



## WITNESS STATEMENT OF ANNA WILSON

I, Anna Wilson<sup>1</sup>, say as follows:

- 1 I make this statement on the basis of my own knowledge, save where otherwise stated. Where I make statements based on information provided by others, I believe such information to be true.

### Background

- 2 I am a mother who has been supporting my 27 year old son for the past 9 years, while he has been suffering from mental illness. My son experienced his first psychotic episode in 2014 and was diagnosed with schizophrenia in 2016. Since Harold has been suffering from mental illness, it has been nine long torturous of years struggling to get help. I have been forced to watch my beautiful boy's life deteriorate in front of my eyes.
- 3 Harold and I were very close when he was young. We are still very close; I could show you messages on my phone saying "love you mum". He was a beautiful little boy, who would often pick flowers for me on his way home from school. He had beautiful school reports, about how kind, gentle, polite and well-mannered he was.
- 4 Harold has developed an alcohol dependency and has suffered from inconsistent treatment and management of his illness. He has a dual diagnosis arising from his dependence on alcohol.
- 5 Harold and I have been through so much trauma. It has been far worse for Harold, but the experience has also been traumatic for me. It has been ongoing trauma.
- 6 Harold has been through a lot of trauma after seeing his father die under horrendous circumstances a couple of years ago. He has told me that he keeps getting flashbacks of his dad covered in blood and dying in front of him. Harold has stated that he drinks to try and stop his flashbacks as it all gets too much for him at times, and so his drinking is a way of self-medicating. His dad was also a drinker, so I believe there may be hereditary factors to his alcohol use. Harold was really close to his dad and at times has said he wants to join him.
- 7 When my son goes off his medication and medicates himself with alcohol, life becomes very difficult and stressful. The neighbours complain and at times it has been so bad that

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<sup>1</sup> The name and details of the witness and others referred to in this statement have been changed to protect their identity.

I have had to sleep in my car. There have been hundreds of nights with no sleep, and not being able to work because I was so exhausted and I had to care for my son.

- 8 There are moments, where Harold is reasonably well functioning and is very kind. For example, there was one man in a wheelchair at my son's supported residential services accommodation who Harold would take out. When I visited Harold at his accommodation people said, "oh, you're [Harold's] mum, he's gorgeous and he is such a beautiful soul." But what I often see now is a totally different Harold, who projects a lot of his anger onto me. Harold fluctuates so much; he has incredible mood swings and does not want to take medication. It is so sad to see him deteriorating so much.
- 9 Despite having many years' experience working as a nurse since 1970 and a mental health nurse since 1977, as well as five years of training in mental health, Harold's illness has been so hard for me. I have no idea how other carers cope without that work experience. Notwithstanding my experience, I have still had huge battles trying to get treatment for my son. Being a mental health nurse has not helped; I have often not been treated with dignity or respect. I have been pushed aside because staff are busy. Mental health workers have said to me "I can't talk to you now" or "I'll let you go now". I've felt like saying "I don't want to be let go". There are times when I don't say anything when people are really patronising or condescending or treat me as if I have an intellectual disability. I have to keep my cool to try and get care for Harold, but more recently I have become more assertive due to my desperation.
- 10 There have been thousands of phone calls, between 20 to 50 calls on some days, yet I have been unable to get my son the help he needs. Sometimes, the situation has to be really drastic before you are taken seriously, and help is provided. I've had to talk to the Mental Health Complaints Commissioner, the Office of the Chief Psychiatrist and, at times, I have had to threaten legal action because otherwise you just don't get listened to. It shouldn't have to be like this.
- 11 I have also not been believed. Usually, Harold will not open the door because he is afraid of being locked up and placed under a Treatment Order made under the *Mental Health Act*, which has happened many times. If the crisis assessment and treatment (CAT) team attends, he will put all of his energy into the 20-minute interview, so as to present quite well. He is extremely articulate and knows the right things to say to the CAT team so that he can return to his bungalow at the back of my house. If he starts to become concerned that they are picking up on certain symptoms, he'll say, "right I've had enough now" and exit the interview.
- 12 The treatment system needs to understand how much the caring role impacts my relationship with my son. When I am the person who has to take him to appointments, contact the police or CAT team, he becomes suspicious of me.

