional support that I
31 was able to offer her, but I also was involved in
32 organising things and checking that things were happening
33 that needed to happen at times as well.
34
35 Q. Your mum passed away in 2013?
36 A. That's right.
37
38 Q. Can I ask you about your brother, Christopher?
39 A. Yeah.
40
41 Q. Your youngest brother?
42 A. Yeah.
43
44 Q. Can you briefly just describe what was occurring for
45 him in 2008 and 2009?
46 A. He was not overly connected to the family during that
47 time and was living in Melbourne but not having lots of

1 contact with us. He was hospitalised three times during
2 that 12-month period with - I think they were manic
3 psychotic episodes, and he was diagnosed with bipolar in
4 that time.

5
6 The third time he was hospitalised he had a horrific
7 accident in the hospital which actually, if he hadn't been
8 in a hospital setting he would have died, so he was
9 attended to immediately and he went into ICU and was in a
10 coma for at least two weeks, may have been longer.

11
12 I came down immediately and spent - I'm not sure how
13 long I was in Melbourne for but it may have been around a
14 week, to support the rest of the family and to support him.
15 I sat by his bed many, many hours just letting him know
16 that I was there.

17
18 Q. He had been doing relatively well health-wise up until
19 William passed away earlier this year?

20 A. Yeah.

21
22 Q. Can you talk about what happened three days after
23 William's funeral?

24 A. So, he and his partner and two very young children
25 were staying at our house for the weekend. It became quite
26 evident that he was struggling just in general, and we all
27 were, but it seemed that he - I felt that there was
28 something not quite right with him, but felt that it was
29 more to do with the shock and the sadness of losing
30 William.

31
32 I helped him with the kids extensively, and he was
33 really struggling to just be present to them and sort of
34 know how to manage them. I helped him put them in the car
35 and he went to pick up his partner from work and they then
36 went home, which is about an hour and a half away from
37 where I live.

38
39 Then I got a phone call from his partner, maybe three
40 or four hours later; she was very distressed and she was on
41 the phone to me trying to tell me that he had fallen
42 backwards and wasn't moving, and she was also on the phone
43 to the emergency services to let them know what had
44 happened. I worked out that she needed me to be there and
45 so I jumped in the car and stayed on the phone with her the
46 whole way to their place.

1 Q. And that's a 70 kilometre drive?

2 A. Yeah, it's about 70Ks away, to just calm her because
3 she was so distressed and she had the two little ones with
4 her and she was too frightened to go outside because she
5 didn't know what was happening.

6

7 I arrived and the police had got there, the ambulance
8 still hadn't arrived, I don't know how long ago that had
9 been, but it had been quite some time. He was on the
10 ground, disoriented, not really making sense, not able to
11 move, so I sat with him until the ambulance arrived. They
12 then made a decision that he needed to be taken to
13 hospital. I had to have a conversation with them that he
14 couldn't go to the hospital where he'd had his accident
15 because that was too traumatic for him, and by this stage
16 he had regained some sense of being able to talk and was
17 very adamant that he didn't want to go to that hospital, so
18 I had to talk to the ambulance about that.

19

20 Q. And, was he taken elsewhere?

21 A. He was taken elsewhere.

22

23 Q. Did you come to understand later that he'd experienced
24 a psychotic episode?

25 A. At that --

26

27 Q. Later on did you come to understand what had happened?

28 A. Yes, yeah.

29

30 Q. And he ended up being in Emergency at the hospital for
31 many hours?

32 A. Yes. So, I then followed the ambulance to the
33 hospital and I stayed with him, so we arrived at around
34 10 o'clock in the evening. He didn't leave emergency until
35 about 6 o'clock the following night. He was seen by a
36 psychiatrist at approximately 10 o'clock the next morning
37 where I had to advocate very strongly that, once again, he
38 not be placed in the hospital where he had his accident.
39 They said that they would try but couldn't guarantee that.

40

41 Q. And he ultimately did have a hospital stay in a mental
42 health unit for three weeks?

43 A. That's right.

44

45 Q. And again, was that a different hospital?

46 A. It was. It wasn't in the hospital where he'd had his
47 accident, yeah.

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Q. During the time that he spent those three weeks in hospital, what was your main role in relation to other family members?

A. So, my main role was supporting his partner and two young children, which at that stage I was - and supporting him and liaising with the mental health system around what was happening and what we all needed, what he needed; making sure that his partner was getting the support that she needed. There was a lot of organising and I was, you know, trying to engage other supports within our community, our social supports and family supports which was very challenging because they live so far away.

Christopher's partner didn't drive and didn't live anywhere near public transport, so there was a lot of organising of her being able to spend time with him. She also was very isolated with these two young children, so in the end what I decided to do was, I would spend Thursday night to Saturday with her and the children, just so make sure she could go and do some shopping and the kids had some time to do normal stuff, because they were pretty traumatised.

And the youngest one would often, whenever he saw me, he would just repeat what he saw happen to his dad in a really concerned manner, and so I would have to just go through it with him, and I was very calm with him, and I would just let him know that, yes, those things had happened but that his dad was okay now. But, whenever he saw me, he would repeat that to me. He wouldn't do that with anybody else, but whenever he saw me he did that.

Q. Can I just take you to when Christopher's discharge was being considered. One of the things you say in your statement is that you had to push to be kept informed about what was happening?

A. Yeah, and it felt like up until his discharge I felt like I had been quite kept in the loop, although I made a very - I mean, I had enough experience with the mental health system to know that you don't wait for phone calls, you actually need to be very proactive to let them know that you want to be informed and to remind them of who you are in relation to the family and supporting the family.

So, towards the end when they were looking at discharging it was a little bit unclear as to how that was

1 all going to happen and when it was going to happen, and
2 what was going to happen next. And so, I remember having
3 conversations with his partner and she would often say to
4 me, "Can you please ring them, I don't quite understand X",
5 and so I would often do that.

6
7 And so, towards the end it felt like a little bit
8 like, the box had been ticked, he was ready to be
9 discharged and so we didn't need to be as informed, and
10 certainly it felt like they'd had that conversation with
11 her so they didn't necessarily need to have it with me, and
12 so, I felt like I really did have to say, "Hang on a
13 second, we need to understand this better, and I know you
14 guys feel that this is really clear but it's not for us."

15
16 Q. One of the things you say in your statement is that
17 there seemed to be a lack of understanding about the
18 support that other family members provide and the
19 importance of sharing information with them, which is what
20 you've just described?

21 A. That's right.

22
23 Q. So, when Christopher was ultimately discharged and
24 went back home you stayed for the first few days with the
25 family?

26 A. That's right, and on request of Christopher's partner,
27 she was very scared and worried, she'd never experienced
28 any mental health issues in her family or with anybody that
29 she knew, and she felt really unsure and was actually not
30 wanting him to come home unless he was going - she wanted
31 him to go into PARC before he came home but there wasn't a
32 bed available so he had to come home first and then he was
33 to go into PARC, which is why she wanted me to stay there
34 with them.

35
36 Q. Did he end up going into PARC for a stay?

37 A. The day kept moving when a bed availability changed.
38 It was meant to be Monday, and then it was Tuesday. By the
39 time he went there he'd had three or four days at home, and
40 he went, but he left the same day because he said he just
41 felt like he couldn't stay there because he'd already had
42 this time at home and felt it was too hard for him to be
43 away from the family. By that stage his partner had
44 experienced enough of him being at home and relatively well
45 that she felt okay for that to have occurred.

46
47 Q. And so, after he returned home after that brief PARC

1 visit, there was an arrangement where you would actually go
2 and stay with them and then they would come and stay with
3 you?

4 A. Yep, which is still the way things are. So, they stay
5 with me every second weekend, where I mainly look after the
6 children on Sunday so that they can both do some work and
7 have some time away from the kids, and then the alternate
8 weekend I try and spend at least a day with them where they
9 live.

10

11 Q. Can I ask you some questions about William?

12 A. Yep.

13

14 Q. He was married with two children and had a stable life
15 as far as everyone could tell?

16 A. Yep.

17

18 Q. He was employed long-term with the same employer?

19 A. (Witness nods.)

20

21 Q. He had some problems with anxiety in his early 20s?

22 A. Yeah.

23

24 Q. But he really didn't have any mental health issues as
25 far as anyone could tell for 25 years?

26 A. That's right.

27

28 Q. But, in November or December 2012, things changed for
29 him?

30 A. Yep.

31

32 Q. Can you just describe what happened?

33 A. It's a little bit unclear.

34

35 Q. Or at least the events that occurred?

36 A. Sure, sorry. What I mean by "a little bit unclear",
37 as to why he went from being a fully functioning, really
38 hands-on loving father, and participated in the world in a
39 really normal way, to becoming extremely unwell, very
40 depressed. I wasn't aware or didn't see any of this, but I
41 think there was some potential manic moments in the early
42 stages of him becoming unwell, but certainly it was the
43 depression that became the most obvious in his experience.

44

45 He went on some medication and within a very short
46 period of time he tried to take an overdose, he was
47 hospitalised, and from that point on the next two to three

1 years was just this horrific in and out of hospital,
2 suicide attempts, his whole life fell apart.

3
4 He tried really hard. He was able to - he had some
5 really, really difficult moments of being in hospital and
6 nothing worked. The only thing that the hospital could
7 suggest was ECT, which is what he had on more than one
8 occasion which completely wrecked his memory, which he
9 would comment on all the time. In the last few years of
10 his life he would comment that his brain just didn't work
11 any more and he was sure it was to do with that.

12
13 Q. One of the things you say in your statement is that it
14 had a huge impact on his smaller family unit, so that being
15 his wife at the time and the children?

16 A. Yeah.

17
18 Q. And eventually they separated?

19 A. They did, and it was a very painful experience for
20 both of them and there is no doubt that they both
21 absolutely still loved each other, yeah.

22
23 Q. One, I guess, consequence of that, or an effect of
24 that was that you became the prime carer for him in around
25 2013?

26 A. Yep. His ex-partner asked me, she sort of said, "I
27 can't do this any more, I need to focus on the children",
28 and she asked me to take over the looking after and care of
29 him.

30
31 Q. You were living in Newcastle and you would come to
32 visit him in Melbourne?

33 A. Yeah.

34
35 Q. Particularly when he was very unwell?

36 A. Yeah.

37
38 Q. Those times you'd be trying to get a plan in place in
39 order to help him?

40 A. Yeah.

41
42 Q. What stands out to you in that time? Think about
43 those times you were coming to Melbourne trying to get the
44 plan in place, what stands out for you?

45 A. I think the not knowing, the trying to get a clear
46 picture of what was happening for him, what the hospital
47 were saying, what the staff were saying; just, the flow of

1 information, it was really hard to get information. It was
2 really hard to be a part of any planning, particularly
3 around discharge, and being part of - for me, it was about,
4 I wanted to understand his illness so that I could support
5 him the best I possibly could, and it was always really
6 hard to get a sense from staff, whether it be at the
7 hospital when he was in community mental health services
8 around participating and trying to get that information to
9 help me.

10
11 Q. You talk about a time in 2014 where you describe
12 William's condition becoming very bad and ultimately you
13 made the decision with his partner to send him to a sort of
14 a therapeutic environment?

15 A. Yeah.

16
17 Q. Which didn't work out for him?

18 A. Not at all, yeah.

19
20 Q. And so, he was admitted to an Emergency Department?

21 A. Yep.

22
23 Q. And you had to make the arrangements for that to
24 occur?

25 A. Yep, and I was interstate, I was recovering from a hip
26 replacement at the time. I remember calling all sorts of
27 people to try and get him out of where he was and
28 eventually a friend of mine agreed to drive the 120Ks to
29 pick him up and drive him back to the local Emergency
30 Department of where he normally lived in order to be
31 admitted into that mental health unit rather than being far
32 away from his usual supports.

33
34 It took quite some time to convince the Emergency
35 Department that he needed it. And I remember my friend
36 ringing me and having to talk to her about the sort of
37 language to use in order to get him admitted.

38
39 The next day he was admitted and the next day the
40 doctor almost - and it wasn't deliberate - but it felt
41 accusingly talking to me about how bad he was, and I just
42 said, you know - I remember just thinking, one part of that
43 system was like, he's not unwell enough and the other part
44 of the system almost saying, you know, you've caused this:
45 it was incredible, I remember that really clearly.

46
47 Q. Over the next period of weeks, the next few weeks, he

1 was given further ECT?

2 A. Yeah.

3

4 Q. And ultimately was considered well enough to be
5 discharged?

6 A. Yeah.

7

8 Q. During that time you were advocating for him not to
9 lose his job?

10 A. Absolutely. So, I was talking to his workplace and
11 the union in order to make sure that he had a job to go
12 back to, because I was really concerned that, if he didn't
13 have that to go back to, that that would just make life so
14 much harder for him. The workplace really struggled to
15 begin with, but as soon as I brought the union in that
16 paved the way for it to work, basically, and I was really
17 thankful that happened.

18

19 Q. And he was able to keep his job at that time?

20 A. He was, yeah.

21

22 Q. That was then followed by a period of time where he
23 appeared to be doing well, at least on the surface?

24 A. Yeah.

25

26 Q. And he'd found a share house to live in and was
27 working and apparently engaging in life?

28 A. (Witness nods.)

29

30 Q. Can you just describe what happened after the period
31 where he had officially divorced from his partner and then
32 bought his own apartment and that time?

33 A. So, my partner and I had moved back to Melbourne by
34 that stage and became - William and I were always close -
35 but I think really during those last couple of years
36 particularly close because he seemed to feel comfortable
37 just being with me and not having to convince me that he
38 was okay.

39

40 We spent a lot of time together. He actually borrowed
41 some money from us in order to buy the house because the
42 settlement hadn't quite happened, and so, we just did that
43 for him. I remember feeling quite concerned that he was
44 going to be moving into a house on his own, but he was
45 really clear that he wanted a space that he could have so
46 that the children could spend as much time with him as
47 possible, and that was a real driver for him around having

1 his own house, or it was an apartment.

2

3 He moved in and I think the loneliness really kicked
4 in really quickly and I could see that was going to be his
5 ongoing battle, and he really struggled with depression on
6 and off for those couple of two to three years.

7

8 He would take time off work in order to manage it. He
9 had a lot of leave up his sleeve so he was able to do that.
10 I think that the formal ending of the marriage was
11 something that really impacted on him, and his youngest
12 child really struggled to be comfortable with him. She
13 really wanted to and she never stopped loving him for a
14 moment, but I think she was trying to protect herself and
15 so she really didn't engage a whole lot with him, and so,
16 the apartment that he bought didn't really become the place
17 where his children spent a whole lot of time so he
18 definitely was on his own a lot.

19

20 Q. So, in March 2018, he quit his job?

21 A. Yeah.

22

23 Q. And didn't inform anyone in the family that that was
24 going to happen?

25 A. Yeah, so that was a really difficult experience for
26 all of us, we were really shocked, and he soon after
27 realised that he'd made a really bad decision and he did
28 try to actually see if he could get it back but he wasn't
29 able to, and from there things just spiralled completely
30 out of control for him.

31

32 Q. And there was a point in June 2018 where he attempted
33 to end his life?

34 A. That's right.

35

36 Q. And ended up in a psychiatric ward but didn't want to
37 remain there?

38 A. He ended up in a medical ward; they wanted to put him
39 into the psych ward after he was medically well enough, but
40 he and I negotiated that he not do that because he really
41 was adamant that he didn't want to go into the psych ward,
42 so he came to stay at our house.

43

44 Q. The idea was that that was with support from the
45 outreach service by the CAT Team?

46 A. Yeah.

47

1 Q. And you and your partner were able to be present at
2 home and manage your work hours to facilitate his care with
3 the CAT Team?

4 A. That's right, yep.

5

6 Q. The arrangement did work well for some time?

7 A. Yeah, it worked really well.

8

9 Q. And he ended up being connected to a community mental
10 health caseworker?

11 A. That's right.

12

13 Q. However, that was only for a limited time?

14 A. A very short period of time, and this had happened on
15 more than one occasion where he'd be linked in to that type
16 of support for a very short period of time, and he always
17 travelled better when he was linked in to a service and he
18 was always much more vulnerable when he wasn't.

