Treatment and support for personality disorder

A summary of research by SANE Australia



Introduction

Personality disorder involves pervasive and persistent patterns of thoughts, emotions and behaviour that can be distressing, and make daily life difficult.

Living with personality disorder can be challenging. Providing care and support for someone with personality disorder can be rewarding and life-saving, but can also be stressful. It can be difficult for people living with personality disorder, and carers, families and other support persons, to know where to find information or how to access support. The right support is critical for recovery and improving quality of life.

The National Mental Health Commission (NMHC) funded SANE Australia's research into what helps in the treatment of personality disorder, and what services and supports are available across Australia. SANE's research also involved speaking with people living with personality disorder and their carers. Participants explored what they found helpful and challenging on their recovery journey.

The full report can be found here*

This document summarises the findings of SANE's research, and what it means for people with lived experience of personality disorder, their carers, clinicians and Primary Health Networks (PHNs).

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^{*}Carrotte, E, and Blanchard, M. (June 2018). Understanding how best to respond to the needs of Australians living with personality disorder. Melbourne. Prepared by SANE Australia for the National Mental Health Commission.

What are the key messages of the research?

- Without help, living with a personality disorder can be difficult for many people and those who care for them.
- Evidence-based treatment is an important support for people living with personality disorder.
- Most research has explored treatment for people living with borderline personality disorder (BPD).
- Treatment may also be helpful for other kinds of personality disorders (see Table 1).
- There are major barriers to accessing treatment. Currently, the mental health system in Australia is not designed to meet the needs of people living with personality disorder.

What the literature says

According to the most recent national survey, approximately 6.5% of Australian adults experience personality disorder. Around 1% of the general population experience BPD. Neither men nor women appear to experience personality disorder more frequently.

The best treatment for personality disorder is regular, long-term psychotherapy. Research has looked at treatments for BPD, however little research has been completed on treatment for other personality disorders. Guidelines have been developed which identify important treatment principles across all therapies (see full report from SANE for further details).

Support in the mental health system

Treatment can be provided by a range of health professionals, including general practitioners, psychiatrists, psychologists, mental health nurses and allied health professionals. Professional support is available in both the public sector and private sector. The private sector provides fee-based services and funding is available for treatment from initiatives such as the Medicare Benefits Schedule (MBS) Better Access initiative.

Cost, long wait lists and a lack of appropriate services make it challenging to access treatment. Most specialist services are hospital-based and are in capital cities, making it difficult for people in rural and regional areas to seek treatment.

There are services available to support carers, however few of these are specific to personality disorder.

Table 1. Evidence quality for different therapeutic approaches

Diagnosis	High quality, consistent evidence	Good quality evidence
Borderline personality disorder	Dialectical behaviour therapy (DBT); mentalisation based therapy (MBT); transference focussed therapy; schema therapy; systems training for emotional predictability and problem solving (STEPPS); and cognitive analytic therapy (CAT)	Cognitive behaviour therapy (CBT); acceptance and commitment therapy
Antisocial personality disorder		CBT; MBT
Avoidant personality disorder		CBT; social skills training
Obsessive- compulsive personality disorder		Supportive- expressive dynamic therapy; CBT; interpersonal therapy

The experiences of people affected by personality disorder



Twenty-four people affected by personality disorder participated in the research, including people with lived experience, carers and families.

Six key themes were identified in the research (see below).

(Mis)communication

Many participants described the value of finding a warm, understanding clinician and developing strong therapeutic relationships with their support team. For many, this was just as important as the type of services they accessed.



Participants reported that communication with health professionals was sometimes unclear. Some did not receive a clear diagnosis or their diagnosis was not explained to them. Some participants reported accidental communications of diagnosis, such as seeing 'borderline personality disorder' written on a report, rather than having this diagnosis communicated in person. These occurrences were described as very distressing, resulting in participants distancing themselves from the diagnosis. Clear communication of diagnoses and treatment plans is vital.