- 13 I have felt so disempowered and exhausted from constantly battling to get my son the support and care he needs. I believe strongly that we have to improve the mental health system. It is shocking what consumers and their carers are going through.

### ***The importance of a good case managers***

- 14 A good case manager makes a huge difference to Harold's life and to my life. One who provides support to both of us and is able to show compassion and empathy. Harold has had some mental health practitioners who have been shocking, and some who have been great.
- 15 One case manager Harold had was managing 28-29 people over three days of work. She was so overworked and probably burnt out. This was at a service that cancelled its mobile support team and introduced a model where health workers would undertake three days of case management and two days in the CAT team. With so many people to manage, I question how they can do their job properly.
- 16 Recently, for a few months, Harold had a support person from Mind Australia, and a case manager, who were brilliant. They both worked together to help Harold. One of them took Harold to UnitingCare ReGen for alcohol support, and the other took Harold to a place where he could receive free food and would teach Harold about practical survival skills. One very special worker saw all the positive things about Harold, which is so important. He'd say "*he is so kind, he is so gentle, he has got such a beautiful soul*". Due to Harold's refusal to take his medications and to abstain from drinking as well as becoming difficult for staff to manage, he was evicted, and I had to bring him home. This change in location meant a loss of his workers, due to geographical boundaries. It is difficult to get good case managers. In contrast, some clinicians only say negative things about Harold. I recently spoke to a senior clinician who only said negative things about Harold, for example that he was "*self-sabotaging everything*". I was in tears after that call.
- 17 Harold's previous case manager had supported both Harold and me. When his hospital treating team were considering a Continuing Care Unit, the case manager was strong enough to say in front of the treating team they were setting him up for failure. I was grateful for her support. I always try to give feedback to the mental health workers and call the organisations and ask them to pass on my thanks.

### ***Hospital based care and inappropriate discharge***

- 18 Sometime ago a psychiatrist at the hospital said to me, "*I think it would be best if your son was in the secure unit ... how do you feel about that*". Although the secure unit is pretty drastic and restrictive, I responded, "*I think it could save his life*". I also saw this as a chance of rehabilitation for Harold.

- 19 In desperation and because I was exhausted and worried sick and needed a break too, I went along with the idea of a SECU. Harold deteriorated. The psychiatrist left and Harold was not admitted.
- 20 The safety of patients while in hospital is a major concern. While Harold was an inpatient another patient attacked him because that patient wanted a cigarette and Harold said no because he only had a couple left. Harold has also been severely bashed on public transport. I worry that he may have sustained a brain injury as a result of these incidents.
- 21 It is almost impossible to get a bed in a hospital-based care setting. People are often restrained on trolleys in emergency departments, drugged up with diazepam and other sedatives and then sent home. On one occasion Harold was restrained to a trolley in the emergency department for hours yelling and screaming, which was horrendous and traumatic for Harold and awful for the people around. The Royal Commission needs to look into the huge waiting lists for people who need long-term rehabilitation and are a danger either to themselves or to others.
- 22 A number of times, where I have been really worried and felt he needed to be admitted, I have rung the emergency department saying, *"this is his mum, I love my son very much, I know he has challenging behaviour but please keep me informed"*. The hospital didn't ring me to say they had discharged him. When I call the emergency department again, they say, *"oh we discharged him a couple of hours ago"*.
- 23 A few months ago, Harold was missing for eight hours and was in a confused state after he had been drinking alcohol, was medicated in the hospital emergency department and then discharged without the staff informing me. I have heard many times of family and carers not being informed when their loved one is being discharged.
- 24 On a number of occasions my son has been discharged back to me when it was not appropriate. On one occasion, when he was suicidal, Harold was discharged from hospital within 48 hours. He was discharged to his supported residential services accommodation, with no support organised to get him back to his accommodation and no call notifying me of his discharge. I have heard that if a hospital needs a bed, whether that be because there are people waiting on trolleys or ambulances piling up, they will discharge whoever they can that has a home to go to.
- 25 There have been times when the psychiatry team has conducted mental health assessments after he has been highly medicated and subdued in the emergency department and therefore he is deemed not at risk. This is not good enough and it is not safe.