19

20 Q. There was a point in time towards the end of 2018
21 where he found casual work?

22 A. Yes.

23

24 Q. However, he was let go from that job in January 2019?

25 A. That's right.

26

27 Q. And things became worse for him after that?

28 A. They did, yeah.

29

30 Q. Can you just detail the point in time when a friend of
31 his notified you that they were worried about him?

32 A. So, a very good friend of his who was an incredible
33 support texted me to say he'd just spent some time with
34 William and was very concerned for him, in that, he had
35 said something like, you know, "There's nothing else for
36 me, you should just put me down" or "I should just shoot
37 myself", you know, he made that type of a comment.

38

39 So I rang him and spoke to him and encouraged him to
40 come and spend some time with us, which he said he would
41 do, and so he came the next day. It just so happened that
42 I had five days off work in a row and so I was able to
43 spend that time with him. It was probably the most intense
44 five days of my life, apart from the five days I spent with
45 my mum before she died, and it - I felt like I was on
46 suicide watch for most of that time.

47

1 I spent every - apart from sleeping - I spent every
2 hour with him, and we just - I really wanted him to come to
3 a point where he could see that he needed help. I didn't
4 want to be the one that had to say, you need this or you
5 need that. And so, I would check in with him and he was
6 really unsure about what he wanted and what he needed.

7
8 Things had gotten a little bit tricky with his
9 ex-partner and kids around one of his kids not travelling
10 so well, and he was really anxious about that and I think
11 he felt to blame that that was occurring and that he
12 couldn't do anything about it.

13
14 It was coming to the end of the five days and I was
15 not confident that he should be on his own, so I'd arranged
16 with my other brother for him to go and spend the next
17 however long with him and his family, and William was fine
18 with that. However, I was really concerned about the state
19 of his mental health, and I remember getting up and getting
20 ready to go to work - I think it was a Tuesday or a
21 Wednesday - and he said to me, "I need help" and so that
22 was when I was able to - I asked him what sort of help and
23 we had a conversation, and I said, "I'll ring the mental
24 health triage" and they suggested that I bring him in.
25 They gave him a choice and he said, no, he will come in.

26
27 Q. He then went into like an assessment-type unit for
28 three days?

29 A. Yep, that's right.

30
31 Q. And he was assessed in that time, and there was a plan
32 made for him to move to the psychiatric ward?

33 A. That's right.

34
35 Q. Then progress to a PARC?

36 A. That's right.

37
38 Q. And have some referral to long-term mental health
39 management?

40 A. Yeah. It was really clear. It was probably the first
41 time I'd experienced such a clear plan coming from the
42 mental health service themselves, and they were really
43 clear with us what he needed and that he needed long-term
44 support. And I remember feeling so relieved that, finally
45 it felt like the system got it, and he was open to it, and
46 that maybe there was a way forward for him.

47

1 Q. Can I ask you about the last time you saw him when he
2 was in hospital.

3 A. My partner and I had organised to bring his car,
4 because his car was at our place, back to his apartment, so
5 we did that and met back at the hospital to spend some time
6 with him. I remember the nurse, there was this fantastic
7 nurse who had been there when we first came into the unit,
8 and she was there the day that I visited and she was really
9 clear with me that - she said, "You know, he presents so
10 much better on the outside but on the inside he is really
11 bad, he's travelling really bad", and she said that day
12 that he had given himself a 1 out of 10 for how well he was
13 feeling.

14

15 So we spent time with him and the plan was, the plan
16 hadn't changed, she said, "The plan is, this is what we're
17 doing", but she said, "There is an issue with the beds in
18 the psych unit at the moment, so look, we're just hoping
19 that will change as soon as possible."

20

21 Q. You left the hospital then on the Sunday?
22 A. That's right.

23

24 Q. You texted him on the Monday?
25 A. Yep.

26

27 Q. And by then he hadn't been moved to a psychiatric
28 ward?
29 A. That's right.

30

31 Q. You texted again on the Tuesday?
32 A. Yep.

33

34 Q. And what did he tell you?
35 A. He said, "I have been discharged and I'm going to stay
36 at Christopher's."

37

38 Q. And you immediately then contacted the hospital to
39 find out why that had happened?
40 A. That's right.

41

42 Q. And you were told that he'd been further assessed on
43 the Monday and that they had determined it was okay for him
44 to be discharged?
45 A. That's right.

46

47 Q. Were you told why you weren't included in any of that

1 discussion?

2 A. No.

3

4 Q. And so, he didn't end up going to a PARC?

5 A. No, he didn't.

6

7 Q. And so, how were you feeling at that time with all of
8 this going on?

9 A. I remember the panic that I felt when I found out that
10 he'd been discharged and I remember talking to the doctor.
11 By the end of the phone call I was hardly able to actually
12 say anything because I was almost in tears and then, as
13 soon as I hung up the phone I was - I was at work but I
14 just broke down and I remember saying to my boss - actually
15 I think I said it over the phone to the doctor, "This is
16 not going to end well." I actually couldn't believe what
17 had happened, that they had actually made a decision to
18 send him home.

19

20 Q. He ended up staying with Christopher for five days?

21 A. Yep, that's right.

22

23 Q. And then he moved back to his apartment on the Sunday?

24 A. Yeah.

25

26 Q. You had some text conversation with him or some
27 exchange?

28 A. Yeah.

29

30 Q. And you felt relieved that you had that connection
31 with him?

32 A. Yes, because things had been a little odd between us
33 and I had felt that there was something that wasn't - it
34 wasn't our usual conversation, and so, by the time I'd had
35 the last text with him it felt like it was a much lighter
36 conversation and that, I remember feeling extremely
37 relieved that that had occurred.

38

39 My plan was to ring him the next day to invite him to
40 come and spend the weekend with us, but I didn't want to
41 sort of put all that in that initial text because I didn't
42 want him to feel overwhelmed with whatever - I don't know,
43 I think sometimes you as a carer, you're always wanting to
44 support, but there's this balance between support and being
45 respectful and I always battled with that, so I didn't want
46 to overwhelm him with, he needed me, I just thought I'll
47 leave that invitation to the next day.

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Q. But the next afternoon you'd found out that he'd died by suicide the previous night?

A. That's right.

Q. Can I ask you about some of the fundamental changes you'd like to see to assist, and you've had exposure to for so long. One of the main things you identify in your statement is that the mental health system suffers because of patchy information sharing with families and carers. So, could you just describe that a little bit?

A. I think the thing that stands out to me is the lack of time that clinicians have in talking to family. From my experience, they're so time-poor. That, I know as a family, we often requested meetings and more information, and you could hear it in their voices, it was like they were so annoyed that that's what we were asking for; or it was just really hard to get them, or they would be saying, "Yes, let's do that", but to try and get that to happen was almost impossible.

Q. And you talk about - I'll leave this to you, this is in your statement, you say:

"It seems like the system uses the confidentiality rights of the individuals as an excuse to not share information with carers. At the same time the mental health system expects carers to provide ongoing support for their family members once they're discharged from hospital and other mental health services."

A. Absolutely.

Q. Another key change that you raise is that the system, the mental health system, should recognise the vital roles that carers play in the care of their family members' lives, and that's something you see as important?

A. Very. I just, I really see that the only way forward to support people with mental health issues is the idea that there are these different components of the team that are supporting that person, and that the mental health system, the clinicians, the people with the mental health expertise are part of that, but the friends and the family are so much need to be seen as being a part of that as well, particularly around ongoing support. Because, you

1 just can't provide - the system can't do it, and yet they
2 expect us to do it, but they give us so little information
3 that we often feel like we're doing it really badly and we
4 wished if we only knew more, or if there was more of a
5 sense of team, then you're not feeling like you're doing it
6 on your own.

7

8 MS COGHLAN: Thank you, Ms Thomas. Chair, are there any
9 questions from the Commissioners?

10

11 CHAIR: Q. I just have one. Thank you very much for
12 being prepared to share those reflections with us today, it
13 was very powerful.

14

15 I noted you said that, at various points along the
16 journey, that your brother connected well with clinicians
17 post the discharge and how important I think you said him
18 being linked in to a service was but that it was usually
19 only for such a short period of time. How was that short
20 period of time explained to you? Why did people say they
21 could only provide that support and how did he respond when
22 the support came to an end?

23

24 A. It's a really good question. I'm not sure why it was
25 deemed that he only required short-term. I think what
26 really stood out to me was the last time when they said he
27 needed long-term, it felt for the first time that they
28 actually got it in relation to what he needed, but it had
29 taken six and a half years: like, six and a half years of
30 being unwell means you need long-term; whereas actually
31 six months being unwell you potentially need long-term, but
32 you don't get it unless you've been unwell for long enough.
33 I don't know, that's my guess, yeah.

34

35 CHAIR: Thank you very much.

36

37 MS COGHLAN: May the witness be excused?

38

39 CHAIR: Yes, thank you.

40

41 <THE WITNESS WITHDREW

42

43 MS COGHLAN: I'm sorry, I'll just wait for the live
44 stream.

45

46 The next witness to be called is Rose Cuff and I call
47 her now.

1 <ROSE CUFF, affirmed and examined: [11.02am]

2

3 MS COGHLAN: Q. Ms Cuff, you've made a statement to the
4 Commission?

5 A. Yes, I have.

6

7 Q. I tender that statement. [WIT.0001.0026.0001] I'll
8 just ask you to sit forward, please, so that the
9 Commissioners can hear you. You are trained in
10 Occupational Therapy and Brief Family Therapy?

11 A. Yes.

12

13 Q. You've been working specifically in the area of
14 children and families where a parent has a mental illness
15 since 1995?

16 A. That's right.

17

18 Q. You've been involved in developing a range of programs
19 relating to children in families where a parent has a
20 mental illness?

21 A. Yes.

22

23 Q. In particular, you were part of the development of the
24 strategy for FaPMI, and FaPMI stands for Families where a
25 Parent has a Mental Illness?

26 A. That's correct.

27

28 Q. And that occurred in 2007?

29 A. Yes.

30

31 Q. You're presently the Statewide Coordinator of the
32 FaPMI program?

33 A. Yes.

34

35 Q. You're based at the Bouverie Centre?

36 A. That's right.

37

38 Q. That's an integrated practice research centre at
39 La Trobe University?

40 A. Yes.

41

42 Q. It is the statewide coordination body for FaPMI?

43 A. Yes.

44

45 Q. What is your role as the Statewide Coordinator?

46 A. My role is to oversee with the Bouverie Centre the
47 implementation of the program across the various adult

1 mental health services and network partners in Victoria to
2 ensure that there's some sort of coordination of those
3 activities.

4
5 Q. I'll ask you a bit more about that later, but
6 separately you hold the voluntary role of Executive
7 Director and co-founder of Satellite Foundation?

8 A. That's right.

9
10 Q. And Satellite is a not-for-profit community-based
11 organisation that aims to provide a voice and creative
12 space for children and young people living in families
13 where a parent has mental health challenges?

14 A. Yes.

15
16 Q. Can I ask you about the FaPMI program. You've
17 explained a little bit about it existing in the area of
18 adult mental health. Can you explain more about it,
19 please?

20 A. So, the FaPMI program is an endeavour supported by the
21 Victorian State Government to really more routinely
22 identify parents with mental illness as they enter the
23 service and as they go through the service, and this is
24 done by the employment of area mental health services of
25 senior clinicians in FaPMI coordinator roles to influence
26 and shape the way that those services are delivered to more
27 routinely identify parents, their children and family
28 members.

29
30 Q. Okay. Sorry, go on.

31 A. It really is, in summary, it's seen as a powerfully
32 preventative opportunity so that parents are identified and
33 their children are identified more routinely so they don't
34 get missed as they come into the service.

35
36 Q. So there's two aspects, there's the identification?

37 A. Yep.

38
39 Q. And then there's how that family and those children
40 might be assisted?

41 A. Yes, so it's identification and validation of role and
42 then having a much more comprehensive understanding of how
43 that family and those children are travelling in their
44 mental health and wellbeing.

45
46 Q. One of the things you say in your statement is that:
47

1 "The FaPMI program works with services to
2 utilise a strength-vulnerability framework
3 rather than a risk oriented one."
4

5 Could you just explain that please?

6 A. I think - and I'm sure the Commission has heard about
7 the pressure that particularly adult mental health services
8 are under and the stretch that they are under to manage a
9 large number of people seeking service, and under those
10 circumstances when there's children, young children
11 particularly, involved there can be, I guess, a danger that
12 it becomes very risk - the lens is risk oriented, and there
13 can be concerns that children are necessarily at some sort
14 of risk or danger when a parent is experiencing episodes of
15 mental ill-health or mental illness.
16

17 And so, what we as a program are endeavouring to do is
18 to assist services, particularly clinical mental health
19 services, to understand a more balanced view looking at
20 both the strength and vulnerability, and trying to skill up
21 the workforce to engage in conversations - I won't call
22 them assessments - but more conversations that take more
23 time but that will engender a view from the parent or other
24 family members about what's going well and what's more of a
25 concern, and what the services, both within mental health
26 and outside mental health, can do to strengthen those
27 supports and those resources and attend to issues of
28 concern.
29

30 So it's more balanced, notwithstanding sometimes there
31 is risk and that needs to be responded to and the services
32 need to know how to do that.
33

34 Q. I might come back to that. One of the things that the
35 local FaPMI coordinators also support are peer support
36 programs for young people?

37 A. M'hmm.
38

39 Q. So that there are specific programs that young people
40 can attend and participate in.

41 A. That's right. We've been developing over a number
42 of years specific and targeted spaces, peer support
43 programs for primary school aged children, teenagers and
44 parents. Some of those programs bring children and parents
45 together that facilitate communication, open
46 communication/understanding about what's happening within
47 that family.

1
2 If we accept that mental illness is still hard to talk
3 about within families, within community, but children in
4 particular can struggle to understand what's happening to
5 their mum or dad and in their family, so the peer support
6 connects them to other children and young people and
7 parents that may have similar experiences and then reach
8 out to - it makes it easier to reach out and connect with
9 community supports as well.

10
11 Q. Can I ask you about what the potential impacts on
12 families living with a parent with a serious or recurring
13 mental illness might be, and I'm really talking about the
14 potential impacts on children.

15 A. Sure. I think when we talk about impact, the first
16 thing I would like to say is that it's not a linear thing,
17 there's what we call a bidirectional impact. So, the
18 impact will vary according to the nature of the mental
19 illness, the episodic nature of the mental illness, and how
20 it moves and how it changes.

21
22 And also in these families the developmental ages and
23 stages of children. So, you know, children change and grow
24 and so they bounce off each other, and so I think impact
25 should be viewed in a sort of fairly systematic way and
26 sort of in a whole-of-family way.

27
28 Aside from that I think the impact is that it can be
29 extremely traumatic for families to experience mental
30 illness in a parent or family member, and particularly for
31 children it can result in family breakdown; there's high
32 rates of separation and divorce in families where there's
33 mental illness, and particularly if it's a later onset; if
34 it happens when the person's already a parent and there's
35 been no sort of formal understanding of that.

36
37 Children can struggle to understand, as I've said,
38 about what's happening to their family. Statistically, we
39 know that this group of children are more at risk of
40 developing their own significant mental health issues.
41 They're more than twice as likely to do that without early
42 intervention and support. We also know that we can reduce
43 that risk with early intervention and family-focused
44 interventions.

45
46 There's also the risk of children being exposed and
47 experiencing cumulative harm. Not always. When I say

1 these things it's not an equal picture, it doesn't always
2 happen, but certainly when families are struggling to
3 manage day-to-day parenting and without adequate support
4 children can be exposed to harm, to trauma, to not getting
5 access to the things that all children and young people
6 need to develop, and they develop their own issues,
7 significant issues.

8
9 Q. One of the things you touched upon was the idea of
10 effective early intervention. Can you just explain that
11 further in terms of the fact that there aren't easy to
12 access programs to assist?

13 A. So, the system at the moment is such that, for
14 children and young people in particular, if they're living
15 in families where there's mental illness in the parent or
16 parents, and they're struggling with their own - the
17 children are struggling with issues themselves and they
18 don't qualify for, say, being seen by a CAMHS service, or
19 CYMHS or even Headspace, there's very little available,
20 affordable, accessible services for children on an ongoing
21 basis to seek support.