Barriers and complexities



All participants identified challenges with seeking support and treatment. A lack of appropriate mental health services was reported and available services typically had waiting lists of up to two years. Many participants reported financial difficulties accessing treatment. Some emphasised challenges working with services and professionals that did not give appropriate consideration to their history of trauma, and at the most extreme, participants described re-traumatisation.

"The MH [mental health] profession needs to shift away from talking about what is WRONG with a person and instead look at what HAPPENED to a person. The symptoms of BPD are perfectly normal reactions to extremely abnormal situations.

The MH profession needs to shift to a trauma informed model rather than a medical model."

Lived experience participant



Identity and discovery

Participants described treatment as a journey of self-discovery. It took time to figure out the Australian mental health system, with some having to research personality disorder and become their own advocate. Many participants wished the process had been more straightforward from the start.

"[The BPD diagnosis] rocked me. I didn't know what to do... but at the same time it was... cathartic in the long run."

Lived experience participant



Finding what works (for me)

Many participants experienced a long process of determining which services, treatments and other supports were most beneficial to them. They discussed the importance of family, friends, hobbies, study, or work in their recovery. Talking to other people with lived experience was highlighted as an important part of the recovery journey.



An uncertain future

Most participants worried about their recovery prospects and identified a need for positive change. Suggestions included a significant funding increase for specialist services, change in the term 'personality disorder' and moving towards a trauma-informed model of care.



Carer-specific issues

Carers reported providing different levels of support ranging from practical and functional support to emotional support and friendship. They spoke about difficulties with changes in the role of a carer, significant stress and worry, and a lack of specialist carer resources available, particularly in rural areas.



Stigma and discrimination

Common through all themes was how stigma and discrimination impacted participants' treatment and recovery. This shows there is very little understanding of personality disorders in the general community and some health services. One effect of stigma was that participants experienced negative assumptions made by others. For example, some people assumed that participants were dishonest, violent, attention-seeking, or could not be effective employees. Many participants described instances of self-stigma, where they internalised others' blame and prejudice, resulting in self-blame for their symptoms and challenges in recovery.

What the research means for people with lived experience

With the right kind of support, people living with personality disorder can lead longer, more fulfilling lives. Below is advice, strategies and resources based on the research by SANE.

Seeking professional help

For many people, finding regular, evidence-based psychotherapy is the key to effective treatment. Community-based treatment is usually recommended unless you are in an emergency or crisis situation.

Research shows the benefits of psychotherapy for people with BPD, but people with other personality disorders can also benefit from psychotherapy.

Psychotherapy involves talking and learning about thoughts, feelings and behaviours with trained mental health professionals. Regular sessions help people to reduce the feeling of being low or empty, anxiety about relationships, paranoia, risky behaviour, self-harm, and anger and irritability.

Financial support

The MBS Better Access program subsidises up to 10 individual and 10 group therapy services with a psychologist per calendar year. This is available under a GP mental health treatment plan, or through a psychiatrist or paediatrician. Consultations may be provided through online channels for people in rural and remote locations. Up to five Medicare rebates with a psychologist within a calendar year are available for some people through the Chronic Disease Management program. Medicare rebates are also available for sessions with psychiatrists.

You may also be able to access free or low cost support through Primary Health Networks or the public health system.

Centrelink, the National Disability Insurance Scheme, and other services may be able to provide financial support, depending on your individual situation.

How to find treatment

Speaking with an understanding GP about psychotherapy and its benefits is an important first step for treatment. Online directories can also make this process easier.

Remember self-care

Setting up good routines, like healthy eating, exercise and sleeping well, can help improve your overall wellbeing and ensure you're more able to cope with symptoms of personality disorder.

What is needed to better support people living with personality disorder

The research highlighted the importance of evidence-based treatment. But there are also major barriers to accessing treatment. Without help, living with personality disorder can be difficult. For some people, it can be life-threatening.

People who shared their stories as part of the research were clear: they want to make a positive change to their lives. And there are ways to work with doctors, mental health professionals and others to find treatment and support that better meets a person's needs.