### ***Experiences with the police***

- 26 Most police and some public service officers have been fantastic. In particular, some members at the local police station have been outstanding, and in my experience far more supportive and responsive than the CAT team. A number of the members of the local station know Harold and appear to have compassion and empathy.
- 27 Recently, the police attended the house after the neighbours had rung really concerned. There had been a lot of yelling and screaming, threats to kill and lots of weird statements including that Harold was Jesus and God. The policeman who attended was so gentle, compassionate and patient with Harold. Harold wouldn't open his door and the policeman said *"look we're not going to take you away, I'm not a doctor and I have no intention of taking you to hospital, my intention is to make sure you're okay, I'm doing a welfare check"*. Eventually, Harold settled down and came out and spoke to the policeman. The policeman assertively explained to Harold that breaking windows and disturbing sleep was unacceptable; that they didn't want to have to take him off the property and take out an intervention order so he could not return to his home; and that the best thing for him to do was to stick to his bungalow and let me and the neighbours have peace in our homes.
- 28 Although the policeman was assertive, he was also compassionate, empathetic and listened to Harold. Harold really opened up his heart to him. He showed the policeman all the scars on his arms and the cuts he'd made recently, talked about how his dad had died in front of him covered in blood and how his cat was missing. One of the police officers said to Harold *"I know, I've lost a cat too, it's really hard"* and when Harold spoke about running out of cigarettes, he said *"I actually only gave up smoking a week ago, it's really difficult"*. These police officers were so empathetic and compassionate, they understood he had post-traumatic stress disorder.
- 29 This experience with the police is entirely different to the experience we had with the CAT team who attended a week earlier, after I had repeatedly rung the CAT team, triage and other important people, and threatened to complain to the Office of the Chief Psychiatrist. The CAT team's interview with my son was so cold and clinical, it was like an interrogation – there was no compassion.
- 30 One day Harold totally lost it and became completely psychotic. There had been a lot of noise – music and banging – early each morning, from a renovation next door. The noise was getting to Harold because he's nocturnal and has a very light sleeping pattern during the day. Harold completely lost it. He began yelling and screaming and threw a pot plant and a garden ornament over the back fence.

- 31 When I was trying to settle him down, he threatened to kill me. I can't even remember the full details but the neighbours rang the police. I believe I rang the CAT team and his treating team. When the police arrived, they called an ambulance and the hospital.
- 32 The police said they were concerned about my safety, Harold's safety and not being able to get Harold a hospital bed. The police and the Mobile Support Team suggested that I take out an intervention order. At that point, I was exhausted and felt I had no choice so I agreed to take out an order. Harold ultimately went into hospital. A Mobile Support Team worker supported Harold to get him in to a supported residential service (which I describe below at paragraphs 50 and 51).
- 33 If it were not for the police, Harold would not be alive. Once in the middle of the night, two police officers found Harold in the middle of the road on a ramp off the Monash freeway. He was dressed all in black. They managed to rescue him from the road before he was hit by a car. Harold was under the influence of alcohol and was suicidal. Instead of getting Harold help, the police locked him up for the night and issued him a fine of about \$650. Dealing with the fine was stressful (see paragraphs 56 to 58 below). However, I am grateful that the police were there, as without them, my son would be dead. But the police should not be the main point of call for people who need specialised treatment for mental illness. Earlier interventions are needed.
- 34 At times, Harold has been transported to hospital in the back of a paddy wagon. This has been pretty traumatic for Harold and for me.
- 35 While I have had good experiences with the police, not all members of the police force understand mental illness. Police should not be the main point of contact for people who need specialised treatment for mental illness. I think it would helpful if there were police who were specially trained in mental health who could respond to psychotic episodes, and if there were separate areas in emergency departments dedicated to people suffering a psychotic episode.