22
23 Schools, which are very well placed to understand and
24 provide support, have limited access to school counsellors,
25 at the moment anyway, and so they consistently fall through
26 the gaps, the children.

27
28 Particularly primary school aged children, which I
29 think is, when I talk about early intervention, I'm talking
30 about early, early primary school and young children, the
31 perinatal period. And, if parents aren't identified
32 routinely, if children aren't identified routinely, then
33 they won't be able to be offered anything. They
34 consistently fly under the radar and become invisible.

35
36 Q. One of the things you say in your statement is that:

37
38 "Children who have a parent with a mental
39 illness can become carers for many
40 reasons."

41
42 Can I ask you to articulate those reasons, there are
43 three in particular that you refer to in your statement.

44 A. Yes, children - and I refer to them taking on caring
45 roles and responsibilities. In my statement I talk about
46 the notion of young carers being a term that is used
47 extensively in our service system, and that many young

1 people and young adults do refer to themselves as young
2 carers. But I think one of the issues is that many
3 children and young people don't see themselves as young
4 carers, they see themselves as "doing the work".

5
6 So, children can take on those roles; primarily, the
7 first reason is in the absence of any other adult. So, if
8 we take a family where there's a single parent and very
9 limited other adults in the family, that children, as we
10 know, will step up and take on those roles of cooking,
11 shopping, cleaning, looking after siblings, paying bills,
12 giving medication, because there's nobody else to do it.

13
14 The second reason why a child or young person might
15 take on those roles is because they've just always done it,
16 it becomes normal to their way of life. I mean, I've
17 talked to many children who will just say they're doing
18 extensive amounts of work, missing school for example and
19 staying home to look after their parent, but it's just what
20 they do and they don't see anything wrong with that.
21 They're sort of ordinary children doing extraordinary
22 things, really.

23
24 The third reason is really again an absence of any
25 other social support or networks. They remain invisible to
26 everybody in the community within family, and it's not easy
27 for them to talk about. I think it's not easy for
28 children. There can often be a bit of a code of silence
29 within families. Parents are very - mostly parents
30 particularly are fearful of reaching out for support for
31 fear of being judged, for fear of children potentially
32 being removed from their care, and it's the biggest barrier
33 to help-seeking, is this fear of being judged as being a
34 poor parent or a bad parent.

35
36 Q. Does that exist for children as well in the sense that
37 they might fear being taken away?

38 A. Absolutely, yes. They work out ways to, sometimes to
39 convince people that everything's fine: things like, you
40 know, doing shopping and putting empty cans of food in
41 cupboards with the label around the right way so it looks
42 like, if anyone comes, there's food in the cupboard; those
43 kinds of things that children may do to protect, they want
44 to protect their parent and family. So, won't speak up,
45 will be reluctant to speak up in places like schools and
46 with friends.

47

1 Q. What about cultural background of families and the
2 impact that might have on a child being part of a caring
3 role?

4 A. So there's two parts to that: I think there's the
5 culture within families or family culture and cultural
6 norms that is around how caring is perceived within
7 families, whether it's caring for or caring about, and
8 they're very different things I think.

9

10 And so, if it's in families where you step up and you
11 do things as part of - it's just done, I think that's seen
12 as sort of again normal. I think cultural background is
13 enormously significant in how we talk about mental illness,
14 caring, caring roles, that to some families of different
15 cultural backgrounds - even the language we use around
16 mental illness is not something they would use readily or
17 easily.

18

19 So, we have to really sit in a listening and time-rich
20 space which is not readily available for the system as we
21 know it now, to understand deeply how mental illness as we
22 describe it is understood and experienced by different
23 families of different back grounds.

24

25 Q. Just picking up on that point. In your statement you
26 say:

27

28 "Mental illness is not a term always used
29 by families."

30

31 Can you provide a specific example of that?

32 A. So, I think that Aboriginal and Torres Strait Islander
33 families would - I've never known them use the word "mental
34 illness", they use their own language or other
35 terminologies to describe that: emotional wellbeing might
36 be one of them, but I think we can't assume ever that when
37 we talk about mental illness that it's got the same
38 understanding to the family or the young person in front of
39 us, so we have to find out what language is used and check
40 out - we need to check out all the time that we're saying
41 things and talking about what's happening in this family
42 that resonates for them, not just for us.

43

44 Q. In the example you've just given, it might be that
45 there's not even considered to be a caring role, but
46 rather, it's a family and a community working together to
47 support?

1 A. Yes, and again, I don't think we should assume that's
2 not okay. I think we should again take time to listen and
3 find out how that system of support is operating for that
4 particular family and whether they want or need support
5 from their community and what that might look like.
6

7 Q. I just want to ask you about the main challenges that
8 young carers may face in their caring role. You've already
9 touched on one in terms of struggling to go to school.
10 What about access to school and support services?

11 A. So, one of the things I feel very strongly about is
12 access to services for all families, but particularly for
13 young children in particular. Many families where the
14 parent's got mental health issues or mental illness are
15 struggling with multiple challenges: difficulty in driving,
16 running a car, using public transport, interacting with
17 other parents at school, getting out and doing things that
18 require them to get from A to B.
19

20 If we accept that children and young people benefit
21 from social interaction and doing things, like going to
22 basketball or whatever, those can be mentally challenging
23 for parents and so what happens ultimately is that children
24 and young people don't get to those things, they don't
25 actually get to those very important social places that we
26 know provide protective factors for them.
27

28 So access, whether it's through paid for transport or
29 community support, there's very little possibility for
30 children to get from A to B. They can't even go on
31 volunteer transport because that's not legal for children
32 to travel by themselves.
33

34 Q. Sorry, just to move on to the challenge of struggling
35 to keep up with the requirements for school.

36 A. So, I've already mentioned that it's not unusual for
37 children to stay home from school to keep an eye on their
38 parent, particularly if there's no other adult in the
39 house. That can mean that they miss out on, not just
40 education and doing their educational work, but also their
41 friendships, their social connections.
42

43 They're more at risk of being bullied for not getting
44 to school enough, not doing the things that they think
45 other children do. There's even examples of children being
46 ostracised by their peers because they may have seen one of
47 the parents being at school and perhaps looking different.

1 So, there's many stories of children finding school very
2 lonely and challenging places, particularly if the school
3 isn't able to provide support.
4

5 Children in caring roles also can experience a really
6 wide range of emotions. All children do, we all do, but
7 they can range from feeling extremely worried and concerned
8 and anxious about their parent or parents and family, and
9 overwhelmed and overburdened, to then feeling very
10 resentful and angry about the work that they're doing and
11 the sense of losing out on what - of being different and
12 looking at other friends and peers to be doing stuff they
13 never get to do. I think that's very challenging when they
14 have nowhere to take those - where do they take those
15 feelings?
16

17 I think the other one is that children, if a parent's
18 perhaps - if you think, if you accept that they can take on
19 these significant roles and responsibilities within the
20 home at various times, and that's part of their identity,
21 and they feel valued in that role: if a parent is perhaps
22 receiving treatment in an inpatient facility or a PARC and
23 then comes back and wants to understandably resume that
24 role, that can create conflict within a family. And, when
25 there's no way of that being communicated, or there is a
26 service that can facilitate some conversations around the
27 roles, parenting roles, children's roles, family roles,
28 that can very quickly spiral into conflict for a child or a
29 young person and the parent.
30

31 Q. In your statement you say this, in summary really,
32 about all of those challenges:
33

34 "They can contribute to a young person who
35 has that caring responsibility not having
36 hopes and dreams for the future."
37

38 Could you just explain that?

39 A. I think that comes from one of the other challenges I
40 omitted to say before and I've mentioned already, is
41 isolation. We've heard a bit about that this morning
42 already, that very quickly families can become isolated and
43 managing things on their own. For children and young
44 people, if they are feeling a sense of isolation and that
45 their future, their trajectory, is one of their parent
46 perhaps not recovering - the whole notion of recovery I
47 think is incredibly important to keep in mind here and how

1 we discuss with children and young people, and families,
2 the recovery-oriented approach; that children can very
3 easily wear this sense of hopelessness and the revolving
4 door in and out of hospital and not having the possibility
5 of them going on to finish school or to have a career or to
6 make friends or to achieve in their own right, and that's
7 something that we hear, that's a very common expression
8 from children and young people in these families, is that
9 they worry that also they are going to become - they will
10 end up being like their parent, to be frank; that they
11 worry that they will also inherit bipolar or schizophrenia
12 or depression, that's a very common fear for children, so
13 that contributes to the sense of really uncertainty about
14 their future.

15
16 Q. I've already asked you about FaPMI, but in the context
17 of seeking to reduce the impacts you've talked about
18 earlier, can you just briefly talk about FaPMI and then
19 also about Satellite?

20 A. So, the FaPMI program, as I said, is really working to
21 improve the way that mental health services can work and
22 respond to, in particular, parents in the adult system. A
23 large part of that is really working to equip services and
24 clinicians to have these, what I'll call conversations in
25 which they engage with the whole family ideally, but in
26 particular the parent as they come into the service so that
27 the parent's fear of being judged and discriminated is
28 reduced and they can actually set up mechanisms for support
29 early on.

30
31 So, really, that's done through consultation,
32 workforce training, but also sometimes role modelling those
33 kinds of conversation that can occur between a clinician
34 and a parent or a family, and sometimes a child as well.

35
36 Q. Then what about the programs developed by Satellite?

37 A. So, the programs developed by Satellite really aim to
38 fill a gap that, really around harnessing the potential and
39 strengths and resources of children and young people,
40 recognising that for them to individuate in a sense and
41 realise their hopes and dreams and do the things that all
42 children and young people need to do, that we create spaces
43 where they can come and meet others, but also use art and
44 creativity as a way of tapping in - to give them a voice.

45
46 I think that's one of the key things about the
47 programs, is children's voices get lost in this narrative.

1 It's very hard for them to be heard, they become invisible.
2 In those spaces, in the same way as the other peer support
3 programs, they actually get heard, they get seen and they
4 get listened to.

5
6 Q. Can I just ask you about those peer support programs,
7 there are a number of programs that currently operate. Can
8 you just describe what they aim to achieve?

9 A. Yes. So, I should add that the programs that I'm
10 describing aren't routinely available across the whole
11 state. We're developing them and they are under the - some
12 of them under the banner of the FaPMI program, but they are
13 not implemented statewide as yet.

14
15 Q. Sorry, just before you move on then, can you just name
16 those programs, please?

17 A. Yeah, so the CHAMPS program was initially developed by
18 me many, many years ago and is a program for primary school
19 aged children, so around 8-12, who have a parent or parents
20 with a mental illness, and the key component of that really
21 is providing a peer support space, facilitated space where
22 children can come together. It's a psycho-education
23 component, so they get to understand what different mental
24 illnesses are. They learn about self-care and
25 self-compassion, and meet others, share stories and also
26 have fun, which is pretty important.

27
28 The program's been recently reviewed to include a
29 parent component. So, in that model, that CHAMPS model,
30 the children come at the same time as their parent or
31 carers, or sometimes grandparents or aunts or uncles, and
32 they spend some time together. Then they separate off and
33 look at a particular topic and then they come together
34 again, and that facilitates much more open communication
35 once they go home, which is where most of the conversations
36 occur, around how they talk about mental illness, how they
37 communicate with each, so it promotes much more open
38 communication within the family.

39
40 Q. What about Space4Us?

41 A. Space4Us is a program for 13-18-year-olds that has a
42 similar core aim, which is to provide a space where
43 teenagers can meet other teenagers. Both the programs,
44 CHAMPS and Space4Us, have a peer leader component or a peer
45 facilitator, so a young person with lived experience who
46 comes to co-lead the program and talk a bit about their
47 story and what was helpful for them.

1
2 Both those programs can be run as holiday programs.
3 They've been adapted so they can be run also as a camp and
4 also as after school programs over about eight weeks.
5

6 Q. Then, what about SKIPS and Mi.Spot?

7 A. So, SKIPS stands for - all these acronyms - SKIPS
8 stands for Supporting Kids in Primary Schools. That's not
9 a direct program, it's a mental health promotion program in
10 primary schools. It has been running for a number
11 of years, it's not currently running because of funding
12 limitations, but it goes into primary schools in Grades 5
13 and 6 and works with students, with teachers and with
14 parents and includes a person living with a mental illness
15 and a young person who's, I guess, a young carer, and talks
16 about the spectrum of mental health and wellbeing, talks
17 about what mental illness is and what it isn't and how
18 people might experience a mental illness and the kinds of
19 things children might notice. It's a really wonderful way
20 to equip teachers in primary schools to be more attuned to
21 a student who might be in a family where this is happening.
22

23 One of the outcomes of that program was that children
24 felt more able to approach their teachers, to say, "That's
25 my family, that's what's happening in my family; that's my
26 mum or that's my dad."
27

28 Q. What about Mi.Spot?

29 A. Mi.Spot is a fairly new online intervention, it's
30 still in its proof of concept stage, which is an
31 online six-week program for young adults aged 18-25 who
32 have a parent or family member with a mental illness. It's
33 all online and it has different topics that goes through
34 week-by-week, it has a chat facility as well.
35

36 Q. And what's its purpose?

37 A. Its purpose is to both connect, via online, connect
38 people into seeing they're not alone. All of these
39 programs have a very similar core thing: you're not alone,
40 you're not responsible for your parent's mental illness,
41 there are other people like you, it's important to look
42 after yourself, there's information you can get about
43 what's happening to both you and your family, so there's
44 some very core key messages in all these programs.
45

46 Q. Can I move on to ask you about ways in which the
47 mental health system could better support young carers and

1 families. You've obviously given some examples of programs
2 that might not be running at present, but other key aspects
3 which has arisen in your evidence, the idea of the routine
4 identification of children of parents with mental illness?

5 A. That would be my key message, I think, and what the
6 FaPMI program is endeavouring to do, its system change
7 takes time, but routine identification and engagement
8 with - it's not enough to identify, we need to take time as
9 a service system, both within mental health and all the
10 services that wrap-around the service system in the mental
11 health system.

12
13 So, GPs is a good example and primary health services,
14 to be on the lookout to understand that vulnerable parents
15 take time, and that if we take the time to identify,
16 acknowledge and engage with vulnerable parents and their
17 children in the long-term we're going to be able to put
18 supports in place for those children and potentially break
19 that cycle of intergenerational trauma and vulnerability.

20
21 Q. What about the idea of planned respite?

22 A. So, planned respite used to be readily available, it's
23 very hard to do now. I think that's part of this idea of,
24 the other key thing is care planning. We plan for
25 bushfires, our families are encouraged to do bushfire plans
26 in high fire prone areas, but the idea of family care
27 planning for a time when a parent becomes unwell is
28 critical and that everyone contributes to that care plan.
29 And so, children are part of that: children know what to do
30 if their mum or dad becomes unwell.

31
32 They know very well what to do, often they're very
33 attuned to the warning signs, and there's a plan put in
34 place and that might be going to stay with a family member,
35 it might be a case manager, it might be someone calling a
36 family meeting. But we want to make it less reactive and
37 less crisis-driven. I'm sure the Commission's heard a lot
38 about the system being stretched and being quite reactive
39 at times. I think for children we need to take a step back
40 and think, we need to act early, we need to plan and we
41 need to have things in place. I think that's another core
42 way the system could be changed.

43
44 Respite's a good example, I think there's a lot of
45 stigma around this notion of respite, that somehow the
46 parent has failed. It should be seen as a strength, it
47 should be seen as a parent making really good decisions to

1 put things in place when they need to be put in place.

2
3 Q. You've already talked about targeted online supports
4 for young people, so I won't ask you to elaborate on that,
5 but the next area that you see as a potential area for
6 change is clear access to services?

7 A. Yes, and I've talked a bit about that but I think that
8 when we talk about services I think it's the something in
9 between, there's spaces and places in between that are not
10 available for children and young people and their families
11 in the community, which is sort of that, it takes a village
12 mentality, that where do young people and children go when
13 they've got concerns about their family, where they want to
14 share their stories and their experiences and this plethora
15 of emotions that kind of eats away? Where do they go to
16 get information about what's happening with their parent or
17 family? How do they get just practical support? You know,
18 if they're already doing shopping and cleaning, where do
19 they go to get support to do that.

