Committee Secretary
House of Representatives Standing Committee on Social Policy and Legal Affairs
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We request parts of this submission be confidential as there are personal safety issues relating to our submission. The confidential material is provided as an attachment.

We are writing to share our personal story to demonstrate the challenges and difficulties faced by unpaid mental health carers in Australia. We are doing this because we have a degree of privilege that means we can.

The existence of the Carer Recognition Act 2010 has not made any material difference to our experience, other than provide this opportunity to tell our story in the hope that it makes it easier for others.

The experience of carers is diverse. Carers are not a homogeneous group. Carers share a commitment to support others, frequently a relative, to have a quality of life. We are telling our story to give you a different perspective. Unlike many carers we did this for someone who was not a family member.

We want to highlight that:

- Not everyone recognises who the carers are; the existence of the *Act* has not helped achieve this recognition among publicly funded service providers
- Not all unpaid carers are family carers.
- Not all unpaid carers recognise they are carers and know that there are supports available to us
- Unpaid carers face significant out of pocket costs because of our caring role.
- There is a heavy weight of responsibility that unpaid carers carry. For mental health carers this includes managing suicide risk and other self-harm.
- Mental health carers deal with a fragmented system. It is hard to find services to support people with mental illness who are not connected to the acute system. We need a place to go to speak to someone who can provide a care pathway or clear advice.
- We need more mental health support for carers, at no cost to carers. Mental health care can be traumatic. It is relentless. We had to wait for almost a month for an urgent appointment with our fabulous counsellor.

I will refer to the person we supported as XX.

We supported a young person with complex mental health conditions and challenging social circumstances. They are estranged from their extended family who live interstate. XX was not a member of our family. We chose to support XX and felt a sense of social responsibility to support them, believing that there is intrinsic worth in all people and some people need more support than others in order to live a good life. We had hoped they would get well and not need us anymore. Sadly, that is not how this story ends.

About us

We come from English speaking backgrounds and have post-graduate qualifications. We are familiar with large health and social care systems, have good incomes, strong professional and personal networks and flexible workplaces. Yet the years we spent supporting XX f has been the hardest thing we have done. This has been well outside our life experience and has involved significant personal growth and reflection, as well as financial cost.

From early 2016 until late 2022 I took on a support role to XX due to their circumstances. I was the primary support but my spouse also played a key role in this.

About the person we supported

XX experiences significant, multiple, and persistent mental health challenges. These challenges affect their ability to take care of themselves, maintain employment, continue their education, and impact their personal relationships. They use drugs and alcohol to self-medicate.

XX told me their diagnoses include: complex trauma, complicated grief, PTSD, acute anxiety, and depression. XX experiences acute panic attacks. We have been with them when they experienced high levels of distress, agitation, panic attacks, paranoia and psychosis. They also had unexpected and deleterious reactions to prescription medicines.

They struggle to regulate their behaviour and have a history of violence, anger, and volatility. They don’t care about the impact of their behaviour on others. They justify their behaviour by saying they have been wronged by life and society.

XX is severely triggered by key anniversaries and this required intense support and safety planning.

They have an intense fear of mental health services. They have a history of refusing to engage with mental health services.

I worked very hard to keep XX out of hospital and build a community based treating team including GP, private psychiatrist and psychologist and short term programs.

About the care we provided

I provided XX with general guidance, and emotional and financial support. I gave them hugs, had conversations, went on outings, went grocery shopping, shared meals together and we celebrated their birthday. I reviewed XX’s university assignments and job applications. I connected them to a GP and mental health supports. I wanted to keep XX connected and doing everyday things.

I bought XX groceries, pet food, clothes, internet, mobile phone plans, transport, medication and medical bills. I was their contact person with Centrelink.

I held hope for XX when they were in despair.

We subsidised their housing in the private rental market as we believe that safe and stable housing is a foundation to good health. From time to time when XX was unable to pay rent, we increased our financial support.

Our relationship with XX ended in late 2022 after a serious deterioration in their mental health over an extended period that culminated serious threats of violence against me and my family.

There are specific issues I want to bring to the Committee's attention:

Identifying as a carer

I did not see myself as a carer. I thought I was doing what was needed to support someone who needed that level of support. No-one – including my GP – identified me as a mental health carer, or told me about available supports for mental health carers. This was even though I had been to see the GP over time to express difficulty in managing XX's escalating behaviours. None of the service providers I spoke to while getting XX care identified me as a carer either. It was several years into my support of XX before a colleague who works at Carers ACT described me as a mental health carer. This was powerful moment, gave me a useful frame of reference and unlocked key support such as access to a fabulous counsellor at Carers ACT.

I had not applied the *Carer Recognition Act 2010* to my own situation. This demonstrates the invisibility of carers.