### ***Experiences with paramedics***

- 36 There have been some good paramedics. There have been a couple of times where paramedics have been wonderful. For example, one time when Harold was in his late teens, the paramedics said they were happy to take Harold to hospital. They said to me "you can follow us, and we won't need police unless his behaviour is unmanageable". So the police followed the ambulance to hospital, rather than putting Harold in the paddy wagon. That was special.

### ***Experiences with Mental Health Tribunal hearings***

- 37 Harold has had a number of Treatment Orders and has spent many years under the Mental Health Act. It has been extremely traumatic for Harold and me attending the Mental Health Tribunal hearings. There can be quite a number of people there, including three people on the board, the doctor, the nurse and sometimes a registrar or student. I try to be there to support Harold because he can be completely lost at times.
- 38 During the hearings, the doctors and nurses read material from the reports which have some pretty horrible stuff in them: that he threatened to kill me, that he threatened to kill his step mum. Those things happened when he was psychotic. Harold and I just had to sit there and listen to it all which was difficult as the content was so distressing.

### ***My son's experiences in residences for people with mental illness***

- 39 With a dual diagnosis it can be very difficult to access the support and care you need. There needs to be a separate place of treatment in which people with dual diagnosis can go to receive appropriate care.
- 40 I want my son to learn to be independent and to be able to live in his own home. I'm scared that after I pass away, he will end up on the streets. It breaks my heart when I see people in the city who are homeless.

#### Prevention and Recovery Care Service

- 41 Around five years ago, after an inpatient stay, Harold was transferred from the hospital's psychiatry unit to the Prevention and Recovery Care Service (**PARC**), which is a short term, home-like residence for people with mental illness. I thought this was good because it was a lovely service. Harold knew he couldn't drink on the premises but he went out and had a couple of drinks and came back under the influence. This was against the PARC's policy, so I got a call to pick him up immediately.
- 42 One of my worst experiences was around two years ago, a few months after Harold's father died. Things were really horrendous, and finally Harold was admitted to hospital. He went through detox on the ward. Prior to discharging Harold I made a special request that he be discharged to the PARC. I opened up my heart and told them that my mother was seriously ill and dying, and that she lived in Bendigo, which is two hours' drive away, and that she may only have a week or so to live. Harold really wanted to go to the PARC, and he promised me that he wouldn't drink because he knew I wanted to spend time with my mum. Then on very short notice, I was told Harold could not go to the PARC due to his previous stay there years earlier when he did consume alcohol and that I had to come and collect him. There was no second chance. My mother died ten days later. I only got

to see her briefly, for her birthday, a few days before she died. Harold was too fragile to be left alone and he was too unwell to come with me.

- 43 I put in a complaint to the Mental Health Complaints Commissioner and through the hospital, in relation to the lack of compassion and flexibility in the circumstances, but I felt I never received an appropriate response. It is constant knock-backs, constant rejections and constant failures.

#### Community Care Unit

- 44 Earlier this year, Harold was staying in a Community Care Unit (CCU). There were concerns that Harold was at risk of drinking because Harold was in what they call the pre-contemplative stage, where there is no intent to change behaviour in the near future. One day, I received a call in the morning from the CCU asking "*Is Harold with you, have you had contact with him, he has gone missing*". I told them to ring the police.
- 45 I had spoken with Harold the day before and he was at a local Cricket Ground, so I went out looking for him there. At first, I didn't have any luck but then I saw what looked to be a bundle of clothes at the back of change rooms and as I ran towards it, I realised it was Harold. He was in and out of consciousness. I got him to drink some water and called triple zero, his support worker and the CCU. The CCU said to tell the paramedics he needs to go to his treating hospital but I then received a call from the paramedics saying "*we can't risk it, we need to take him to [the closest hospital]*". When they found him, his blood glucose levels were so low that he was at risk of going into a diabetic coma. The emergency doctor said he was extremely dehydrated.
- 46 Harold came close to dying and he ended up in intensive care for a short time, before being transferred to a medical unit and then a psychiatry unit at the hospital. At that time, I was told by the psychiatry registrar in the emergency department that it was the last bed available in the whole of Victoria.