20
21 There needs to be more use of, not just online
22 supports - I think online for young people is good, but we
23 also need to think about younger children having a voice
24 here and their parents and family. So, I think there's
25 potential for some sort of targeted online supports being
26 enhanced. Like, Kids helpline is a good example, that's a
27 great resource, but I'm not sure that Kids helpline is
28 targeted enough for this group of children. I encourage
29 children to ring Kids helpline, but their knowledge and
30 understanding of this particular issue is perhaps limited
31 and could be enhanced.

32
33 Q. Just finally, and this has come up in the course of
34 your evidence, the idea that there need to be universal
35 messages of recovery and possibility for children?

36 A. Yes, I think that there is real scope for us as a
37 community and as services to be more - I haven't talked
38 much about the fragmentation of the system, but I think
39 there's evidence in earlier witness statements - but I
40 certainly feel strongly that the service system is
41 fragmented and hard to access.

42
43 But that, if we have messages in community, public
44 health messages almost, within schools and places where
45 families go routinely about that, as community and as
46 services we are up for those conversations, that we are
47 prepared to talk with children, with families, about mental

1 health and wellbeing right from very early on when people
2 might have concerns that something's not quite right,
3 through to where there's a serious and recurring mental
4 illness, and that there's so many elephants in the room at
5 those times that we need to use public places and social
6 media to get messages to young people that it's okay to
7 talk about this and, wherever you go, you can talk about
8 it. I think it's far too separated.

9
10 MS COGHLAN: Thank you, Ms Cuff. Chair, do the
11 Commissioners have any questions?

12
13 CHAIR: Q. I just have one, please. Thank you very much
14 for your evidence. We have heard throughout the course of
15 this Royal Commission some very powerful recollections from
16 children and younger people about navigating the mental
17 health system alongside their parents and the challenges
18 that poses very often.

19
20 So, we've heard, despite their resilience and great
21 determination and love, how hard it might be when someone's
22 in crisis to get the support, so how to navigate the triage
23 systems that are mental health and other things. I think
24 we heard very powerfully this morning of even adults having
25 to coach others on how to use the right language.

26
27 In the models that you've anticipated for the future,
28 what role of advocacy is there for young people who are in
29 caring roles to navigate this complex mental health system
30 that we're thinking of? Is that something that the FaPMI
31 in the area mental health services should be taking on when
32 they identify and engage with young people or where would
33 you think that might come from?

34 A. I think it should be part of the work that's
35 undertaken at every level of work, in the planning and care
36 of a person with a mental illness if they're a parent or
37 any family member, that the children and young people who
38 are in those families and, with the consent of the parent,
39 should be supported to have those skills, to be able to
40 navigate systems, to know how to seek help, to know who to
41 ring at any time of the day or night, about how to talk,
42 how to get the right language to get the right help, about
43 how to access the independent mental health advocacy
44 support services.

45
46 So I think it's actually, it's almost like coaching
47 not to be afraid to help young people to take on those

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skills and to support them in building those skills, and it's certainly part of the Mental Health Act that children should be supported in their caring roles and that's part of that, is equipping them with the confidence and not to feel scared to do that.

I think sometimes the mental health service can be quite confronting when it's a young person who is advocating on behalf of their family or their parent or their loved one and maybe feel that they're too young to be doing that. With the right support I think sometimes it's the only way and it gives the young person some agency as well. So, I see that very much as part of what the FaPMI program can do, is to advocate for that kind of support.

Q. I presume also, if there's a greater take up of advance statements, that also might become part of that process as well?

A. Yes, that would be very good. I think the uptake of advanced statements has - I'm not sure exactly how it stands, but I think if it was routinely - certainly in the training that was provided around advance statements and nominated persons, the issue of young people, young carers was part of that and that they should be included where they've asked to be in with - you know, where it's appropriate they should be included.

CHAIR: Thank you. Thank you very much.

MS COGHLAN: Thank you. May Ms Cuff be excused?

CHAIR: Yes, thank you.

<THE WITNESS WITHDREW

MS COGHLAN: Chair, is now a convenient time for a morning break?

CHAIR: Yes, thank you very much.

SHORT ADJOURNMENT

MS COGHLAN: The next witness to be called is Jesse Morgan, and I call him now.

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<JESSE MORGAN, sworn and examined:

[12.04pm]

MS COGHLAN: Q. Jesse, you've made a statement with the assistance of lawyers for the Royal Commission?

A. Yep.

Q. I tender that statement. [WIT.0001.0029.0001] You've been a carer for your mum since you were a teenager?

A. In an unofficial role and in an official role, yes.

Q. When did you commence an official role?

A. In about 2015.

Q. You are now 25 years of age?

A. Correct.

Q. Can I just ask you about your experience of being a carer, that unofficial role that you mentioned and growing up. First of all, who was in the home when you were growing up as a teenager?

A. As a teenager, it was myself, my mum and my brother. And in the unofficial role as a carer I was - my mum had significant mental and physical health issues that meant that she - including agoraphobia, which meant that she stayed in the house and would stay in her room, and it just meant that, yeah, I kind of had to step up into - and be more mature than I was and, like, do a whole bunch of stuff around the house, go shopping, provide --

Q. Can I just interrupt. You were around 14 years of age at the time that you're describing?

A. Correct, yeah.

Q. And your brother then was about 8 years-old?

A. Correct.

Q. Sorry, I interrupted you, you were talking about the things you had to do?

A. Yeah, so at that time I had a job which, at different points, I was working six days a week to earn money to help provide for the family, while going to school and doing extracurricular activities, yeah, as well as trying to be at home and trying to be responsible for myself and mum and my brother.

Q. You said you did cooking as well and that one of the things you say in your statement is that you ate a lot of

1 pesto pasta?

2 A. Yeah, I wasn't a great cook, so we had the same
3 rotation going through tuna - pasta is banned in our
4 household now.

5
6 Q. Never to be eaten again?

7 A. Yeah. I kind of didn't really know much about cooking
8 or anything so I just stuck to what I was okay at cooking
9 and easy things that didn't really need much, and they were
10 cheap, 'cos we didn't have a lot of money.

11
12 Q. What supports were around for you?

13 A. I didn't really have much support. That was a
14 combination of - yeah, mum had her case managers and people
15 that she kind of would interact with, but myself and my
16 brother didn't interact with supports. There was a couple
17 of reasons for that, the first being I didn't like talking
18 to people. I had a bad experience with a counsellor when I
19 was younger and, yeah, I didn't really like sharing
20 emotions. I didn't know how to deal with them and, yeah,
21 wasn't great at it so I just decided not to.

22
23 The other reason for that being, we kind of lived in a
24 constant fear of being separated from each other. The
25 Department of Human Services kind of hung over our heads as
26 a threat of, if they came and knew the extent of how we
27 were living and the issues that were going on in the
28 household, then my brother and myself and my mum would all
29 be separated and taken into different foster care
30 situations. How true that was, I don't know, but we always
31 felt like engaging - or at least I felt like engaging in
32 help and telling people the extent of what was going on,
33 that threat would be realised.

34
35 Q. You talked earlier about the things you were doing
36 around the house, I guess in terms of practical things.
37 Another aspect of you caring for your mum was that you had
38 to take turns to leave the house, you and your brother,
39 that you'd rotate that role, someone had to be home with
40 her?

41 A. Yeah. I guess that mainly started when I was outside
42 of school, outside of high school. I would stay home
43 during the day and help around the house with mum and make
44 sure that she was going okay, and then when my brother got
45 home from school he would take over and, like, often times
46 we would end up fighting about who had to stay home just
47 because we both had plans on a Friday night or whatever it

1 was. Yeah, we agreed that one of us needed to be home in
2 case mum needed something.

3

4 Q. Can I ask you about 2015?

5 A. Yep.

6

7 Q. And just about your mum's condition then. What
8 happened for her at that time?

9 A. In 2015 towards - well, it started about halfway
10 through the year but it came to a head towards the end of
11 the year, my mum had poisoning, she was being poisoned by
12 the medication that she was on, and to the extent that she
13 was having hallucinations, both audio and visual. She
14 could feel things in her skin, on her skin, that weren't
15 there. She had voices telling her things, she had - like,
16 yeah, we've got a lot of stories about different things
17 that happened.

18

19 It came to a point where, as a carer, I was helping
20 her in the bathroom, going to the toilet, showering, just
21 helping her to get up from chairs; like, we pretty much had
22 to be in the same room as her just to make sure that she
23 wasn't falling over or something.

24

25 Then, towards the end of the year she came home from
26 something and she had fallen over in the front yard, and I
27 remember being asleep and I could hear screaming. I got
28 woken up to screaming and I ran outside and mum was on the
29 ground and she was telling me that someone - or she was on
30 fire, she felt like she was on fire.

31

32 I remember being like, I need to call an ambulance but
33 having a real conversation in my head as to whether I
34 should call an ambulance because my mum had specifically
35 told me that she doesn't want me to call an ambulance
36 because she'll get taken to the psych ward. So, it was,
37 yeah, a real kind of battle in my head of whether I, in my
38 mind, betray my mum's trust or call an ambulance to get her
39 the help that she needs.

40

41 Q. Ultimately, you did call the ambulance?

42 A. Yeah, I called an ambulance and she got admitted to
43 hospital, firstly to Box Hill, and then she was put on an
44 involuntary order - I'm not sure the name of it.

45

46 Q. Yes.

47 A. But where she got admitted to the psych ward where

1 they tried to wean her off her medication, and like, yeah,
2 she was put onto medication. I remember on Christmas Day
3 in 2015 we went to go and see my mum at Maroondah, and we
4 had to travel by public transport, and the round trip was
5 about five hours on public transport to go and see my mum,
6 and we got there and my brother didn't want to go in the
7 room because he didn't want to see mum in that state.

8
9 And I went in there and mum was drooling, she couldn't
10 control what she was doing, she didn't recognise that I was
11 there. She, like, had no idea we were there. I stayed
12 for, like, five minutes just being in the room and we left
13 back home to, I think, have a frozen meal for Christmas.
14 Like, yeah, it was pretty hard.

15
16 Q. And she spent three months there?

17 A. Yeah. She spent three months from admission to
18 getting checked out, and it was a pretty tough
19 three months. I kind of had to, like, look after my
20 brother. He was almost an adult at that time so didn't
21 need much looking after, but kind of we were in it together
22 and he was - yeah, we were trying our best.

23
24 Mum came out of hospital and was off the majority of
25 her medication, but she was treated in a way that was
26 inhumane and, like, she was almost comatose by medication
27 to a point where we didn't recognise who she was and she
28 was just - yeah, she wasn't our mother. But she came out
29 of it and was determined not to go back, not to get into a
30 position where that could happen again.

31
32 Since then she's empowered herself and done a really
33 amazing job at creating and maintaining a support network
34 for herself that, yeah, allows her to get better and
35 better, but it was self-driven.

36
37 Q. You say in your statement that she now only needs
38 assistance for a few things such as going to the shops or
39 lifting heavy objects and things like that?

40 A. Yep.

41
42 Q. And that essentially it's easier to be her carer now
43 as compared to other points previously?

44 A. Yeah, I feel like my role as a carer now is less
45 around physical help and more around emotional support and
46 championing, and just kind of, yeah, trying to keep her
47 going and telling her she's doing a good job; whereas it

1 used to be much more physical and, like, laborious.

2

3 Q. You mentioned earlier about being an official carer
4 and so what you mean by that is you actually receive a
5 carer's allowance for your role?

6 A. Yep.

7

8 Q. You first started receiving that in around 2015 or
9 2016?

10 A. M'hmm.

11

12 Q. But before that you didn't know you could get it?

13 A. No. I was on a youth allowance which meant that I
14 was - at times I was on youth allowance and having to look
15 for a job that, I knew that I wasn't going to take the job
16 because I was caring, so I had to just look and not care
17 about the result of it. But, yeah, I got on to the carer's
18 allowance after I think it was one of mum's social workers
19 or something was, like, "Why aren't you on the carer's
20 allowance? Like, that's what you're doing."

21

22 Q. Can I ask you about your own experiences with mental
23 health issues?

24 A. Yeah. So, when I was - from 0-6 we were with my
25 father and my father was an abusive person: physically,
26 emotionally, sexually. He had significant impacts on all
27 three of us, which have led to different mental illnesses
28 for all of us.

29

30 I was, as a result of him and his impact on our
31 family, for a significant portion of my life, up until I
32 was about 20, I was an angry person. I was physically
33 violent, I was verbally abusive because that was the
34 example that I got shown of how you are meant to, yeah,
35 deal with your emotions, that's what I knew.

36

37 So, that was part of it, and then as I got into my
38 teens I started dealing with undiagnosed, what I think is
39 depression. I've never got a formal diagnosis of it, but
40 like, having been around depression, done my own research
41 into it, I feel that's what I had. It often times would
42 rear its head when I had a lot on my plate.

43

44 I dropped out of Year 12 as a result of it. It was at
45 a point when caring was really hard, Year 12 is extremely
46 difficult, and it just got to a point where I felt like,
47 instead of going to school and dealing with that, I would

1 just not do it and focus on one thing that was stressful
2 enough. And, I've had several points since then where I've
3 almost become a recluse and wanted to just stay in my room
4 because, yeah, I didn't want to deal with anything.

5
6 Q. Can I ask you about what you see needs to change with
7 the system?

8 A. Yeah. So, there's probably two aspects that I feel
9 like I can speak into in that. Firstly, in terms of
10 caring, as a young carer I was listening to Rose and what
11 she was saying and, yeah, I'd like to echo a lot of what
12 she was saying in terms of, yeah, everything was hard.
13 Like, as a young carer I didn't know what I was doing. I
14 was, like, I don't how to deal with my own emotions let
15 alone help and support my mum who's going through a really
16 difficult time, and then be a crutch for my brother who is
17 dealing with his own stuff as well.

18
19 I didn't want to engage with help because of the
20 threat of being separated from my family and that hanging
21 over us, so I feel like, if one thing can change, yeah,
22 really looking into that and trying to set up supports that
23 aren't threatening. Like, the peer-based supports that she
24 was talking about sound great. Mum was telling me that I
25 could have engaged with those but I didn't because I was
26 scared. So, yeah, finding ways to make them less scary.

27
28 As well as, my mum had a case manager and people that
29 she was working with to help get her supported, and I
30 didn't have that. Like, if I had someone who was telling
31 me what was going on, like how I could be doing things
32 better, or someone to interact with if I didn't know what
33 to do; like, having my own case manager probably would have
34 helped.

35
36 Then in terms of my experience with mental health and
37 young men's mental health, like, the statistics into young
38 men's mental health are atrocious. Men are three times
39 more likely to commit suicide than women and it's the
40 leading cause of death in young men - more than the road
41 toll, more than anything. So, yeah, young men don't know
42 how to share, and I know that's a generalisation, but like,
43 I have experience myself, with my brother, like groups that
44 I'm a part of where it's just really hard for young men to
45 tell people, like, life sucks sometimes.

46
47 So, early intervention into that, telling guys what it

1 means to be masculine isn't - like, being tough and
2 suppressing your emotions. It's, like, having the ability
3 to say that I'm not okay and getting around each other,
4 that's 100 times better.

5

6 I know there's a few organisations out there, but
7 organisations like The Man Cave, getting supported. An
8 organisation that go into schools and talk about
9 masculinity and talk about emotions and do it in a way
10 that's purely for guys to recognise how to do things
11 better, yeah

12

13 MS COGHLAN: Thank you, Jesse. Chair, do the
14 Commissioners have any questions?

15

16 CHAIR: No. Thank you very much, Jesse, for your very
17 powerful statement and time with us here this morning.
18 Thank you.

19

20 MS COGHLAN: May he be excused?

21

22 CHAIR: Thank you.

23

24 <THE WITNESS WITHDREW

25

26 MS COGHLAN: I call Mary Pershall.

27

28 <MARY KATHERINE PERSHALL, sworn: [12.25pm]

29

30 MS COGHLAN: Q. Mrs Pershall, you've made a statement to
31 the Royal Commission?

32

33 A. Correct.

34

35 Q. I tender that statement. [WIT.0001.0039.0001] What
36 you talk about in your statement is your exposure to the
37 mental health system in Victoria which has arisen through
38 your daughter, Anna?

