WHO CARES?

A CASE FOR IMPROVING PRACTICES FOR PEOPLE LIVING WITH MENTAL ILLNESS:

THE CARERS' PERSPECTIVE

BY THE MOOD DISORDERS CARERS SUPPORT GROUP
AUGUST 2022

Mood Disorders Carers Support Group
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EXECUTIVE SUMMARY

1.INTRODUCTION

The Mood Disorders Carers Support Group (MDCSG) has been active for 30 years, supporting carers of loved ones with mental health issues. It is one of the largest carers support groups in South Australia.

We are at the coal face of mental illness and we believe the system needs reform. There needs to be a more collaborative approach to mental health care, with more inclusive practices, an "it takes a village" attitude.

We invited the members of MDCSG to complete a survey drawing from their experiences within the mental health system in South Australia. Following are the groups insights and perceptions on what is working and what is not working within the current mental health system in South Australia.

2. BARRIERS TO EFFECTIVE MENTAL HEALTH SUPPORT pg.4

- Community Mental Health Services should be ongoing.
- The concept of long-term care of people with chronic conditions needs to be embraced.
- We need more psycho/social programs.
- Too many of our loved ones are not eligible for an NDIS plan.
- The method of training doctors is not conducive to support a person with mental health issues.
- Government renumeration for psychiatrists needs to make bulk billing a viable option.
- Carers need to be included in their loved one's mental health care.
- The existing medical model is outdated.

3. SOLUTIONS FOR REFORM pg.5

- More affordable psychosocial supports.
- Early intervention not crisis intervention.

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- The "Step Up, Step Down" concept.
- Urgent Mental Health Care walk in centres.
- Continuity of care.
- More community support is required.
- A psychiatric system where our loved ones feel empowered.

- Carers feel invisible in the current mental health system.
- Support Services need more awareness around the role of the carer.
- Extensive educational programs for carers.
- Peer workers in the area of carer support.

- From a Carer's Perspective.

- Statistics collected from carers survey.

- Comments collected from carers survey.

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BARRIERS TO EFFECTIVE MENTAL HEALTH SUPPORT

- **Community Mental Health Services should be an ongoing** support for people living with mental health challenges, mental illness is ongoing and episodical. There should be a case manager responsible for the unwell person and this should be in place long term.

- **The concept of long-term care of people with chronic conditions needs to be embraced.** Not just treating people for 6 months after an episode and sending them back often to a non-existent GP or to a GP who does not know the person or family. Brief therapy leads to revolving door admissions and to endless episodes. The concept should be to avoid episodes and not assume absence of episodes means a cure. It means the person is stable not cured! Like stabilising a person with diabetes, it does not mean the diabetes disappears and no more treatment is needed. Treatment often needs to be lifelong.

- **We need more psycho/social programs**. There are some great programs currently offered in government & non-government organisations however we need more. Also, most are only on offer if you have a NDIS plan, so no plan - no support.

- **So many of our loved ones are not eligible for an NDIS plan** therefore are slipping through the cracks. There needs to be alternative and affordable support for these vulnerable people.

- "About 690,000 people in Australia have a severe mental illness. Just 21,700 receive psycho-social support under the NDIS. Up to 91% will have to rely on non-NDIS community mental health services". *From* "Defining the Missing Middle" https://www.orygen.org.au/Orygen-Institute/Policy-Areas/Government-policy-service-delivery-and-workforce/Service-delivery/Defining-the-missing-middle/orygen-defining-the-missing-middle-pdf?ext=#:~:text=The%20'missing%20middle'%20is%20a,enough%20for%20state%2Dbased%20services.

- **The method of training doctors is not conducive to support a person with mental health issues.** We believe that GP's cannot take over from psychiatrists just like they cannot take over from oncologists, cardiologists and other medical specialists. GP's are insufficiently trained and very few are prepared to take on extra available courses to make them better suited to help patients with a mental illness. Carers and the people they care for would also benefit from their GP educating them about supports that are in the community for them to access. This very rarely happens.