#### Boarding house

- 47 After the intervention order was issued, I wanted to find Harold a place to live, that wasn't my home. I was exhausted. I just couldn't do it. I needed a rest. I was also in a lot of pain and had to have surgery. I knew Harold had to learn to live without me. I said to Harold that "*you can't come back until you get help for your drinking*". I didn't want to reward bad behaviour, and I had to establish some boundaries. I refused to take him back, which was a very, very hard thing to do.
- 48 I tried to ring the social worker at the hospital many times. I left so many messages and talked with other staff to ask them to pass on to the social worker that I needed to talk to him. I was so worried about what was going to happen to Harold when he was discharged.

Then I found out a decision had been made for Harold to go into a boarding house. When the social worker drove Harold there from the hospital, he said "I'm taking you to a crack house". Despite this being completely unprofessional, sadly it wasn't far from the truth.

- 49 The boarding house was horrible. On the few occasions I went there, I was terrified. There were all these really heavily drug affected men. Harold has been through so much trauma, it was an inappropriate environment for him to go into. The boarding house was not a safe place for Harold with his mental illness, alcohol dependency issues and a history of trauma from being physically assaulted. Boarding houses are often understaffed and staff untrained. There is also potential for violence and heavy drug use from other residents. The boarding house was considered so dangerous that the local mental health clinicians were not able to visit there. I tried to explain to the social worker that Harold needed an occupational therapy assessment because he wasn't capable of managing in that environment; he'd lost weight, he was not up to cooking and needed assistance with his day to day living skills and budget. There was a nice lady running the boarding house, she was doing the best she could, but I knew it wouldn't work for Harold given the residents were required to live independently. He was there for a few weeks but in the end he ended up hitting the grog, but all these places require no drinking so he was evicted. But so many people seem to hit the grog to medicate themselves, because of their trauma.

#### Supported residential service

- 50 Harold then moved to a supported residential service, where there was no quality of life. It was a horrible place but I couldn't survive with him at home. It was our last resort. They accept people at the end of the road and who had been rejected from other places. It was unjustly expensive, costing \$400 per week. They offered no programs or facilities whatsoever, other than a TV and a newspaper. I would often visit Harold to help him, take him to appointments or take him out to the Buddhist Centre or to films, but I had to set boundaries as he hadn't engaged with any type of alcohol counselling.
- 51 The supported residential service had a policy of no alcohol use, although they did allow it sometimes. When Harold was living there, I was so in need of a break that I would hide evidence of his drinking and clean it up for Harold. I didn't want other people to have to clean up after Harold if he had been vomiting or incontinent. He couldn't face the cleaning himself. This may have been enabling, but I knew this was the last resort. Otherwise, he would have to come back to me and I wasn't well enough. Or he'd be out on the street.

#### Living at home

- 52 Unfortunately, Harold has been bashed at his place of residence in both boarding houses and an SRS and was evicted from both. I was also worried with coronavirus, because he

also has a number of physical health conditions, including cardiac issues and liver problems, which would make him very high risk if he were infected. There was nowhere else for Harold to go so I had to take him home.

- 53 Harold is nocturnal and often roams around at night yelling and screaming, talking to himself, muttering all sorts of bizarre things, including plans to kill me. I have had broken sleep almost every night, and sometimes only a couple of hours of sleep.
- 54 Over the past month, Harold has really deteriorated. He is now seriously unwell. He is so thin, just skin and bones, has a very poor appetite and is in and out of psychosis. He has his good moments where he appears quite normal, however, at other times it has been really scary to the extent that I am fearful for my life and the safety of others.