39

40 A. Correct.

41

42 Q. I'll just ask you to sit forward a little bit, please,
43 so the Commissioners can hear you.

44

45 A. Okay. Is that better?

46

47 Q. That's better, thank you. How old is Anna now?

48

49 A. She's great, she's got a really good relationship with
50 the family and she's doing some very positive work.

51

1 Q. And, how old is she?

2 A. She's 30.

3

4 Q. And, where is she living now?

5 A. At the Dame Phyllis Frost Centre which is Victoria's
6 Maximum Security Prison for Women.

7

8 Q. What led her to be there?

9 A. She killed someone.

10

11 Q. I want to ask you about some of Anna's early years and
12 perhaps signs that you could see in early childhood for her
13 that she might be suffering from mental health issues, and
14 really asking about those younger years and primary
15 school years.

16 A. Yeah, before she went to school she was a delightful
17 little happy child. She looked like a little fairy and we
18 used to say that she was "off with the fairies" because she
19 seemed to spend more of her time in her imagination than in
20 reality. And she never asked us - or she never begged for
21 toys like children do when they see ads on TV. The only
22 thing I remember her asking for is, we used to watch reruns
23 of The Addams Family as a family, and she wanted one of
24 those hands that comes out of the table and gets things for
25 you.

26

27 Q. Did she get one ?

28 A. I was pretty surprised when she asked for that for
29 Christmas. When she went to school, she hated school from
30 the very beginning. She'd been so bubbly and happy before
31 that, just never - you know, always happy. And after that
32 she would cry when she woke up in the mornings and say, "Is
33 it a school day?" And that was really sad. I think it was
34 partly because she didn't - she loved being out in our
35 backyard playing for hours or imagining things with her
36 Duplo characters and she didn't like being told by the
37 teacher what to do, she didn't like that structured
38 environment.

39

40 But the worse thing was that other children didn't
41 like her. They didn't appreciate her fantasies about
42 little spiders that she would find in the school yard and
43 prattle on about, and so she became isolated. She was
44 ostracised by the other children. She wasn't physically
45 bullied as far as we knew, so I don't think we took it
46 seriously enough. I mean, we felt so sorry for her, that
47 she was so sad about being isolated, but I don't think we

1 treated it as seriously as we should have; that being
2 isolated was just so hard on her developing brain, being
3 shut off from the group.
4

5 Q. What about early high school?

6 A. Well, that was really hard for Anna because it's so
7 important to fit in at that stage. She was very unhappy,
8 and we tried a lot to keep her happy at home. People used
9 to say later, people would say, "You spoil her, you need to
10 set boundaries", but we just wanted her to smile and be
11 happy at home.
12

13 Q. There was a point when she was around 14 years of age
14 where she began to restrict her intake of food?

15 A. That's right. At first we didn't take too much notice
16 of it because she said it was because she didn't want to
17 get pimples. She was very - she'd always - well, she still
18 has beautiful skin and she didn't want to have acne. And
19 she'd always been skinny, a thin child, so we didn't
20 connect that - we thought anorexia was around body image
21 and she'd never been concerned about that at all.
22

23 We didn't realise what was going on really until we
24 realised that she was hardly eating anything, just
25 basically watermelon and Diet Pepsi, and that was causing a
26 lot of stress within the family trying to convince her to
27 eat. But, you know, how do you make a person eat?
28

29 So she finally agreed to go to the doctor, our local
30 paediatrician, and she was admitted almost immediately to
31 the Children's Hospital. We were shocked at how
32 compromised her condition was, that she needed to be on a
33 heart monitor at night to make sure that her breathing
34 didn't stop. So, that was a shock.
35

36 Q. She ended up being treated as an outpatient until she
37 was aged 18?

38 A. That's right.
39

40 Q. You say in your statement that she received excellent
41 care during that time, "And I was so grateful to our public
42 health system"?

43 A. Yeah, she was seen once a week by a doctor that we are
44 still in contact with regularly. We call her "Dr D" in the
45 statement. She saw her once a week for an hour each time,
46 and she didn't want to talk to me about what they talked
47 about, she was very protective of that relationship, she

1 valued it highly, and she also saw a counsellor once a week
2 through the Children's Hospital during that time.

3
4 Q. One of the things you say in your statement is that,
5 "That's not to say that Anna's teens were trouble-free."

6 A. That's right, she finally found a friend and she was
7 so attached to that friend, she would do anything to keep
8 the friend on side if she saw her drifting away a bit, or
9 she didn't even want her to have other friends, she just
10 wanted them to be together.

11
12 One particular day she and the friend were walking
13 down the street when some boys got interested in them and
14 the friend was talking to them, and this enraged Anna so
15 much that her friend was paying attention to someone else
16 that she - this was in our major shopping centre in our
17 suburb - she turned to an estate agent and managed to kick
18 in the window of this thick plate glass window. So, she
19 was brought home in the police divi van.

20
21 Q. There was also another time where the police called
22 you to inform you that she'd been train surfing?

23 A. Yes, and that was also to impress this friend.

24
25 Q. You talked earlier about this idea of being told to
26 set boundaries. As a result of all those things going on,
27 that was a message that was communicated to you, you need
28 to set boundaries?

29 A. That's right, especially her counsellor, who was a
30 great support to John and me during that time because we
31 could ask her advice. And she said, especially after the
32 train surfing incident, you know, Anna's putting her life
33 at risk, you really need to set boundaries. She said, one
34 thing is, you know, you've told me she stays up most of the
35 night, you should give her an early bedtime.

36
37 She was 16 by this time, it was the summer before she
38 went into Year 11, and so we said, alright, you have to go
39 to bed at 9.30 or 10. So, I was really surprised when she
40 agreed to it, but I was worried, I was just uneasy about
41 something, so I went into her bedroom to check on her at
42 about 11 o'clock and there was just a roll of bedding in
43 the middle of the bed to look like a body and the window
44 was open and she was gone.

45
46 We had no idea where she was for a couple of days. We
47 called the police but they said we don't look for teenage

1 runaway, she'll come back. We found out that she and her
2 friend had gone to live with the friend's dad on the other
3 side of the river, so they stayed there for a few weeks.

4
5 Q. You ultimately convinced her to return in time to
6 begin Year 11?

7 A. That's right.

8
9 Q. And, drawing on what you've said in your statement,
10 you talk about those years commencing from when she was in
11 Year 11 to the first couple of years of Uni as her
12 best years?

13 A. Yeah, they were the best years of her life. She went
14 to a senior secondary college and she finally made the
15 friends that we'd been hoping all along that would happen,
16 that she would find some people who really appreciated her
17 individuality and her intelligence and her quirky sense of
18 humour, so she really enjoyed having those friends.

19
20 And then she went to university to study psychology,
21 and she met a wonderful young man who was so devoted to
22 her. I think they were always - I think they still love
23 each other really to this day, but she just became so sick
24 that it didn't work out. But during those years when she
25 was with him it was, you know, it was - we had hope that
26 all along through her childhood and teenage years when she
27 was in so much pain at school and with her peers, we always
28 thought as she matured it would get easier for her and that
29 eventually life would work out for her.

30
31 Q. By the time it got to her third year of university,
32 looking back you could see that things were starting to
33 unravel or fray around the edges, as you say?

34 A. Yes, because she started saying people didn't like her
35 at university any more and it was getting too hard, but
36 John, her father, convinced her to stay. He said, if you
37 just get your degree it would so important to your life and
38 then I won't nag you to do anything else. She did manage
39 to get her degree in psychology.

40
41 Q. She was then expected by, probably her family and
42 others, to get a job or to continue her studies?

43 A. That's right. We thought she'd get a job or do
44 postgraduate study, but looking back, she just didn't know
45 how to be an adult, and we just kept thinking - well, I
46 thought, you know, why isn't she doing something towards
47 getting an adult life? But John had promised her we

1 wouldn't nag her, which she kept reminding me of, so we
2 waited and hoped that she would come good.

3
4 She was living full-time at that stage with her
5 boyfriend and his mother, and then the boyfriend got a good
6 job and bought a house and they both moved in to that
7 together.

8
9 Q. But she later stopped living with him?

10 A. Yes, during that year the relationship disintegrated.
11 He still adored her but, like us, he couldn't do anything
12 with her. He was suggesting different paths that she could
13 take, because she's such an intelligent - you know, a girl
14 with such a good vocabulary. People can't, including us,
15 couldn't understand why. If we like convinced her hard
16 enough, our tools were words, like do this, do that, try
17 this. But she couldn't and we didn't realise during
18 that year that she was deteriorating as much as she was.

19
20 Q. And she was using alcohol and drugs?

21 A. That's right. She moved back with us when she was 24,
22 and it was only then that I realised the extent of her
23 drinking and drug problem, because she'd never had it as a
24 child or even when she was in university. She didn't even
25 have a glass of wine with us at night, so it was a shock
26 for me to see that she was. At that stage it was mostly
27 synthetic cannabis that she was using. She'd just sit out
28 in our backyard and smoke bong after bong.

29
30 Q. You've talked about her moving home and it was really
31 for a year that she would be living that kind of life?

32 A. That's right, and I think that, looking back, she had
33 quite a few markers as a child. I believe she had auditory
34 and visual hallucinations even as a little kid, but we
35 thought she'd outgrow it, you know, it was childhood
36 fantasies. But I believe her mental health was always
37 fragile and, with constant use of synthetic marijuana,
38 synthetic cannabinoids, cannabis, was really very harmful
39 to her brain.

40
41 Q. You talk in your statement about an activity that Anna
42 did engage in, which was getting dressed up and going out
43 on the train?

44 A. Yeah, that was - we couldn't get her to do anything
45 else, but that was one activity she really enjoyed. She's
46 a beautiful young woman, she always looked a lot younger
47 than she was. She'd go to Kmart and buy these little

1 dresses from the children's section so that, you know, she
2 could wear like a size 14 child's dress. So, she'd put
3 that on, do her hair and put on a lot of make up, she'd go
4 out looking like a - you know, very attractive, and her
5 method was to just chat with guys on the train. Just go up
6 to random guys and start a conversation with them and they
7 would be interested and take her home and give her drugs.

8
9 That was her method of getting her drugs supply
10 mainly, and attention, she loved the attention she got from
11 the guys. But we wouldn't know where she was, so as this
12 pattern continued we would be frantic with worry about
13 where she was and what was going to happen to her.

14
15 Q. And sometimes she would be gone for days?

16 A. That's right.

17
18 Q. Towards the end of 2013, a man that she met on a train
19 gave her ice?

20 A. That's right, that was a terrible period of our lives
21 because, as usual, she went off on the train and she came
22 back a few days later in a very fearful state: shaking and
23 saying, look what this guy's done to me and she had
24 cigarette burns on her arms. But then when she sobered up
25 she realised she really - well, I think now and Katie
26 thinks too, that she decided that she really liked ice, so
27 she went back to this guy for a few days. Then she rang me
28 again in a really distressed state saying, "He's holding me
29 captive but I've managed to run over to a neighbour's house
30 and get away from him." I said just get in a taxi and come
31 home. That cost \$95, so that was how far away she was.
32 But again, a few days later she wanted to go back to him.
33 We were beside ourselves as a family, we thought he was
34 going to kill her, so we begged her to stay. I even rang
35 the police and said, can we physically restrain our
36 daughter? And of course we couldn't, so we just had to let
37 her go.

38
39 Q. You've talked about Katie, and that's Anna's sister?

40 A. (Witness nods.)

41
42 Q. So, you've described calling the police, but at that
43 time as well you were trying to get help for Anna through
44 the mental health system?

45 A. That's right.

46
47 Q. But you couldn't get it?

1 A. Well, it took us a long time to actually attach the
2 words "mental illness" to Anna, because we'd always just
3 done the best we could for her to try and alleviate her
4 pain. It was only when she was so - just, it seemed like
5 she was just slipping further and further away from us and
6 we couldn't see any way of helping her any more, we finally
7 realised that she did need help beyond what we could give.
8

9 So first I reached out to Dr D and she tried to hook
10 us in with systems, and I tried by trawling the internet,
11 ringing up places. I didn't know where to start because I
12 had no connection with the mental health system before, but
13 it was very difficult to find help.
14

15 Q. There was a nightmare Christmas where, finally, Anna
16 agreed to go to a rehab the next day?

17 A. That's right. That was one night when we just begged
18 her not to go back to this guy who gave her ice and hurt
19 her, and I think that's the night when I rang the police
20 and asked if we could keep her, restrain her and they said
21 no, so I was like crying. And I think that finally got to
22 her, when I was just begging her to stay. Because she was
23 saying, "Well, this guy loves me" and I actually talked to
24 the guy on the phone and he said, "I think I should marry
25 your daughter because you're not talking very good care of
26 her."
27

28 So, I begged her to stay, saying this guy's known you
29 for a few weeks and we've taken care of you for 25 years.
30 So, she agreed to go to rehab the next day. That's how
31 naive we were, we didn't realise that you had to go to
32 detox first.
33

34 So we went to Dr D's office and spent hours there with
35 not only Dr D but other doctors trying to find a place for
36 Anna. They finally said, we've got a date for an
37 assessment in 10 days' time, which was useless, ridiculous,
38 because we had barely been able to keep her for 24 hours,
39 and to think that she would go to an assessment in 10 days'
40 time, that wasn't going to happen.
41

42 Q. When that appointment rolled round, you had no idea
43 where she was?

44 A. No. We often didn't know where she was in those days.
45

46 Q. You talk about, in your statement, the next few months
47 being "a blur of pain as our beloved girl slipped further

1 and further away from us". You talk about trying to get
2 help, trawling the internet as you've described, trying to
3 find programs for help. You say that:

4
5 "By the beginning of 2014 any semblance of
6 structure had vanished from her life."
7

8 A. That's right. She didn't have a pattern of, you know,
9 day/night. She would just put herself into a coma with
10 synthetic weed, alcohol, Seroquel. She seemed to be able
11 to get endless scripts for Seroquel and she would just take
12 so much of that that she was literally comatose, we
13 couldn't wake her up. There were times when John had to
14 rescue her from various places, and just pick her up and
15 literally carry her, because she was unconscious.
16

17 So, that's the way she would "sleep": she would put
18 herself into unconsciousness and be like that for a couple
19 of days. Then she would be up for two or three days. She
20 didn't shower, she wore the same clothes for day after day.
21 She wouldn't eat until she was just ravenous, and then she
22 would want us to go and buy her KFC, or if she had some
23 Centrelink money left she might order food in. So, her
24 life was chaotic.
25

26 Q. In relation to 2014, you say in your statement that:
27

28 "One of the terrible things we dreaded did
29 happen to Anna around the middle of
30 that year."
31

32 A. Yes, she was in Brunswick at a party and she got angry
33 at the people she was with, got separated. Again, she went
34 up to some random guy which was her usual method of
35 operation, and this guy took advantage of her: he took her
36 into a dark alley and sexually assaulted her. After that
37 she was very - that was a downward spiral, still another
38 downward spiral with her mental health. Before then we
39 hadn't known where she was, but after that she was afraid
40 to leave the house without one of her family or a close
41 friend.
42

43 So, in a way it was a relief because we knew where she
44 was, but in another way it was a huge burden, because by
45 that stage she was suicidal a lot and we just were
46 basically on suicide watch looking after her 24/7,
47 literally. It was like having a baby again as far as sleep

1 deprivation went.

2

3 Q. You talk in your statement about an occasion you
4 describe as one of the most awful days of your life in
5 relation to Anna grabbing a knife in the kitchen?

6 A. That's right. One morning I got up and she was, as
7 usual, hadn't been to bed, she was in the kitchen reading a
8 book and drinking a beer. And John got up and he'd been
9 endlessly patient with her, but that morning you know it
10 was too much, he said, "Put the alcohol away and go to
11 bed", and she reacted by jumping up quickly and grabbing a
12 cook's knife and thrusting it towards her chest, and John
13 was able to grab it.