- **Government renumeration for psychiatrists needs to make bulk billing a viable option.** Without an improvement in this area only the moderately unwell who are able to earn a living will continue to have good care. Those on government pensions have no hope of accessing specialist care. The current system has been designed that psychiatrist see clients every 15 minutes. 15 minutes is not long enough to build rapport and trust. Longer appointments would be of more benefit and have better long-term effects than a 15 min appointment and a referral to a GP who doesn't have the specalised expertise in mental health.

- **Carers need to be included in their loved one's mental health care.** Confidentiality, seems to be a code word for "I don't want to spend the time with my client explaining to them the advantages of having a family member or friend helping them". Clients are intimidated or just too unwell to advocate for themselves. At least if you have a cancer or other physical illness you are not treated as stupid. The stigma is still there even with some practitioners who should know better. There are some who think a list of medications is sufficient to send someone out into the community after a period in hospital. This is not the intent in the Code of Ethics. Treatment should be more proactive, not reactive.

- **The existing medical model is outdated**. It no longer works just medicating people living with poor mental health and then sending them on their way. We need to break down this dominating medical culture. The current system focuses on the deficit. There should be a shift to a strength-based model. The current system is crisis intervention focused and should be early intervention focused. A trauma informed approach should be in practice, the concept of "what happened to you?" rather than "what is wrong with you?".

SOLUTIONS FOR REFORM

- **More affordable psychosocial supports.** The reintroduction of a mentoring program like PHaMs (Personal Helpers and Mentors Service).
  https://www.dss.gov.au/sites/default/files/documents/07_2013/part_c1_phams_guidelines_april_2013.pdf

- **Early intervention not crisis intervention**. Keep people struggling with mental health issues out of ED, saving costs on hospital beds and staff. Early intervention is much more cost effective than crisis intervention. Early intervention education programs should run in parallel with NDIS support for the people who have slipped through the cracks, who don't get or unable to get NDIS due to insufficient support through lack of family or another caring person. There needs to be more focus on community services.

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Following is an excerpt from "Defining the Missing Middle" by Orygen "*Economic evidence and international consensus positions early intervention and community mental health care as the greatest model of care to reduce distress and economic burden in mental health, largely due to a reduction in hospital service use".*

Following is a link to The Economic Case for Investing in Mental Health Prevention from The National Mental Health Commission.

https://www.mentalhealthcommission.gov.au/getmedia/ffbf9cc5-f815-4034-b931-dfc0c1ecb849/The-economic-case-for-investing-in-mental-health-prevention

- **The "Step Up, Step Down" concept** of transitioning people living with mental illness back into the community after a crisis and hospital stay works well. We need more intermediate care centres that are accessible in all areas of the community.

- **Urgent Mental Health Care walk-in** centres are working well. These services take huge pressure off hospital emergency departments, consequently saving money. We need more centres that are accessible in all areas of the community.

- **Continuity of care** in supporting a person with mental health issues is vital. A system where the clinician, GP, support/peer worker and family/carer communicate with each other - focus on connection. Our loved ones would benefit if mental health services took a more inclusive attitude to support with a multidisciplinary methodology, involving the person's family or friends where possible. A more holistic approach is necessary with education for our loved ones around good physical and mental health.

- **More community support is required**. Many South Australians live with a long-term mental health condition, yet not enough people are connected to mental health support that enable them to better manage their illness on a daily basis, overcome stressors in their lives and other factors that can undermine their mental health.

  The program that has recently been established with homelessness reform in South Australia the "Toward Home" alliance, would translate well into the mental health sector. It uses the concept of offering a range of services that are designed to offer ongoing support to a person living with mental health challenges. It provides a more effective way of practicing psychosocial support: a use of services which collaborate and communicate making sure the client doesn't slip through the cracks. https://towardhome.org.au/

[redacted]

- **A psychiatric system where our loved ones feel empowered**. Where time is taken to build trust and rapport. You can't underestimate the value of building a relationship, using the right language, making people feel safe, listening and validating. Where families and carers are included in the treatment planning process (wherever possible). Where training doctors includes input from consumers and carers, drawing on the experience of people who are living with mental illness. A more humane approach to mental health support is required to give our loved ones their self-esteem back. The system needs to foster an approach that puts our loved ones in the driver seat, empowering them to be in charge of their health and wellbeing. The World Health Organisation encourages the implementation of mental health services to encompass a recovery-based approach with an emphasis on supporting individuals to achieve their aspirations and goals. Key elements of the approach include:
    - *listening and valuing a person's own understanding of their condition and the impacts on their life*
    - *listening to the person's view of what helps them in recovery*
    - *working with people as equal partners in care. This includes enabling people to have a choice regarding treatment and therapies, and choice on care providers*
    - *using peer workers and peers supports who can provide mutual learning and encouragement, a sense of belonging, and knowledge from lived experience (WHO 2013).*