Invisibility of mental health carers

Carers seem to be invisible in the mental health area. In patient safety policies we see an increasing focus on the impact of the involvement of family or friends (unpaid carers) in reducing health care–associated harm in hospital. Yet in mental health services, carer involvement in patient safety, care planning and wellbeing support is not well understood and does not appear to be valued. People who are unwell are often too overwhelmed, intimidated or confused advocate for themselves. Of course we have to take confidentiality and patient preferences into account but we also need to recognise that there are direct and indirect consequences for carers.

Privacy trumps planning ahead

While I supported XX to attend a variety of appointments with clinicians and support services, I was not able to be included in care plans, nor could I contact any of these service providers to warn of impending problems. I had no recognised role in XX's care, and their privacy outweighed other considerations.

XX's perspective was the only perspective the service providers saw, and XX can be very charming. They did not see XX when they were enraged, shouting and flailing about wildly, hitting things. They did not drive them to hospital for treatment after breaking ones in a violent rage. They did not read their increasingly ranting, venomous, threatening, angry messages and emails to me.

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The need for mental health support for carers

From our experience the focus is on what mental health carers can do to support the person they care for and there is not an equivalent focus on the needs of mental health carers.

As a carer you are a support person, a guiding hand, a safety net. It is not about you but the person you support and care for. I prioritised the acute needs of XX over my family when needed. I regularly prioritised their needs over my own. XX's needs increased incrementally over time but we didn't notice. Their behaviour changed, their needs increased day by day, one episode at a time. XX's behaviour got steadily worse, but we did not see it as it we had normalised it. We were frogs in boiling water wondering how on earth we got to this point.

This is one of the benefits of counselling for mental health carers. Counsellors can hold up a mirror and invite you to look at the situation from a different perspective. The counsellor at Carers ACT was instrumental in helping us to understand the risk to our safety as things were unravelling. The counsellor talked us through this and supported us to understand the risks and introduced the notion of safety planning for us. Ironically, I was very accustomed with this term as I frequently did safety planning for XX.

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Education programs for mental health carers

There is a need for education programs for carers to help us navigate the mental health system and help us to stay well and be a better support for the person we are caring for. For people living with chronic conditions we often talk about the first 12 months after diagnosis as being a year of learning to understand the disease or condition, the services available to them, the treatments and to think about what they value and want to prioritise. It is about setting themselves up to live well with the change in their health. We need a similar approach for carers.

Financial costs of caring

The financial support was constant. I reviewed some bank records across 10 months between April 2019 and February 2021. In that period, which was not unusual, I spent $2,900 on XX, on items such as clothes, groceries, medication, cat food and kitty litter, bus fares to Sydney to see his psychiatrist, phone bills and his internet plan. On top of this, we paid for meals out, and small treats. This did not include housing costs. He also asked - and got - financial support from his paternal family.

Navigating the mental health system

I worked hard to assemble a treatment and support team for XX.

I arranged for XX to have a usual GP and for their treatment to be bulk billed.

The treating team included (over time)

- a private psychiatrist in Sydney. XX saw this doctor quarterly to adjust medication.
- a private psychologist in Canberra (subsidised by a mental health plan).
- a support worker in the New Path Program with Woden Community Services (a nine month program, funded through the ACT Primary Health Network).
- a support worker from StandBy. StandBy is a suicide prevention program dedicated to assisting people and communities bereaved or impacted by suicide.
- A worker with Transition to Recovery program (TRec), a Woden Community Services (a 12 week program, funded through the local PHN).
- XX accessed regularly a range of online phone support programs including Lifeline, Mensline Australia (telephone and online counselling service, BlueKnot (specialising in complex trauma), SANE Australia (support to anyone in Australia affected by complex mental health issues). This was often the case in the evening when XX is frequently most distressed and agitated but many health services are closed.

I was able to find and organise this assistance because of my understanding of the health system.

Short term care is not a fix for long term illness

The community services are short term programs. They made a significant difference for the short time XX was on the program and took pressure off me as I felt there was support. Once the program ended I had to increase my caring workload for XX until I could find another program to support them. XX would have benefitted from a paid case manager who had responsibility for stitching together long-term support program. This fell to me.

XX sometimes used their complex array of diagnoses as an excuse to not engage with service providers before they had even engaged deeply with them believing that their case is too difficult for any service or clinician to deal with.

The short-term response exacerbates the problems XX faces; trying to fix anything in a few weeks that has taken a life to create is not realistic for anyone.

Personal safety of mental health carers

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There is a focus on the safety of the person living with mental illness but the safety of mental health carers is routinely overlooked. Mental health carers experience psychological, verbal and emotional abuse. Many I know, like us, actively safety plan for when the mental health of the person they support deteriorates.

Conclusion

As you can see from our experience, there are many systemic challenges that impact on unpaid carers. We wish you well in your consideration of the issues and the look forward to seeing the recommendations from the report.

We would be happy to talk to the Committee about our experience. Again, I want to stress the personal safety issues that are currently impacting my family and we would need to do this confidentiality.

Yours sincerely

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