14

15 Q. As a result of that, you called the crisis team?

16 A. Yeah. We had been in touch with various crisis teams,
17 and I called the number but I was put on hold, and so I
18 called Dr D and she said, "You'll have to call the police."

19

20 Q. And so, you did call the police and they came?

21 A. Yeah, I was afraid to call them because of all the
22 stories you hear about people being hurt by the police, but
23 in fact they were wonderful. They were so understanding,
24 especially the - I can't remember her name but the woman.
25 She sat - sorry. Sorry.

26

27 Q. Okay, Mary, would you like to have a break?

28 A. I think I'm okay. We had some hope that day because
29 the police said that they would take Anna to the hospital
30 and she would get some real help, but at the end of the day
31 she was just - we were just told to take her home.

32

33 Q. So, the police ended up taking her to the Emergency
34 Department, and you were told she wasn't going to be
35 admitted?

36 A. (Witness shakes head.)

37

38 Q. And she was sent home?

39 A. Correct. And that was just so hard, because we
40 thought she was gonna die, and to be told that she's not
41 sick enough to be admitted was terrible.

42

43 Q. The arrangement was made that the CAT Team would come
44 the next day?

45 A. Yeah.

46

47 Q. And days after that?

1 A. She'd already had involvement with the CAT Team by
2 that stage, and before she became agoraphobic, when they
3 came she wouldn't be there. There would be an appointment
4 made but Anna wouldn't honour it, you know, she would be
5 gone. After that incident at the hospital, when the CAT
6 Team came she would be unconscious, so I think after three
7 failed visits - what's called a "failed visit" - they don't
8 come back, so that was not really helpful for us, the CAT
9 Team.

10
11 Q. There was a time after that where, on two separate
12 occasions, Anna was admitted to 10-day detox programs?

13 A. Yeah, that was one of the positive parts of the mental
14 health system, that she was given detox. It didn't really
15 work for her because, like a couple of days afterwards
16 she'd be back drinking and doing drugs, but it was such a
17 relief for John, me and Katie, just to know that she was
18 somewhere safe because it was a constant worry that we were
19 going to find that - well, she said she wanted to die and
20 it looked like she did.

21
22 As Justice Jane Dixon said at her sentencing, you have
23 zero level of self-care. We felt like we were keeping her
24 alive. And she'd find ways to hurt herself. Even though
25 after the knife incident John went to Bunnings and got a
26 huge steel box to put all the knives in and everything we
27 could think of that she could hurt herself with, we'd still
28 get up in the night - or we'd hear things in the night like
29 bump, bump, bump and she would be hitting her head against
30 the wall.

31
32 One time I got up and she was hitting her head with a
33 can of corn, you know the sharp edge, and it was bleeding.
34 It was a constant strain.

35
36 Q. There was a point in time in December of 2014 where
37 she was using ice again?

38 A. That's right.

39
40 Q. Ultimately there was a decision made that she couldn't
41 live in the home any longer?

42 A. Yeah, we got a call - well, she was scheduled to go to
43 detox for the third time and she'd learned by this time
44 that if she got totally blotto before she went in she'd get
45 the maximum amount of Valium, so she had a guy come over -
46 she used to hook up with people on the internet. After she
47 couldn't leave our place any more, that's how she would do

1 it. She would go on dating sites and get people to come
2 and see her, so she did that, and we didn't like that
3 because a lot of them were drug addicts and we were scared
4 of them.

5
6 We were also afraid of that guy that gave her ice
7 because we didn't know when he was going to come back and
8 it was scary to be afraid in your own home. And also, we
9 began to be really apprehensive of her, because she was
10 calling Katie and telling Katie that we had been - even
11 though we still looked like her parents - that we had been
12 replaced by imposters and that she'd say, "Katie, you've
13 got to realise, it's not mum and dad any more, it's like
14 these evil incarnations of them." So that was pretty
15 scary.

16
17 So she was heading off to detox, but instead she went
18 off with a guy for the weekend and got - again, she was
19 like smoking a lot of ice we found out later. Someone rang
20 me and accused John and me of a lot of horrible things that
21 we'd done to our daughter, and by that time we'd just had
22 it, you know, we were exhausted, we were scared and we just
23 said, you know, we can't have her living with us any more,
24 so that's the last time she was in our house.

25
26 Q. There was an incident that led to her actually being
27 admitted to a locked psychiatric ward?

28 A. Yes, we had so hoped that she would be taken into a
29 secure psychiatric ward because she couldn't control
30 herself, and we couldn't. But three days after we said she
31 couldn't come home I got a call from a hospital saying that
32 Anna was in the emergency ward, and she wanted to see me.

33
34 So I went over there and I was told that she'd been
35 picked up naked in a service station in Footscray and I
36 later found out, because Katie and I actually tracked down
37 this service station that she had been in, and the nice
38 young man there who had actually been on duty that day said
39 that she walked into the service station and asked politely
40 if she could use the rest room, and he said yes, and when
41 she came out she was totally naked and stood by the door so
42 that she would be seen by people coming in.

43
44 So, he naturally called the police, and that's when
45 she was taken to the psych ward. She later told - she told
46 both Katie and me that she was afraid to call the police
47 because she thought that the gangs that were after her

1 would kill her if she contacted the police, but yet she
2 wanted to be taken in, she wanted to be protected so that's
3 the way she figured out how to do it.

4
5 Q. And so, she remained in the secure ward for
6 approximately one week?

7 A. That's right.

8
9 Q. She was transferred later to an involuntary ward?

10 A. Well, that's - we were so relieved that they had a
11 plan at that psych ward. They were going to put her in an
12 involuntary part for a while and then go to PARC. But as
13 soon as she got in the involuntary part - well, she
14 wanted - she was picked up by a man who she knew, an older
15 man, and taken away and we had no say about that. We were
16 absolutely horrified, it was just such a disappointment
17 that there was finally a plan for her.

18
19 We were desperately wondering why we weren't involved
20 in that decision because, even though she was an adult, she
21 wasn't capable of making a rational decision at that point,
22 she was still really delusional, she still thought gangs
23 were after her, that's why she wanted this guy to come and
24 take her because she thought, he was a security guard, he
25 could protect her, and he was a person that we had known
26 through our carer's group. We were allowed some hours of
27 respite and he was the person that was sent to us to give
28 John and me some respite so that we could have a few hours
29 on our own, and we were fine with the work that he did, but
30 he wanted to pursue a romantic relationship with her so he
31 picked her up from the psych ward and took her home with
32 him.

33
34 Q. And she ended up staying with him for a little while?

35 A. Yeah, a few - couple of months from my recollection.

36
37 Q. Can I take you then to a Saturday night in the middle
38 of winter?

39 A. Yeah, she was very angry at me, about not being able
40 to go home, and so she didn't speak to me for quite a few
41 weeks and neither did the person we called Jim. But then
42 one night I got a call saying - another hospital calling
43 and saying, your daughter's in the emergency ward, she
44 really wants to see you, we're admitting her into a
45 psychiatric unit under the Mental Health Act, but the psych
46 unit was at another hospital and they were going to send
47 her there by ambulance. And they said, if you meet her

1 there, you'll be able to see her. So I went over there and
2 I was really excited because I was going to at last see
3 Anna again.
4

5 But when I got there the security guard said, you
6 know, "Obviously it's not visiting hours, what are you
7 doing here?" And I was like, "But I was told by this other
8 hospital that I could see her", and he just was very
9 adamant, "No, you have to go away." So, you know, there
10 was nothing I could do, but that was just one more
11 disappointment.
12

13 Q. If you could then flash forward a few days after that,
14 when you went to the psychiatric ward during visiting
15 hours, what happened there?

16 A. Well, it was interesting because I'd already been a
17 few times by then. I went to visit her every day I think
18 while she was at that psych ward, and a nurse that I had
19 gotten to know a little bit happened to be going off shift
20 when I was coming in and she said, "I've got to know Anna a
21 bit, I really think she needs to be in secure psychiatric
22 care for a long time and I'm going to do everything I can
23 to make sure that happens."
24

25 So I went in and Anna was really distressed, crying,
26 and by this time she'd realised what a predicament she was
27 in. She knew she couldn't look after herself, she knew
28 that we couldn't look after her, and she said, "I really
29 need to stay here", she goes, "I need the help that they're
30 giving", and she said but the person in charge had said,
31 "You can't have a bed here just because you want it."
32

33 She'd already had experiences at boarding houses by
34 this time, she was really scared to go back to a boarding
35 house. And he said, you know, "You either go to a boarding
36 house or you'll go back to Jim's place." She had felt
37 unsafe at boarding houses, they'd stolen - she'd had things
38 stolen.
39

40 And I begged the - that person wasn't there who'd made
41 that decision, but I begged the person in charge on that
42 night, I said, "Please, can't you keep her? She's sick,
43 she really needs help", and she said, "Well, if you care so
44 much about your daughter, why don't you take her home?"
45 And, it was impossible. I mean, I might have done it, but
46 I had other people to consider as well, so she ended up
47 back at Jim's briefly, but then he had to kick her out

1 because she was violent with him.

2

3 Q. Can I ask you just to briefly describe then the time
4 that Anna went to live at the older gentleman's house, the
5 man who ended up being killed.

6 A. Yes, she always seemed to have an endless supply of
7 guys that she knew. One of the guys that she met at
8 detox - of course, they're not supposed to exchange phone
9 numbers, but they do - he knew about a place in the outer
10 suburbs where an older man rented out his rooms, sublet his
11 rooms, so that's where Anna ended up.

12

13 It was actually a really interesting place because,
14 even though the house was in a lot of disarray physically,
15 there was quite a vibrant community gathered around her
16 victim, who I came to know quite well, because I often
17 visited her there, and he was very - well, he was a
18 gentleman, and he had a lot of very close friends who spent
19 a lot of time there in his kitchen drinking sweet white
20 wine from morning till night and watching SBS and yelling
21 at the television in various languages. But they were
22 happy and he was very fond of Anna, very supportive of her,
23 and me.

24

25 Q. One of the things you mention in your statement is:

26

27 "I'm not sure how many times the guys
28 [those guys that she was living with]
29 called the police to stop her attacking
30 them, but I know it was at least twice and
31 I think it was more times."

32

33 A. That's right. Yes, we were grateful in a way that
34 they called the police rather than retaliating themselves.
35 She'd already shown - looking back, she'd shown that she
36 could be so strong and violent. Like, when she kicked in
37 that plate glass window when she was an anorexic teenager,
38 and we also saw at times when she was just - she seemed to
39 have this powerful anger that would just erupt, and that
40 was coming out more and more often, because she wanted this
41 house which was quite stable when she went in there as far
42 as I could see, she wanted the guys to clean it and she'd
43 get these ideas and then, when they wouldn't do it, she
44 would get violent, and yeah, and then they'd have to call
45 the police to calm her down.

46

47 I got to know one of the other guys in there quite

1 well and he said at one stage, "I had to call the police
2 because she attacked me but when they got here I said this
3 girl doesn't need to be arrested, she's sick and she needs
4 to go to a hospital."

5
6 Q. Yet she didn't receive any treatment?

7 A. No.

8
9 Q. And Anna herself spoke to you about being afraid of
10 her own violent outbursts?

11 A. Yes. One time when she actually attacked her ultimate
12 victim, she called me, she was in hysterics, she said, "I
13 can't believe it mum, I hit" - I'm not supposed to say his
14 name, am I? But she said his name and she said, "What am I
15 gonna do?" And I couldn't believe it either, you know,
16 that she would do that. She knew that she was not in
17 control of herself, and she wanted help at that stage, but
18 we couldn't get it for her and she couldn't get it.

19
20 Q. Can I ask you about 22 November 2015. This is a time
21 when Anna was pregnant.

22 A. Yeah, she was four months pregnant and she had really
23 tried to do the right thing, she desperately wanted this
24 baby. She wanted him to be healthy. So, she tried not to
25 drink or do drugs, but up until then she'd been more or
26 less medicating herself, you know, dealing with all the
27 pain.

28
29 She had a lot of voices in her head by this stage
30 which I think were brought on by the synthetic marijuana
31 but they never went away, so they were just telling her
32 terrible things. She used weed and marijuana and alcohol
33 and also prescription medication to keep all those voices
34 at bay. But she was trying so hard not to use those
35 substances while she was pregnant. She was smoking weed,
36 but then they ran out of weed and they ran out of
37 cigarettes, and she couldn't get herself together enough to
38 get her prescriptions filled, which Katie and I used to do
39 for her, but - yeah, I won't go into that story, but she
40 didn't even have her prescription medication. She never
41 used to use it as she should anyway, but she used to just
42 take it to sleep. All of that was gone and I think her
43 brain just imploded.

44
45 Q. Then, on 22 November, you got a call from the police?

46 A. That's right, and for so long we'd expected a call to
47 say that she was dead, but then we got a call instead to

1 say that she'd killed someone else.

2

3 Q. And so, from that time on, she's been in custody?

4 A. That's right.

5

6 Q. And she's serving 17 years?

7 A. That's right, 13-year non-parole sentence.

8

9 Q. As you say in your statement, this:

10

11 "As it's turned out prison life for Anna is
12 better than I hoped."

13

14 A. Yeah, her mental health is better than it's been since
15 she started school at the age of 5. Partly because she's
16 got a structure imposed on her day. She has to get up at a
17 certain time, she gets her medication monitored, she's on
18 quite a high dose of antipsychotic and lithium and
19 antidepressants, and she's also got good nutrition, she's
20 got sleep and she's got a community around her which is so
21 important to her. She says for the first time in her life
22 she is actually learning how to have relationships, because
23 she doesn't have to worry about the adult things.

24

25 Nobody asks her why she doesn't have a driver's
26 licence, because she could never learned to drive. She
27 doesn't have to worry about getting a job. She does jobs
28 at the prison, she's had a job ever since she's been there,
29 and she can work on how to get along with other people,
30 which she's doing really well.

31

32 Q. You mentioned earlier that the relationship you all
33 have is great now?

34 A. Yeah. Katie says it's the first time she's really
35 felt that she can relate to Anna as her sister, rather than
36 another carer for Anna. It's amazing to have a
37 conversation with her now. We realise now that she could
38 never really have a conversation before, it was just her
39 talking about things that she was interested in. But now
40 she makes an effort to ask questions, you can see that
41 she's learnt it but she's doing it really well. Like, she
42 asks the other person a question, she might say something
43 and then she waits for them to answer and tries to bring
44 them out.

45

46 And the other girls really appreciate her at the
47 prison, she's very well-liked and they go to her for help

1 with various English assignments and other things.

2

3 Q. Just finally, can I ask you about, given the
4 experience you've had over the years with Anna in the
5 mental health system, the changes that you see are
6 necessary?

7 A. Well, first of all I'd like us all to think about
8 children and the idea that they can actually have a mental
9 illness, which didn't occur to us at the time, and I think
10 we should watch out for those quiet children who don't
11 demand attention. And, when they get to the stage where
12 it's a crisis like Anna did, I think it would be great if
13 there could be a team approach, that families could be
14 listened to.

15

16 We felt that we were never listened to or consulted,
17 and if we were listened to, it was as if we were looked at
18 as if we were drama queens, or exaggerating the extent of
19 Anna's problems. We really wished that families could sit
20 down with a team of professionals and discuss what might be
21 best for that person, and beyond that, we really as a
22 family think that there should be much better accommodation
23 at all stages, more crisis accommodation, and longer, for
24 people in a secure environment that they can't get out of
25 to go off with strange people and get drugs.

26

27 And, once they're stabilised and able to make rational
28 decisions, we think they should be able to be in supported
29 accommodation, I think that's really important.

30

31 I believe that Anna will always need some sort of
32 support if she's going to be an active contributing member
33 of our society. I think she can be, but she'll need help
34 with practical aspects of life, and I believe that she
35 should have that support and other people in her position.
36 And, of course, it's going to cost a lot of money, but it
37 costs so much money to keep people in prison, and there's
38 more than just Anna who are in prison because of similar
39 issues

40

41 MS COGHLAN: Thank you, Ms Pershall. Chair, do the
42 Commissioners have any questions?

43

44 CHAIR: No, thank you very much for coming in today and
45 sharing those reflections with us. I think there was just
46 one issue I wanted to touch on. In your statement you talk
47 about the fact that there's a vital issue in the dilemma of

1 dual diagnosis and the divide between mental illness and
2 addiction. When you're thinking about what would improve
3 in the scenarios that you've talked about, what would have
4 been helpful from your point of view?