As part of their findings, SANE has recommended further research into the prevalence of personality disorder and how to effectively support people with lived experience. SANE has also recommended actions to streamline treatment pathways, improve treatment access and reduce financial burden.

"I belong to a... Facebook group... and again, it's a group who understands where you're coming from, understands the struggles in life... but literally just provide a social group, if you want to attend. Just to say, well you're a normal person, just like anyone else. We've got these... conditions, but again, it doesn't define you. It doesn't mean you have to avoid life or avoid relationships."

— Lived experience participant

More information for people with lived experience

This summary presents key findings from a larger research report by SANE Australia which can be found at https://www.sane.org/pd-report

Other resources that may be helpful for people with lived experience of personality disorder include:

- SANE Australia Facts and Guides Borderline Personality Disorder https://www.spectrumbpd.com.au/resources-and-support/for-carers
- Forums for people with lived experience of personality disorder https://saneforums.org
- Accessing treatment for personality disorders, Spectrum BPD https://www.spectrumbpd.com.au/
- Find a Service, Project Air https://projectairstrategy.org/servicedirectory/index.html
- Find a Psychiatrist, RANZCP https://www.yourhealthinmind.org/find-a-psychiatrist
- Find a Psychologist, APS
 https://www.psychology.org.au/Find-a-Psychologist
- Find a Clinical Psychologist, ACPA https://acpa.org.au/find-a-clinical-psychologist/

Talk with your GP if you'd like to learn more about treatment for personality disorder, or contact the SANE Helpline on 1800 18 SANE (7263). If you are in a crisis situation, try calling Lifeline on 13 11 14 or the Suicide Callback Service on 1300 659 467. In an emergency, please call 000.

What the research means for carers

Carers provide people living with personality disorder with the support, love and resilience to help make changes happen. With more access to support, everyone can benefit.

Seeking professional help

Professional help, such as psychotherapy, is often critical to a person's recovery and ability to lead a full life.

Psychotherapy involves talking and learning about thoughts, feelings and behaviours with trained mental health professionals. Evidence shows that regular sessions of psychotherapy help people to reduce the feeling of being low or empty, anxiety about relationships, paranoia, self-harm, and anger and irritability.

Many carers need support themselves. Help is available and can reduce stress and other issues in providing care. Mental health professionals can help carers develop skills in managing issues that come with providing care. With less stress, it can become easier to study, work, spend time with friends and enjoy life. The research identified some specific programs available to support people caring for someone with BPD. Carers of people with other personality disorders might also benefit from speaking to someone from a carer organisation.

Becoming involved in treatment

Becoming involved in a person's care provides an opportunity to learn about the diagnosis and treatment. It's possible to provide feedback to mental health professionals in treatment review sessions, and talk with others about providing support. It is beneficial to you, the person you support, and their treatment team to discuss options for how you can be involved to support the recovery process.

Financial support

Carers, families and other support persons may be eligible for rebates through the MBS Better Access program if experiencing significant psychological distress. Carers may also be able to access Medicare rebates to engage with the treatment of the person they support. The Better Access program provides more affordable access to mental health treatment. Some carers can also access financial support through Centrelink.

Remember self-care

Try not to do too much and be mindful of signs that you are becoming stressed. Allow for regular 'time out' and ask about respite care to give everyone a break. Setting up good routines, like healthy eating, exercise and sleeping well, can help you feel more in control and more able to care for someone with a personality disorder.

It can also be helpful to have an emergency or crisis plan, and to set clear boundaries.

What is needed to better support carers

Many carers we spoke to felt that they needed more support than what was currently available. Some carers wanted to be more involved in treatment processes, but this was not always possible.

As part of their research, SANE has recommended developing a holistic approach to meet the needs of families and friends of people living with personality disorder. This might involve more carer resources and support groups, but also improving options for financial support.

"There are public statements about how important carers are. But they really are undervalued."