THE ROLE OF THE CARER

Carers feel invisible in the current mental health system. Wherever possible carers need to be included in their loved one's mental health treatment. A carer knows their loved one better than anyone does. They know what kind of person they were before they became unwell. Carers are often the first point of contact in the mental health system.

"Psychiatrists shall encourage the patient's family/whānau (and/or other supporters involved with the patient's care) to participate actively in clinical care of that patient where appropriate, but take confidentiality,

cultural factors and patient preferences into account". from The Royal Australian & New Zealand College of Psychiatrists "Code of Ethics".

It is our experience as carers that the above very rarely happens.

Following is a link to the Mental Health Act 2009 facts sheet for the "Rights of Carers" of people receiving mental health care. These rights are not being acknowledged by the current medical model.

https://s3-ap-southeast-2.amazonaws.com/sahealth-ocp-assets/general-downloads/Factsheet-Rights-of-Carers-20190808.pdf

- **Support Services need more awareness around the role of the carer.** A carer requires as much resilience as those directly affected by mental illness. It has been reported that 70.6% of carers experience poorer physical and mental health related to their caring role.

- **Extensive educational programs for carers.** We need more educational programs for carers to help them navigate the mental health system and help them stay well and be a better support for their loved one. Information is power.

- **Peer workers in the area of carer support**. It would be of great benefit to carers if there were more carer lived experience/peer workers in government and non-government services. Supporting families and carers by connecting them with experienced and trained carers that can walk alongside them on the caring journey. Mentoring the carer and their family, support them in their caring role.

A CASE STUDY:

FROM A CARER'S PERSPECTIVE *by Helen*

"As I look back now, my son was experiencing problems in his early teens - some signs were there but he was a bright and interested student, so any concerns raised at school were quickly dismissed. It became more evident in his mid-teens that he was struggling but with excellent Year 12 results and University admission, I hoped that he would find his way.

During this time there was also illicit drug and alcohol use, although he didn't think this was a problem. I encouraged him to make appointments with a GP and was so relieved when he finally did. Different medications were trialed and different GP's were consulted but he wasn't improving. He then 'found' another GP on the other side of town, who had an 'interest' in mental health.

[redacted]

For the next few months, I drove him there to attend every appointment. He was spiraling downwards, and all aspects of his life were impacted, including studies. I decided to make an appointment to see this GP alone - I didn't need to be told anything about my son's mental health as I was living it with him, and knew he was very unwell.

I am also fully aware of Doctor/Patient confidentiality and intended to discuss some issues that I thought were important for the GP to know. I was abruptly told 'I cannot discuss your son' and felt very intimidated and out of line for wanting to help my son, and left feeling a failure.

However, he was finally referred to a private psychiatrist - about 2 years after initially presenting with mental health issues. Despite more medication and therapy, his health continued to deteriorate, and not knowing what else to do, I phoned ACIS (Assessment and Crisis Intervention Service), which led to my son being detained under the Mental Health Act and hospitalized.

It was a frightening and isolating time for all, and he wouldn't speak to me for days. I hoped that we were on the road to recovery - every time he received medical care, I had this moment of hope, which unfortunately never lasted long. He was discharged within a week, into the Public Mental Health Service, with a Community Treatment Order and some support from the community team.

I was taking him to many different appointments and trying to look after him both physically and mentally - which was a 24 hour job as his sleep patterns were very disturbed. For the next 5 years, it was a rollercoaster of different psychiatrists and GP's (some of whom tried so hard), and different diagnoses and medication changes. Psychosocial support was very limited and short-lived, and follow-up care was non-existent.