5 A. I understand that that's slowly being addressed, but
6 three years ago when we were trying to get help for Anna we
7 found it extremely frustrating that we actually tried so
8 hard to get her into one of the residential places for
9 people with addictions, and found that she was turned away
10 because her mental health problems were too difficult. But
11 then, she was actually found a place at PARC, and she
12 actually turned up there on the first day - we were so
13 relieved and happy that she could get a few residential
14 weeks of mental health care, but she decided that they
15 might not let her have enough Seroquel so at the last
16 minute, as she said, "I didn't really think this through",
17 she stuffed a bunch of Seroquel into her underpants so that
18 when she walked into her room that she was going to have,
19 the Seroquel fell out and they said, well, that's against
20 the rules so you can't be here.

21
22 So, she was turned away from the mental institution
23 because she abused drugs and she was turned away from drug
24 rehabilitation because she was mentally ill, so there was
25 that real split between the two.

26
27 CHAIR: Thank you. Thank you very much.

28
29 MS COGHLAN: Thank you. May the witness be excused?

30
31 CHAIR: Yes. Thank you very much, Ms Pershall.

32
33 **<THE WITNESS WITHDREW**

34
35 MS COGHLAN: Is now a convenient time to break for lunch?

36
37 CHAIR: Yes, thank you very much, we're adjourned.

38
39 **LUNCHEON ADJOURNMENT**

40
41 **UPON RESUMING AFTER LUNCH:**

42
43 CHAIR: Before the proceedings resume, I will take a moment
44 to acknowledge the courage of all those who have shared
45 their stories with us. Today, and indeed right throughout
46 these hearings, we have heard some incredibly powerful
47 stories, whether that be from people experiencing

1 challenges to their mental health, family members, carers
2 and those working in the sector.

3
4 We have all been deeply affected by people's
5 willingness to share their experiences. Your strength in
6 sharing often painful stories so that others might avoid
7 treading a similar path is incredibly generous.

8
9 I also take this opportunity to encourage people to
10 ask for help. For those that are with us at the Town Hall,
11 there are counsellors here if you need support.

12
13 For those joining us via the live stream, there are
14 services available. If you or a loved one requires support
15 you can contact lifeline on 131114 or Beyond Blue on
16 1300 224636.

17
18 Once again, I and my fellow Commissioners, extend our
19 gratitude and admiration to all those who are contributing
20 to the Commission's work. Thank you.

21
22 MS NICHOLS: Chair, the next witness is Dr Margaret
23 Leggatt and I call her now to give evidence.

24
25 **<MARGARET STEWART LEGGATT, affirmed and examined: [2.10pm]**

26
27 MS NICHOLS: Q. Dr Leggatt, were you the Founding
28 Director of the Schizophrenia Fellowship in Victoria?
29 A. Yes, I was. We founded the Schizophrenia Fellowship
30 in Victoria in 1979 and it was an organisation that was
31 started by a psychiatrist, a social worker, myself and
32 several families.

33
34 Q. Are you also on the board of Tandem presently, which
35 is the peak body for mental health carer organisations
36 across Victoria?

37 A. Yes, I am on the board of Tandem.

38
39 Q. For your work with families with those suffering
40 schizophrenia, were you awarded a Member of the Order of
41 Australia in 1987?

42 A. Yes, I was.

43
44 Q. Can you tell the Commissioners briefly about your area
45 of research in connection with families and carers of those
46 suffering from schizophrenia?

47 A. Yes, I can. I originally trained as an occupational

1 therapist and worked in psychiatric hospitals here and
2 overseas. I came back and wanted to go back to university,
3 did an Arts Degree in Sociology and then wanted to go on.
4

5 I was working at the time as an occupational therapist
6 and I became very aware of the fact that families were not
7 being helped at all. It was at the time when the very big
8 hospitals, the big mental institutions, were being closed
9 down, and there was this talk of people not having to spend
10 their lives in hospital but being cared for in the
11 community, and I rather felt that care in the community had
12 really become family care.
13

14 It was a huge burden given to families, so I really
15 wanted to find out what it was like for them, so I spent
16 the next four years researching a group of families and
17 documenting everything that happened in their lives. And,
18 I have to say, after two years of doing that, I was so
19 distressed by the stories I was hearing - and remember,
20 this is way back in 1979 - that that really led to the
21 beginning of the Schizophrenia Fellowship.
22

23 Q. What was behind the choice of the name for the
24 Schizophrenia Fellowship?

25 A. Well, because most of the people that we were working
26 with at the clinic where I was an occupational therapist
27 had a diagnosis of schizophrenia.
28

29 Q. Was there a piece of advocacy about the choice of
30 name, to be very clear that "schizophrenia" was something
31 that should be recognised?

32 A. Oh, yes, absolutely. I have to say that, when I
33 advertised the name "The Schizophrenia Fellowship of
34 Victoria", I was rung up by some mental health clinicians
35 who said, "What the on earth do you think you're doing,
36 woman? You can't bring that name out into the open." And
37 I said, "Yes, we can, and we're going to talk about it."
38

39 I think a lot of the work of the Schizophrenia
40 Fellowship in the very early days was going after the media
41 to get this very frightening word understood ever so much
42 better than it was at the time.
43

44 Q. Since that time, have you spent quite a considerable
45 period of time with people who are caring for their loved
46 ones, and their friends, with various forms of mental
47 illness?

1 A. Yes, I have. The work of the Schizophrenia Fellowship
2 was very much about finding ways to help and support the
3 families. The organisation developed something like 33
4 family support groups throughout Victoria. We had an
5 extensive helpline so that families could call us and get
6 the sort of help and information that they needed.

7
8 So, yes, I've spent many, many years working for
9 people for whom I have the most profound respect. I think
10 carers of people with mental illness, I don't think the
11 community, and I'm quite sure very many mental health
12 professionals, really do not understand what they cope
13 with.

14
15 Q. Thank you, Dr Leggatt. Can I ask you about your
16 observations about the different kinds of roles that carers
17 and families perform when caring for those with
18 schizophrenia in particular.

19 A. Right. Well, I was here this morning and we heard
20 some incredible stories about caring, but I guess I can put
21 that into four categories.

22
23 I think the caring role starts with the very, very
24 difficult, frustrating business of seeking help, and in so
25 many instances that takes such an incredible amount of
26 time. The person that they're trying to get help for
27 deteriorates while there is this extraordinary delay in
28 getting help, and often help doesn't come until the
29 condition is totally out of control and the police have to
30 be called, with all the terrible horribleness that goes
31 with having to call police and having your son or daughter
32 dragged away in a divi van.

33
34 Q. While we're on help-seeking, what challenges do you
35 think families and carers face in seeking help,
36 particularly early on?

37 A. Well, particularly early on: let's take the situation
38 where somebody who is developing schizophrenia is not aware
39 that they're becoming unwell. So they say, "I'm not sick,
40 I do not need help." The families know that they certainly
41 are unwell and they need help.

42
43 But the family will go to the GP, and the GP will say,
44 "Well, I can't do anything, I've got to see the person who
45 is sick", but the person says they're not sick so they're
46 not going to the GP. So, stalemate, nothing really
47 happens.

1
2 These days there is some chance maybe of getting a CAT
3 Team, a Crisis Assessment and Treatment Team, but we've
4 recently heard that those teams are very under-resourced
5 and not able to do all the work that they should do, and
6 are now known as the "Can't come today team", or the, "Call
7 again tomorrow team", which isn't really very helpful,
8 because again that's delay in getting the help that people
9 need.

10
11 Q. Can I ask you about the observations you've made about
12 families and carers being the landlords, as well as the
13 primary carers, as well as the social support. What are
14 your observations about the combination of those things?

15 A. Yes. The caring role in mental health is absolutely
16 enormous and all-consuming. It is the process of getting
17 help that is difficult. Families then become the primary
18 carers, often there's a need to monitor medication regimes
19 because a lot of people hate the medication they're on and
20 don't want to take it. And, if they're saying they're not
21 sick, they don't need help, well, they're not going to take
22 medication. That creates enormous tension in families.

23
24 There are other forms of primary care, psychological
25 help, trying to get your family member to not give up their
26 lives, not lose their friends, but they do. So, the family
27 then becomes the support network, the person with mental
28 illness becomes very isolated. But in the process of doing
29 that, so do the families; I mean, the families have to give
30 up their own lives in order to care.

31
32 Q. Just on that subject, you cited in the statement you
33 provided to the Commission a study carried out by Orygen
34 Youth Health that:

35
36 "56 per cent of family care is experiencing
37 a first episode of psychosis in a son or
38 daughter suffered a level of anxiety and/or
39 depression that fitted the criteria for a
40 psychiatric illness."

41
42 Can you say a little bit more about that?

43 A. Well, I'm not surprised at all because I think the
44 incredible worry, the incredible frustration, the feeling
45 that something's going wrong with my son or daughter, I
46 don't know what it is, they're not the person they are or
47 whatever; the tension and the anxiety of not being able to

1 do anything just gets more and more, and worse and worse.

2

3 When that study was done, that was what they found,
4 that 56 per cent had anxiety or depression to the level of
5 a psychiatric illness.

6

7 Q. Is there a persistent problem of stigma that families
8 faced when trying to engage in finding help for their loved
9 ones?

10 A. Sorry, the question?

11

12 Q. Stigma.

13 A. Stigma?

14

15 Q. Yes.

16 A. Well, I think families suffer stigma in an incredible
17 way. First of all, if the diagnosis is schizophrenia: the
18 most recent example that I've had is a mother who rang me
19 and said, "Yes, my son's been diagnosed with schizophrenia,
20 but we're not saying that. We're saying that he's been
21 diagnosed with the early symptoms of dementia." So, you're
22 labelling a 25-year-old child with dementia. So, that's
23 part of the stigma.

24

25 But I think the stigma also makes families very
26 reluctant to go and seek help, seeking help for a mental
27 illness, or perhaps it might just go away, so then again
28 there's further delay.

29

30 The difficulties of telling your friends about what's
31 happening in your family is awful, so you stop seeing your
32 friends. So, all of this is stigma of mental illness for
33 families, which hasn't been researched at all.

34

35 Q. Hasn't been researched?

36 A. No.

37

38 Q. So, your observations are from your anecdotal evidence
39 over the years?

40 A. Evidence, yes. I think what I could also say about
41 stigma for families is that, when we did set up these
42 family support groups and families were able to talk with
43 each other about their situation, and to share experiences
44 and very much to learn from each other about how to manage
45 certain situations, that I think the stigma started to -
46 that released the stigma a bit, they became not so ashamed
47 or feeling blamed or guilty about what was happening.

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Q. Can I ask you now about what research tells us about the benefits of including family and carers in the treatment of people with schizophrenia, and although it might seem an obvious proposition, there is research about this question, is there not?

A. This is one of the things that makes me scream with range, quite frankly; there has been so much research done on involving families in treatment and care; research studies going back 35 years at least. And a lot of these research studies have actually found that, by involving families, there has been a huge reduction, up to 20-25 per cent of people having to go back into hospital.

So, involving families cuts down the re-hospitalisation rate, it has shown that people with - I'll say schizophrenia because that's my area of greatest knowledge - become much more compliant with their medication and they therefore suffer fewer psychiatric symptoms.

Those research results are on a thing called the Cochrane database which runs out of the UK. There have been other studies done that haven't quite met what's known as the gold standard for research, the randomised controlled trial, and it falls under the bracket of "psychosocial research" which has shown other very, very interesting phenomena, that people become more engaged with their communities, there's been an increase in getting some people back into employment. One of the other major findings has been very much less burden or trauma for families.

There have been some studies done, and one of them was actually done in Australia, that showed that, once you involve families, this became very much more cost-effective. Well, obviously, if you're going to cut down on acute hospitalisations, you're going to save an awful lot of money.

Q. I might take you back through some of those points, Dr Leggatt, if I may. You say that, of the findings of the research, there is a finding that there is a reduction in relapse rates of up to 20 per cent, including a reduced number of hospital admissions and that that's established by randomised controlled trials conducted in the UK?

A. Well, not only in the UK, also in - because I went to

1 visit where all of this research was being done - but in
2 Portland in Maine. Then there was also a very famous
3 New Zealand psychiatrist called Dr Ian Falloon who did a
4 lot of this sort of research and he is very well published,
5 so yes.

6
7 Q. And so, does the fact that they were randomised
8 controlled trials mean that people without support, their
9 relapse rates were compared with people who did have family
10 involvement in their care?

11 A. Sorry, I didn't quite get the question.

12
13 Q. I'm interested in the basis on which it was
14 established that there was a significant reduction in
15 hospital re-admission rates.

16 A. Well, the research documented hospitalisations before
17 they involved the families, and then after they involved
18 the families and worked with the families the
19 hospitalisation rates reduced by 20-25 per cent.

20
21 Q. And that has a number of flow-on effects, including
22 cost?

23 A. Oh, including, yes. Yes. As I said, the study that's
24 being done in Australia on cost actually shows that too.
25 Only, don't ask me the details at the moment.

26
27 Q. I won't. From a more human perspective, what are the
28 essential reasons why involving families and carers in the
29 treatment, or the care rather, has those sorts of effects:
30 relapse rates improve, better adherence to medication and
31 so on. What is it about the involvement of the family that
32 has those effects?

33 A. Well, the nature of the research projects that have
34 been carried out, where clinicians work with families over
35 a period of time, a year or 18 months, where the clinician,
36 the consumer and the family all work together: one of the
37 first things they really work on is improving communication
38 between the person who has become unwell and the family
39 members.

40
41 I remember one mother saying to me once that, "When
42 mental illness comes in the front door, communication goes
43 out the windows." So, the nature of mental illness is such
44 that communication breaks down, so the first step really is
45 to develop communication patterns where the family and the
46 consumer and the clinician all work out the best way to
47 communicate with each other and that's incredibly

1 important.

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Part of all that is lowering what has become known as expressed emotion. We know that atmospheres where there is hostility, tension, anxiety, frustration, anger, is the sort of environment that will increase the person's symptoms, and those symptoms as they increase, that of course leads to relapse. So, a lot of the work is based on developing much better communication patterns between family members.

The next part of the research has been on solving problems, so it isn't just a clinician saying to a family carer, you should do this, or saying to the consumer, the person with the mental illness, you should be doing this, it's a process of negotiation between everybody to work out what is a way to solve a problem that is amenable to everybody, that everybody agrees on. It's been those two main factors in the research that has really led to the results that we've just talked about.

Q. Has it been shown that there are models and strategies that can be adopted that will increase the involvement of families and carers with the kind of results that you've spoken about.

A. Sorry, have there been?

Q. Models with the involvement of families and carers.

A. Right, you did ask me about models from overseas and I've told you about the one that's called the Multiple Family Groups, which we have tried to get implemented here. I'm glad to say that there is - there are two places in Victoria; I only knew of one but I learned of another one this morning - that are working this program called Multiple Family Groups.

Q. Can I just ask you what Multiple Family Groups is and, before I ask that question, can I ask this: is it the case that there are some well implemented models that are implemented in certain places but they're not widely implemented, certainly not in Australia?

A. Yes, there are very, very good models and they are certainly not widely implemented at all. I mean, I had hoped by this stage - because I started looking at this research something like 25 years ago. And now, 25, 30 years later we've got two places in Victoria that are trying to do this. The first model that you are aware of

1 is called Multiple Family Groups and it was developed in
2 Maine in the United States?

3 A. Yes.

4
5 Q. What's the essence of that?

6 A. The essence of that is that two clinicians meet with
7 five or six families and the families includes the person
8 who is unwell. They meet fortnightly and they go through
9 that process of developing better communication patterns
10 and, as a group, looking at problems and solving those
11 problems. Then they go away for a couple of weeks and they
12 practice the agreed upon solution to the problem to see how
13 they go with it. That's very basic.

14
15 Q. That's been shown where it has been implemented to be
16 effective in the way that you were talking about earlier?