### ***Experiences with fines and Court***

- 55 For a lot of people who are mentally ill, it can be too hard for them to get to Court. The coordination with public transport and timing is just too stressful and difficult for them.
- 56 When Harold received the fine of \$650 when he was found on the Monash Freeway under the influence of alcohol, I took Harold to a drug and alcohol worker and counsellor at a health centre. I used the fine as an excuse to get him to see the counsellor. The worker tried to get Harold to organise a payment plan. I said to Harold *"I'm not paying, it's up to you, I am on a very low income and it is your responsibility"*.
- 57 The fine went to the Magistrate's Court. I called and tried to explain everything and get Harold excused from attending but he was required to attend. He had to attend at 10.00am, which is a difficult time for Harold, because he is nocturnal and sleeps in the morning. I have been trying to get him to not be dependent on me so I told Harold that I would meet him out the front of the Court. It's also for the future: if I'm not around he has got to learn that if there's a court case, he needs to attend on time. I gave him clear instructions on how to get there - he had used public transport to go to the city before. On a recent occasion he had taken a co-resident in a wheelchair to the city. I also made sure he had clean clothes to wear, because he can go for weeks and weeks without showering, wearing and sleeping in the same clothes and not brushing his teeth.
- 58 On the morning of the hearing, I called him to remind him about the hearing and make sure that he attended, but he didn't turn up. So, I went into the Court, with a letter from his treating psychologist, and explained his trauma. Once I explained everything the Magistrate was very compassionate, and it all went well. However, if I had not turned up, the Magistrate could have issued a warrant for his arrest. I just didn't want him getting arrested or locked up.
- 59 It was also extremely traumatic for me attending Court by myself for the intervention order.

***My work life***

- 60 Since Harold's illness, my whole career has gone out the window. My annual income is down from around \$50,000 to about \$5,000. I have been too busy, stressed and exhausted from fighting and caring for my son to be able to work.
- 61 There were nights where Harold was really disturbed and I wasn't able to get him a hospital bed, when I slept the night in the car before going to work. I've always kept a change of clothes and toothbrush and toothpaste in the car for this reason.
- 62 Back then I had to work, because the carer's allowance was only \$63, which was a bit of an insult. Fortunately, I have some superannuation and receive a little bit of help from Centrelink. The carer's allowance has increased a small amount.
- 63 There have been thousands of hours of work looking after Harold. That is just what you do as a mum.

***My experience with Centrelink***

- 64 For Centrelink, there are all these rules and regulations around what you can and cannot claim. For example, you cannot claim travelling expenses, but travelling is a lot of what I do as a carer, whether it is to visit Harold in hospital or drive him to appointments. I often have to drive Harold to appointments as he can get panic attacks when travelling on public transport.
- 65 Centrelink has been a nightmare. I have had real difficulty navigating the Centrelink requirements, I can't imagine how difficult it would be for someone who is seriously mentally ill or has suffered a brain injury. One Disability Employment Services worker said to me, "[Harold] just hasn't got what it takes to jump through the hoops at Centrelink. You've got to help him". I'm sure that Centrelink would have had a negative effect on many people's mental health.
- 66 One time, Harold was unable to attend a Centrelink appointment, so I arranged to attend on his behalf. Having waited a long time, I got to the counter and was told that there was no appointment for him. Fortunately, I had a letter from Centrelink which showed that there was an appointment. I've learned to keep copies of Centrelink's correspondence as they often lose correspondence. At the time, I thought, what if this had been Harold and he'd come all this way on public transport? The effect on him would have been great as would the time and effort to travel there. He would not have had the capacity to advocate for himself and to show that he did in fact have a scheduled appointment.