His mental health deteriorated again, and we took him (at his request) to the ED, where he was finally admitted to the Mental Health Unit. He was in hospital for 12 weeks, trialing different medications with little effect, then a course of ECT. It was a very distressing time and family relationships were severely impacted. It's hard to seek help for yourself. You are busy with your loved one's appointments and care, and often withdraw from social connections because you are so emotionally drained.

Following discharge, he had better support and follow-up this time. He required more ECT and medication changes, and also spent a short time in the Step Up, Step Down facilities, which were a much more positive environment than the hospital mental health units. He had further regular psychiatric consultations with a doctor who was approachable and interested. Unfortunately, when he moved into accommodation with

Housing SA, he was unable to continue with the same public psychiatrist because he was living in a different zone.

We received guidance in applying for NDIS, and he definitely wouldn't be able to manage in his own place without this support of up to 2 hours each weekday - but it's usually his choice as to what is achieved each day. Initially it was very promising as there seemed to be more structure in the type of assistance that was given, which was beneficial. It has allowed me to reduce my caring role, but I still consider myself the main carer due to shortfalls in support of activities of daily living.

Currently, support is lacking in basic everyday tasks such as managing finances, cleaning, laundry, meals and organisational skills. It is assumed that he will do these daily activities, but poor concentration and cognitive deficits don't allow him to stay on task. These problems are exacerbated by (legal) addictions which I don't believe his mental health team consider to be a serious problem. Previous recommendations by an OT and psychiatrist had been made for more structured support but these have not been followed up in the long term.

It should not be assumed that a patient/client gets himself to appointments, has the ability to budget and pay bills as well as buy his medications, groceries and clothing, or undertake daily chores. Questions to loved ones need to be asked in a certain way, so that an accurate and true picture is presented. I would certainly value being offered an occasional private meeting with any of those involved in his care, however I feel it's unfair to ask me to discuss any concerns in front of my son.

Throughout this journey, there have been very limited opportunities for discussions with any of his team. We feel invisible yet have so much to offer and the desire to help our loved ones. We want to see them independent and living their own life. As a carer, my health and well-being have been severely impacted, along with career opportunities and financial independence. Thankfully support groups such as The Mood Disorders Carers Support Group have been a reliable source of education, information and assistance to enable carers to feel acknowledged. Sometimes, we don't find this type of help for many years.

Without early intervention and regular, long term follow-up, the road to recovery is very long and difficult. Let's hope the next generation of carers is valued and included in their loved one's journey"

Mood Disorders Carers Support Group
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MDCSG SURVEY RESULTS

Statistics derived from responses to the MDCSG survey.

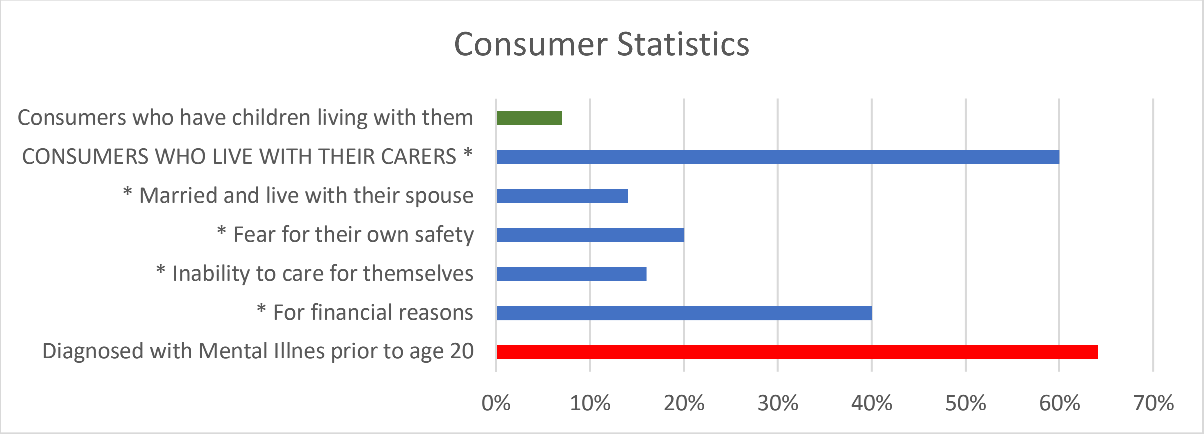
Age of consumers cared for by members of MDCSG	
16 – 45 years of age	50%
45-60 years of age	50%
Consumer statistics	
Consumers with a first presentation of mental illness before the age of 20	64%
Consumers who live with their carers	60%
• *For financial reasons*	40%
• *Inability to care for themselves*	16%
• *Fear for their own safety*	20%
• *Married and live with their spouse*	14%
Consumers who have children living with them	7%
Consumers who have been able to access support	
Government support DSP or other	62%
NGO support	23%
Continued support is sporadic	70%
Currently still receiving supports which address their needs	57%
Have early intervention or crisis support primarily the psychiatrist	33%
Have a GP who is a valuable mental health resource	30%
Have a NDIS plan	32%