17 A. Yes.

18
19 Q. Reducing relapse rates and rates of hospital
20 re-admission and so?

21 A. Yes. In fact one of those Multiple Family Groups in
22 the States turned into a group of families who were trying
23 to get their sons and daughters back into employment, so it
24 was a group purely about how do we get them back into
25 employment or back to study, and that was also very, very
26 successful.

27
28 Q. As far as you're aware, that's really only been
29 implemented in one place in Australia?

30 A. Well, as I said, I found another one this morning.

31
32 Q. Sorry, there's two?

33 A. One in Waratah out in our Inner West, and they are
34 still using Multiple Family Groups, and another one now in
35 Geelong, I believe.

36
37 Q. There's another model called Behavioural Family
38 Therapy. What is that?

39 A. I went over to Birmingham where that particular model
40 of Behavioural Family Therapy was developed and a clinician
41 would go into a family home, usually in the evening,
42 because again, you know, family - mothers and fathers are
43 working and not available during the day, so it was an
44 after-hours program, and would work with that family with
45 the same sort of principles that I've been talking about:
46 developing very much better, more compatible communication
47 techniques with the people and also going through a process

1 of problem solving.

2

3 Q. Has that been implemented much, if at all, in
4 Australia?

5 A. No, it was started here but for all sorts of reasons
6 has not been able to be continued. I mean, there is still
7 this awful business for me really that family work is a
8 sort of an add-on, everything else seems to take precedence
9 and, if you've got time to see the family perhaps. And I'm
10 not criticising our clinicians for that, it's just the fact
11 that they're not trained in how to work with families, the
12 training is always on the sort of clinician-patient
13 relationship rather than the relationship between the
14 clinician, the patient and his or her social network.

15

16 Q. You started discussing just then the implementation
17 barriers to these models which you say have been shown to
18 be quite effective. One of the problems you discuss in
19 your evidence is research results not being widely known.
20 What do you mean by that?

21 A. Well, what I mean by that, if there is a breakthrough
22 in pharmacology. You've got the big pharmaceutical
23 companies that will push their new medication and that
24 becomes all important. In fact, if you talk to many
25 consumers as I am still doing, they are sick to death of
26 what they call the medical model. It's just, okay, you've
27 got hallucinations, delusions, we'll stuff you with
28 medication and that's it, you know, you'll get better.

29

30 Now, medication is incredibly important - I'm sorry
31 I'm being a bit naughty in saying it like that, but there
32 has become an over-emphasis on medication, or medication is
33 the only thing that will help people. It is the, well,
34 what we call the negative symptoms of schizophrenia, the
35 behavioural problems, the issues with lack of capacity to
36 pay attention, the loss of motivation, all of those
37 problems that have somebody - as a mother said to me the
38 other day, my son stays at home in his bedroom smoking
39 himself to death because he's got no initiative, he's lost
40 all his friends and he doesn't know what to do.

41

42 So, it's these sorts of issues that I think need a lot
43 of attention and they're not getting the attention, it is
44 the medication that gets the attention, not all the other
45 needs, yes.

46

47 Q. Is your point really that there are very good ways of

1 incorporating families in care but they don't receive
2 sufficient attention, it is not prioritised?

3 A. No. In fact, the sort of research results that I've
4 talked about when I was first very interested in all of
5 this, I'd say we've got these magnificent research results
6 and nobody knew about them. It just wasn't seen as
7 important, I think.

8
9 Q. Is one of the other barriers for implementing these
10 approaches to care that involve families, difficulties in
11 relationship between families and the person suffering with
12 the illness?

13 A. Oh, yes. I mean, the relationships become very, very
14 fraught, but that's what I'm saying, when you include
15 everybody you can reduce those very, very difficult
16 inter-family interactions.

17
18 Q. You mentioned earlier lack of training of professional
19 staff?

20 A. Oh, yes. I think this is where we in mental health
21 really need a total paradigm shift. I think the idea of
22 treating a patient with a mental illness is not nearly
23 adequate. You have to treat and care the person within
24 their social context or with their social context, which
25 initially is families.

26
27 So, I want to get away from that idea of what they're
28 calling an individualistic model of care. For mental
29 health, I do not believe that works. Not in all cases; I
30 mean, in a lot of cases you do need what I would call a
31 social model of care.

32
33 Q. Is it your opinion that, in order to introduce that
34 model, you need people working in the clinical and
35 non-clinical spheres to be specifically trained?

36 A. Yes. I think training for all people who are going to
37 go into mental health has to radically, radically change.

38
39 Q. You discuss what you call the economic context, which
40 is that there isn't specific funding to facilitate that
41 sort of training, and staff not having the time off to do
42 that kind of training, and also people having very high
43 caseloads in the community.

44 A. Yes. I think what I'm suggesting at the moment, given
45 the parlous state of our mental health services, what I'm
46 suggesting is a pipe dream. I mean, this is why I'm so
47 pleased about the Royal Commission, I just hope that

1 somehow or other these suggestions can be really reinforced
2 or taken up because I really very sincerely believe that it
3 is one of the most important ways forward.

4
5 Q. Are you saying that there needs to be very specific
6 allowance in the structural sense by having funding
7 available for training in these approaches to care?

8 A. Yes.

9
10 Q. And time made available for people who work in the
11 sector to engage in them?

12 A. Yes.

13
14 Q. You've said quite specifically in your statement that
15 each community mental health service should have a Family
16 and Friends Work Implementation or Steering Group. Can you
17 say a little bit more about what you mean by that?

18 A. What I mean by that?

19
20 Q. Yes.

21 A. Yes. I think every, particularly community mental
22 health service, should have a specific group that I have
23 called a Family Work Implementation Group. I would also
24 like to see in services somebody called the Director of
25 Family Work, so that there is a designated group of people
26 who look at, what should we be doing for families, how are
27 we going to do it, how are we going to sustain it, all of
28 those sorts of - because one of the things that also
29 happens is that, some very good programs start and then for
30 all sorts of reasons they're not continued. Staff who are
31 interested maybe in family work leave a hospital and maybe
32 go and work somewhere else and then nobody takes over, so
33 very good things that get started are not sustained.

34
35 So I think also, if you have a group like that within
36 a mental health service, that would help with the
37 sustainability of good family work.

38
39 Q. And so, are you really suggesting that there needs to
40 be a structural way of prioritising this work and keeping
41 it sustained?

42 A. Yes, very strongly.

43
44 Q. Is it the case that it's been reported that the mental
45 health workforce is assisted by having families and carers
46 involved because the environment in which work is done
47 therefore becomes a happier one where people are feeling

1 more satisfied?

2 A. Yes. There's not sort of research evidence of this,
3 but it's anecdotal evidence that - and again this is mainly
4 from the work that I was doing in England. Staff found
5 that they enjoyed their work very much more. In a way
6 having the family on board gave them some extra - what's
7 the word - extra help really, they could understand very
8 much better what was happening in the family home.

9

10 I think they could shift a degree of the - I don't
11 want to use the word "burden", I can't think of another one
12 at the moment. They could share the caring responsibility.
13 And, of course, that's what families wanted as well, but
14 they learnt to understand very much more about the
15 illnesses, I think, by listening to the stories that the
16 families were able to tell them, so that helped them very
17 much in their own work.

18

19 Q. Can I ask you about the relationship between the
20 Mental Health Act which deals specifically with the
21 involvement of families and carers, and what you say are
22 the more practical needs for families and carers to become
23 involved in the care of their loved ones.

24 A. Well, getting back to the 2014 Mental Health Act,
25 there are provisions in that Act for nominated persons and
26 carers to be given information if it is going to affect the
27 caring role, which was a great advancement, I think, except
28 that it just simply is not really happening.

29

30 And, in many ways I think it is not happening because
31 the mental health workforce, for all the reasons we've
32 talked about, overload of work and caseloads are too huge,
33 etc., etc., and also that families are still not considered
34 absolutely essential in treatment and care.

35

36 So, a clause in one of the - which one is it - s.11
37 where it says information must be given to family carers
38 and nominated persons whenever it is possible. And I think
39 what really is happening is that most clinicians for all
40 sorts of reasons are saying, well, it just simply wasn't
41 possible.

42

43 Q. So, in your observation, is that objective, which is
44 expressed in the Mental Health Act, struggling to be
45 implemented?

46 A. Oh, I think so, yes. I mean, going back to my work on
47 the Mental Health Tribunal, we still, you know, we tried to

1 encourage family carers to come and be there for the
2 hearing, but that's incredibly difficult for families,
3 incredibly difficult.

4
5 It's unfair to ask them to talk about their person
6 with a mental illness in front of them. It has dire
7 consequences quite often. I've had terrible situations. I
8 know when consumers have understood that their families
9 have talked about them in front of them and then they've
10 gone home and the situation at home has become absolutely
11 diabolical. It's not a good situation. Sorry, I don't
12 know that I made that terribly clear.

13
14 Q. I think you did. I was going to ask you on a related
15 matter: you say that there's a real conflict between the
16 objectives of privacy legislation that requires information
17 to be protected and the desire and need of families to be
18 involved in the care of their loved ones. How do you see
19 that playing out in practice?

20 A. Well, playing out in practice it just simply means
21 that carers who have a vast amount of information are often
22 not able to give it, because the person with the mental
23 illness says, "I don't want my family involved", so then
24 clinicians say, "Well, alright, we have to observe their
25 privacy and confidentiality, therefore we can't do anything
26 about it, we can't talk to the family carers." That, in
27 this country, is an absolutely huge, huge problem, and
28 quite frankly, it leads to some very, very nasty, dangerous
29 situations.

30
31 Now, if I can get back to the Multiple Family Groups
32 for a moment. When I asked Professor McFarlane, who
33 started the Multiple Family Groups, "How do you handle the
34 issue of confidentiality?" He said to me, "What do you
35 mean?" I said, "Well, the patient's rights to privacy and
36 all that." He said, "Well, we don't have that as a problem
37 because when you involve the family right from the very
38 beginning and you open communication between the family and
39 the consumer, the issue of confidentiality tends to
40 dissipate and disappear."

41
42 Q. From what you know of Professor McFarlane's work, what
43 are the aspects of involving the family in his kind of
44 model that lead to the confidentiality issue not becoming a
45 problem?

46 A. Well, because you've got three people there and you
47 are discussing all of the issues; everybody is hearing

1 everything that anybody else says. And because you are
2 encouraging people in a communication skill that is not
3 going to aggravate the situation, you don't have the
4 enormous flare-up of tensions and hostility and all the
5 rest of it.

6
7 Q. In terms of going forward with this quite vexed
8 problem, is it your opinion that more investment and more
9 priority being given to advancing those models of care will
10 tend to assist the resolution of that problem?

11 A. Yes. Yes, I most certainly do, and we've got the
12 evidence to show that it has and does.

13
14 Q. You have said that, in your opinion, it should be
15 mandatory by law that mental health services have
16 structures and programs that involve the person's social
17 network in their treatment and care.

18 A. Yes.

19
20 Q. And so, why do you think that should be mandatory?

21 A. Well, because I just don't think that will happen
22 unless it is. I think people are going to have to be
23 forced into it, can I put it that way? I just don't think
24 it will really happen. Well, I got that feeling from, I
25 can't remember what country I was in, where somebody
26 actually said that: that unless this is mandatory, it is
27 unlikely to happen.

28
29 Q. We've asked you a question about the very difficult
30 situation that families and carers find themselves in when
31 they wonder what will happen to their loved one when
32 they're no longer able to care for them. What do you have
33 to say about that problem?

34 A. I think it must be recognised as an underlying cause
35 of anxiety and concern for a vast number of families all
36 the time that they're coping with the day-to-day situations
37 of mental illness anyway. There is this feeling, well,
38 when I'm not around to care, what is going to happen to him
39 or her?

40
41 I was talking with a 94-year-old mother yesterday
42 whose son is 65, and she said, "I'll die soon and I'm going
43 to die in a state of terrible, terrible anxiety because I
44 don't know what's going to happen to my son."

45
46 One of the things that we did in the Fellowship, we
47 set up four or five models of supported housing where we

1 were able to transfer the person with mental illness into
2 supported accommodation, and that was a way of helping the
3 adult child leave home, learn to become independent and
4 relieve the anxiety that families feel about, you know,
5 what on earth does the future hold, and so I think I would
6 say that one of the huge needs for mental health services
7 is the provision of supported accommodation.

8
9 Just one factor about one of the places that we set
10 up, we did have it evaluated and, in terms of
11 cost-effectiveness, we found that the 19 people that we put
12 into this facility, we compared their rates of
13 hospitalisation before they went into this facility and
14 their rates of hospitalisation over 19 months in the
15 facility, and the reduction was absolutely huge. So, in
16 many ways very good supported community accommodation can
17 be cost-effective.

18
19 Q. Are there many examples of supported accommodation in
20 Australia that you know of?

21 A. No. It's a desperate, desperate need, and that's the
22 reason why we have so many homeless mentally ill on our
23 streets and in gaol.

24
25 Q. Is it your opinion that the strengthening of the
26 non-government sector is important in this respect?

27 A. Oh, yes. Oh, yes, I certainly do, because it was the
28 non-government sector that was used a lot for getting
29 people into supported accommodation, and the non-government
30 sector also is setting up programs to help people get back
31 into work. So, yes, I think the non-government
32 psychiatric - well, we used to call them psychiatric
33 disability - PDRSS, what was it - support, thank you, yes.
34 But they have recently been very severely cut back and that
35 is disgraceful.

36
37 Q. Dr Leggatt, if you had to identify the most important
38 priority for change in this respect in this area of
39 families and carers being better supported in the mental
40 health system, what would you identify? What do you think
41 should be the real priority?

42 A. Well, the real priority is including families and
43 carers from the very beginning of first contact with mental
44 health services, absolutely number one, and continue it
45 too.

46
47 MS NICHOLS: Thank you, Dr Leggatt. Chair, are there any

1 questions for Dr Leggatt?

2

3 CHAIR: I don't think so. Thank you very much,
4 Dr Leggatt, for not only your very long-standing commitment
5 to this but also your very helpful statement and evidence
6 you've given us here today.

7

8 MS NICHOLS: I tender Dr Leggatt's statement.
9 [WIT.0001.0047.0001] May Dr Leggatt be excused, please?

10

11 CHAIR: Yes.

12

13 <THE WITNESS WITHDREW

14

15 MS COGLAN: The next witnesses to be called are John
16 Murray and Kate Dillon, they are giving evidence jointly.
17 Their evidence is the subject of a restricted publication
18 order and an exclusion order. Chair, will those orders be
19 made now?

20

21 CHAIR: Yes, they are. The Royal Commission has made two
22 orders in relation to the next witnesses. Pursuant to the
23 Inquiries Act 2014, the orders:

24

25 1. Prohibit the publication of any information that
26 might identify the next witnesses, who will be referred to
27 as the pseudonyms, John Murray and Kate Dillon;

28

29 2. Prohibit their evidence from being broadcast on
30 the live stream; and

31

32 3. Excludes members of the public and the media from
33 the hearing rooms while Mr Murray and Ms Dillon provide
34 their evidence to the Commission.

35

36 Those persons able to stay in the room include Royal
37 Commission staff, counsel and solicitors assisting the
38 Royal Commission, any persons who are here to support or
39 represent Mr Murray and Ms Dillon, and any parties with
40 leave to appear and their legal representatives.

41

42 Copies of these orders have been placed next to the
43 door of the hearing room and I now ask that the live stream
44 be cut. If you are attending the hearings today and are
45 not able to remain in the room, please feel free to join
46 our staff in the room across the hallway.

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I note that, following hearing from the next witnesses, the Commission's proceedings will conclude for the day. Thank you.

MS COGHLAN: Thank you, Chair. Perhaps we could take a five-minute break to facilitate that.

SHORT ADJOURNMENT

(CONFIDENTIAL SESSION FOLLOWS)

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<THE WITNESSES WITHDREW

MS COGHLAN: That concludes the evidence for today.

CHAIR: Yes, thank you, adjourn.

**AT 3.58PM THE COMMISSION WAS ADJOURNED TO
MONDAY, 15 JULY 2019 AT 10.00AM**

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