### ***Managing and supporting the wellbeing of carers***

- 67 Overall, carers do not have enough support. Caring impacts our own health and wellbeing and we are so drained.
- 68 As a carer I get criticised a bit. Some people are not that supportive. People can be so judgmental. I'm not perfect but I've tried. Some people have suggested that I don't provide enough discipline, others have told me that that I am too controlling. I can't win. I have received many inappropriate comments from mental health staff who have labelled me as a "neurotic" mother when I battled to get my son support. Or who have said "*you must be feeling guilty*". I do whatever I can to keep myself going.
- 69 I have been receiving support as a carer through the Family Drug Support program. It has been an excellent support to me.

#### Support from Mind Australia

- 70 I have been receiving support through Mind for a few years. The support workers have been wonderful.
- 71 The support workers sometimes organise outings for carers. I used to be hesitant to attend and thought they were for other people. If I organise something with friends, 90% of the time I wouldn't be able to make it and it would be wasted money. A couple of times when I wasn't working and they had cancellations, they would call me and encourage me to attend, saying "*come along we've already got the booking, and someone's cancelled*". So I started attending a few of the outings and I was able to speak with other carers and some really nice Mind workers. Some of the carers really look forward to the events and it's what keeps them going – a day out at lunch or at the movies. Sometimes, Mind were able to get free tickets to the Art Centre and that was something special. With Mind if I was unable to attend something organised in a way, I wouldn't be disappointed because I knew that Mind would understand and that it wouldn't be wasted money because they could ring someone to take my place. I think getting together with other carers to share experiences and support each other is so important.
- 72 Unfortunately, I have heard that Mind are losing their funding for carer support at the end of the year. This is very disappointing for me, and I am aware that it has been devastating for other carers.

#### The gap between supports for mental illness and other illnesses

- 73 When I attended the Town Hall for the Royal Commission, one person there said she had a child with mental illness and a child with cancer, and how different the service was. It is so true. Last year, my sister's husband was diagnosed with prostate cancer. From day

one, they received such amazing service, with specialists including occupational therapists, pain consultants, support and counselling. When it all became too much, my sister had access to a hospice. The hospice was a lovely place, with lovely staff; what a difference that makes. On one occasion when my sister attended the hospice, they immediately noticed she was distressed and said “*you stay put, here’s your cup of tea, we’re going to get the counsellors or the Chaplain to see you*”. I am so glad that my sister and her husband received such well-deserved support.

- 74 Whereas, I find it hard to get support and be listened to. When I’ve been distressed, I have been dismissed. There needs to be a similar wrap-around, family inclusive service for mental illness, as there is for people with cancer.

#### Support for siblings

- 75 I have a beautiful daughter, who is high functioning. She and Harold were close, and she has been shocked at the changes in Harold. She has also missed out on care and attention due to me being busy caring for Harold. Siblings need support too.

#### ***Respite for carers***

- 76 Carers need to be supported and provided opportunities that allow for a break. I am absolutely exhausted. I am doing 24-hour shifts, 7 days a week. Harold fluctuates so much. He often does not shower, brush his teeth or change clothes for weeks and lacks motivation for self-care. He has incredible mood swings and doesn’t want to take his medication.
- 77 One couple I know were relieved when their son was sent to prison, which sounds awful, but I understand because they knew he would be safe, have a roof over his head, have meals, possibly receive a little bit of rehabilitation and there would be an absence of alcohol and other drugs. There’s nothing much else like this, especially when a person hasn’t reached a stage of wanting to attend counselling or hasn’t yet qualified for rehabilitation programs. There have been times when I have wished that Harold had a physical disability just so that I could get the care he needs.
- 78 It is hard for me to get any respite because I am concerned about Harold and also how my absence would affect the neighbours. I feel the need to be there as a protective measure, whether it is to ring for an ambulance or the police, or talk to Harold in such a way, as to counsel him and settle him down.
- 79 There is a lack of accommodation to give carers the respite they sometimes need, and even where it is available, it’s only short term. I think there is a need for a place where Harold, and others like him, could be taken for 24 hour care, even if it is against their will,

when it's all getting too much for the community or the carer, and the person is a threat or danger to themselves or others.