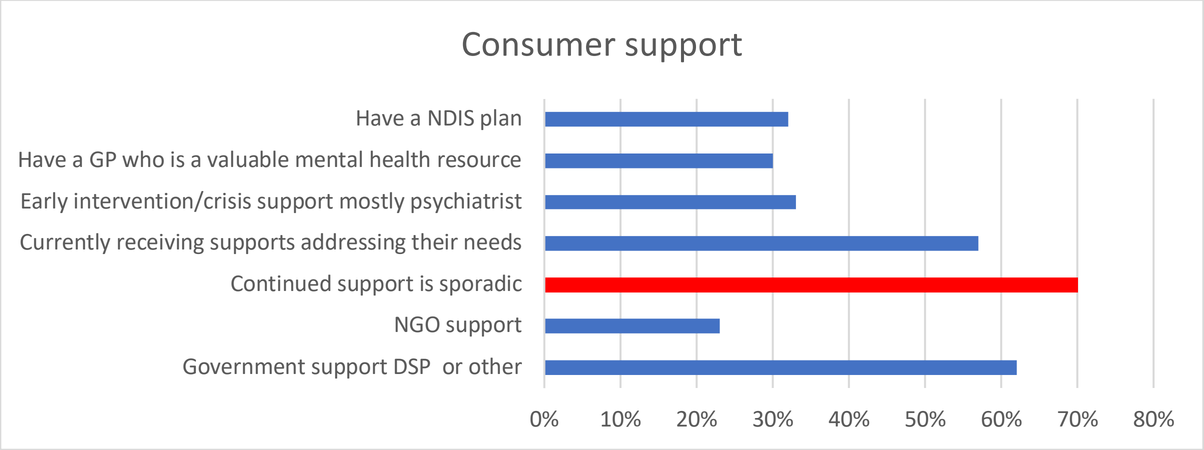
Carer statistics; most often parents.					
Age of carers					
Under 40	40- 49	50- 59	60- 69	70-79	80+
3%	0	7%	15%	60%	15%

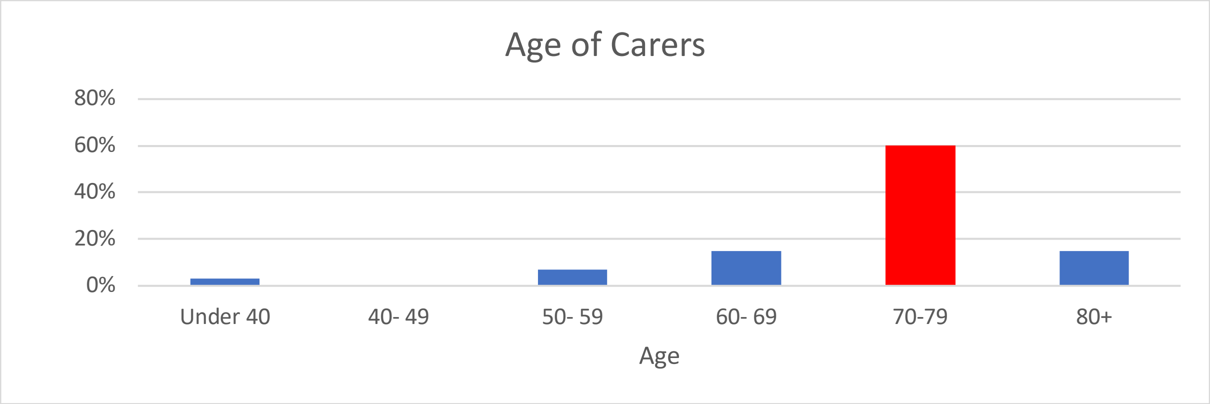
Issues which prevent carers providing optimal care for their loved ones.	
On leaving hospital or transferring to a GP carer **not** included in the exit plan.	70%
Not included in an ongoing care plan.	66%
Carers become **the** crisis care at home when loved one is either discharged while too unwell to be in the community or have been refused admission due to bureaucratic inadequacies. (a lack of beds)	48%
Personal health issues which have arisen due their caring role.	95%

[redacted]

Have expressed financial hardship brought about by their caring role.	73%
Have expressed fear for the future of their loved one after their death.	100%
Stigma	20%







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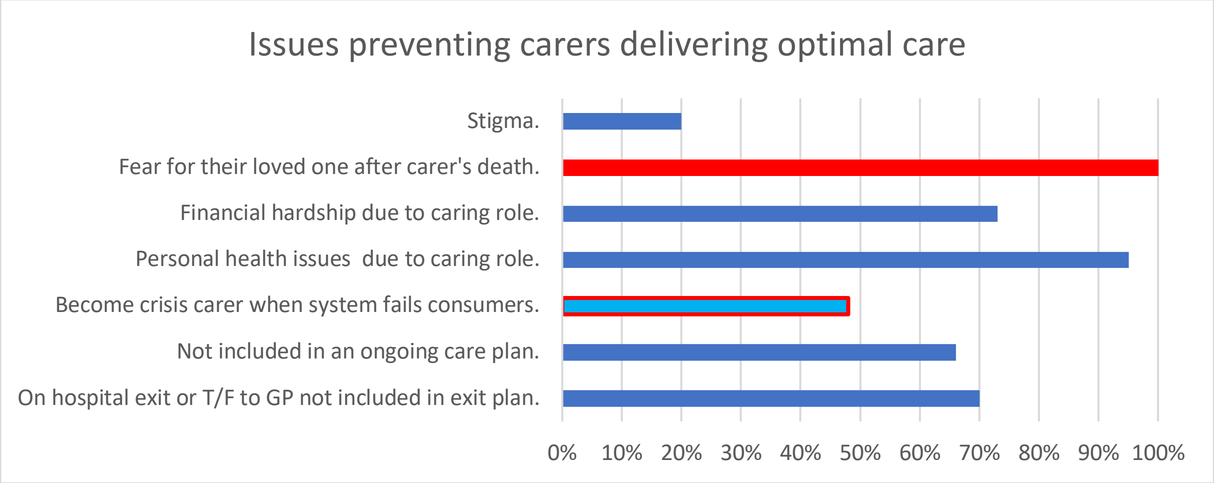

CONCLUSION

We are well aware these changes will have a dollar value attached however investing in early intervention makes good economic sense. Mental health has always been the ‘poor cousin’ in the health system. It is now time to invest in our vulnerable people.

This report has been prepared by carers of loved ones with mental illness. Carers have the unique perspective of seeing the effects of the limitations of the current system on the mentally ill. Carers are the ones left to deal with the effect and fallout due to these limitations.

Thank you for listening. Thank you for caring.

This submission was developed by Paula Smith, Ari Cox, Paul Cox, Robyn Bartel and Marcia Johnson Timm

We thank all the carers who generously donated their valuable time to complete the MDCSG survey and contributed to this important submission.

Mood Disorders Carers Support Group
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COMMENTS FROM MDCSG SURVEY

"You are only as happy as your unhappiest child". Comment from Nola

"The mental health system is too crisis driven, fragmented, failure of early intervention support capacity building in people's lives". Sharon

"The lack of step-down support between crisis care and normal care is critically lacking". Paul

"It is heartbreaking turning up to hospital (when in crisis) and being turned away, or worse, being told it's not worth even trying for hospital admission" John

"Have experienced, early discharge from ED at hospital, without any consultation with us (carers), even when under a 24-hour order". Robyn

"The best support has been family, friends and the carers group. It always helped to know others are going through or experiencing similar situations". Joan

"We are fortunate that we have had good psychiatrists who have treated us as a couple". Kaye