### ***Summary of issues I have experienced in the mental health system***

80 Through all of this, the main issues that I have experienced in the mental health system include:

- (a) **Inaction by CAT team:** I have had experiences where the CAT team has refused to attend my home for a mental health assessment despite both the police and me requesting this. There are a number of CAT team or triage workers who are clearly burnt out. When I call the CAT team or triage workers, they will often say to call the police.
- (b) **Over-reliance on the police and ambulance services:** not all police officers understand mental illness and they shouldn't be the main point of call. It is not their job and earlier interventions are needed.
- (c) **Treatment teams and the mental health workforce not including and supporting family:** I have repeatedly tried and have often been unable to contact mental health staff in regard to my son. When appointments have been made, a number of times they have been cancelled. I've tried to talk to staff about my concerns, but they often don't listen, and I've had an awful time finding anyone who will.
- (d) **No respite for carers other than the limited availability of short-term hospital admissions.**
- (e) **A complete lack of compassion and consideration of trauma on the part of mental health workers:** this was apparent when I was refused support while my mother was dying. It is also apparent when Harold is labelled "*non-compliant*" and "*disengaged*" for not attending appointments using public transport despite his history of trauma having been bashed on public transport. Harold can experience great anxiety and can easily get lost. There are periods when he does not have the capacity to use public transport. There needs to be more compassion in the responses and language used by professional services and the community when dealing with mental illness and substance abuse. Instead of saying "*What's wrong with them?*", a compassionate response would be, "*what's happened to this person?*".
- (f) **Blaming and stigmatising families:** I have received many inappropriate comments from mental health staff, who have labelled me as a "*neurotic*" mother when I battled to get my son support and said, "*you must be feeling guilty*". It is

unacceptable to blame and stigmatise families for wanting to get their family members help and support.

- (g) **Inappropriate discharge and failure to inform carers of discharge:** Hospitals have discharged Harold without a discharge plan or support to get him home and without informing me. This is despite my calls to the hospitals requesting they inform me of discharge.
- (h) **Overloaded and under resourced workforce:** As a result of the overloaded and under resourced workforce, clinicians often discharge consumers from their service before having a chance to build rapport. This means that the only way to get access to support is through a treatment order, because under this they have to receive help. The case loads are often so big for mental health services that they are unable to effectively support everyone.
- (i) **Stigmatisation of dual diagnosis:** People with dual diagnosis (mental health diagnosis and AOD) are known to suffer with low self-esteem, isolation and potential relapse. Stigma surrounding addiction often leads to depression and poorer access to treatment.
- (j) **Physical and other health needs are often ignored:** despite living in “supported” accommodation, there is no focus on supporting personal hygiene or dentistry, or physical and mental health needs.

### ***Areas for improvement to the mental health system for consumers and their carers***

81 There are some things that would make a huge difference to my son’s life and to my life and include:

- (a) **Beds:** being able to get a hospital bed when Harold needs one.
- (b) **Outreach:** there should be more mobile support teams, especially for young people who may not have the motivation to get themselves to services. This includes ensuring CAT teams are willing and able to visit when needed.
- (c) **A workforce that listens to and respects carers:** the mental health workforce needs to listen to and respect the input of carers, parents, siblings and family. They are the experts in the lives and life experiences of their loved one.
- (d) **Strengths:** the mental health workforce should look to and consider the strengths and positives in the people who are being treated for mental ill health. Even small things like nice comments can make a difference and give hope. The current system and approach are so dehumanising.
- (e) **Respite and support:** the need for greater availability of respite and support for carers.

- (f) **Compassion:** the system, the services and the workforce need to be more compassionate and understanding of the immense pain and stress that families and people like my son are experiencing. Workers need patience and understanding to properly engage with people with mental illness.

3 August 2020