"They sent my daughter home from hospital whilst she was still unwell. We couldn't leave her, and she soon had to return to hospital in an ambulance". Anonymous

"Carers need to be acknowledged by the mental health professionals - being listened to and respected particularly in the cases where the consumer has no awareness of their mental illness". Anonymous

"There is definitely a reactive situation in the system while he (son) understandably feels infringed." Ern

"Carers need to be acknowledged and listened to. Don't assume that a patient gets himself to appointments, manages his finances, buys his medications, food, clothing etc, or does any daily chores". Helen

"The NDIS process is too confusing and elaborate and unless an application is written in "NDIS speak" then it's rejected. The present process is soul destroying for sufferers and carers". Robyn

"It is depressing living with a depressed person. Belonging to a carer support group was so helpful". Cleone

(as a carer)" I have fatigue, depression, difficulty maintaining friendships". Nick

[redacted]

"I have had comfort from Mood Disorders Carers Group meeting with others who have had same experience". Yvonne

"I understand that the GP of all the professionals is the most regular, most accessible and therefore important contact. Although the psychiatrist, psychologist are in a strong position with a power of Veto but also with seemingly less real-world visibility and understanding of the situation and impacts". Howard

"Very stressful dealing with psychiatrists who don't listen to my Son. A Pharmacogenomic test report should be routine. I have often felt belittled by psychiatrists. We live with the unwell person and experience, listen and observe their condition". Diana

"It would be good to have a regular contact with the people who see our son i.e., Mental Health Team rather than scant contact then be told it's confidential". Ern

"Wear on the mental strength needed to support adult daughter, grief and loss for her being able to reach her potential, resulting in insomnia". Ari

"I would also like to see early intervention at the onset of mental illness, followed by regular reviews, so that loved ones don't get lost in the system". Helen

"My son is still building a relationship with his psychiatrist. This takes time and is ongoing. It takes a long time to build trust in their relationship". Robyn

"I recently took my daughter to a walk-in mental health care centre as she was in crisis. We were both very distressed however my daughter received some support, but no one asked me how I was. I was clearly very distressed. The carer is so often invisible". Paula

"We must reinstate the activities practitioner at Margaret Tobin. There are no progressive therapies for clients on a daily basis at ALL!! In the ward. Psychological therapy sustains their wellbeing when they leave hospital. Most patients have endured trauma that has induced the psychosis or disassociation. They need to be listened to and supported emotionally. Helped with tools to manage their personal distress". Diana

"Trust is a big thing for our son, to have continuity of a core team that worked with him. His aim is to be able to contribute once again and feel valued". Robyn

"The Mood Disorder Carers Group has given me support many times with both girls". Yvonne

"I very rarely have friends to our home and feel anxious about what will happen to our son as we get older". Alison

"The housing problems are continuous for so many, those with mental illness problems among them". Joan

"Our son has tried to get help when in a mental health crisis at public hospitals in the past but was not even admitted". Barry

"It would be really helpful to us to actually talk to a professional about the implications of his diagnosis so we can understand more and maybe be more helpful to him". Robyn

"I am finding it really hard to access an NDIS plan and I know it would be life changing for my loved one". Anonymous

"A present stay in Margaret Tobin is the first time in 8 years a doctor has asked me what has worked in the past". Diana

"We attended a group for carers and the people they care for. It was facilitated by two mental health professionals. It helped us understand how the illness impacted on both of us". Kaye

"I am regularly amazed that an adult male who becomes stroppy when manic, is not seen as someone who needs help, but rather as someone who is difficult thus to be moved on asap". Lilla

"I would like to see my daughter being treated with compassion, empathy and care. Being kind and gentle and validating how she feels helps so much". Judy

"The Mood Disorders Carers Support Group has been the only constant and reliable source that has been supportive and enabled me to keep informed about relevant mental health issues. I know that I could always contact this group if my world was crumbling around me and I wasn't coping. They have years of lived experience and understanding of the mental health system". Helen

"It would have been most beneficial if Carers SA had referred or introduced me very early on to the Mood Disorders Carers Group SA, since I have found this to be the most informative and aware local organisation and the place where I am learning so much more in the short amount of time I have joined this group". Howard

"My problem is that when I die there will be no one left to help my son". Pam