Carer participant

More information for carers

This summary presents key findings from a larger research report by SANE Australia which can be found at https://www.sane.org/pd-report

Other resources that may be helpful for carers of people with lived experience of personality disorder include:

- Forum for carers of people with personality disorder, SANE Australia https://saneforums.org/
- Family Connections, National Education Alliance of Borderline Personality Disorder https://www.bpdaustralia.org/
- Better Access to mental health care, Department of Health
 http://www.health.gov.au/internet/main/publishing.nsf/content/mental-ba-fact-pat
- Support for families, friends and carers, Spectrum BPD https://www.spectrumbpd.com.au/resources-and-support/for-carers
- How to help in a crisis, SANE Australia https://www.sane.org/mental-health-and-illness/facts-and-guides/how-to-help-in-a-crisis
- Carers Australia
 http://www.carersaustralia.com.au/
- Carers page, Australian BPD Foundation https://bpdfoundation.org.au/carers.php

Talk with your GP if you'd like to learn more about treatment for personality disorder, or contact the SANE Helpline on 1800 18 SANE (7263). If you are in a crisis situation, try calling Lifeline on 13 11 14 or the Suicide Callback Service on 1300 659 467. In an emergency, please call 000.

What the research means for mental health professionals

Mental health professionals in many different settings work with people living with personality disorder. Below is advice, strategies and resources for mental health professionals treating people living with personality disorder, based on the research by SANE.

Treatment approaches

For many people living with personality disorder, finding regular, evidence-based psychotherapy is key to recovery. Carers may wish to be involved in treatment and may benefit from their own professional support. Referral to a specialist service may be an option, if such a service is available in your location.

Most research shows the benefits of psychotherapy for people with BPD, but people with other personality disorders can also benefit from psychotherapy.

Existing treatment guidelines and practice resources can help health professionals to assist people in accessing support that meets their needs (see resources below).

Communication

It is important to be compassionate, empathetic, consistent and non-judgemental. This can help build trusting relationships with people living with personality disorder. Try to be mindful of the spectrum of interpersonal challenges that may affect the therapeutic relationship (for example, some people living with personality disorder experience hypersensitivity, treatment ambivalence, or verbal aggression).

"I was struggling...I guess it's all a learning journey, but it would be helpful if I had more access to stuff off the bat than having to search for it myself and figure it out myself."

- Lived experience participant

Assessment and care plans

People living with personality disorder are at increased risk of suicide and self-harm. It is important to perform thorough risk assessments and distinguish between chronic and acute risk. Develop collaborative care plans and identify self-management strategies.

Conduct a comprehensive semi-structured interview and consider using formal diagnostic instruments or scales. Other recommendations include sharing formulations, acknowledging strengths and conveying optimism about prospects of treatment.

Medication

Pharmacotherapy is not generally recommended as a first-line treatment for personality disorder, and should only be used to target specific symptoms, such as depression. Ensure medications are trialled sequentially in a systematic way. Regularly review the risks and benefits of medication with the person living with personality disorder.

Trauma-informed support

Many people living with personality disorder have experienced traumatic events. Using a trauma-informed approach, and establishing feelings of safety, can help build rapport and trust.

What is needed to better support mental health professionals

Despite the effectiveness of evidence-based treatment, the research found major barriers to getting help for people with personality disorder. We know from past research that some mental health professionals find this work very challenging, and feel they have not been adequately trained.

As part of their research, SANE has recommended actions to streamline treatment pathways and improve treatment access. SANE has also recommended improving training options for mental health professionals.

More information for mental health professionals

This summary presents key findings from a larger research report by SANE Australia which can be found at https://www.sane.org/pd-report

Other resources that may be helpful for mental health professionals working with people with lived experience of personality disorder include:

- Clinical Practice Guidelines for the Management of Borderline Personality Disorder https://www.nhmrc.gov.au/guidelines-publications/mh25
- Treatment Guidelines for Personality Disorders
 https://www.projectairstrategy.org/guidelines/index.html
- Practice guidelines for treatment of complex trauma and trauma informed care and service delivery https://www.blueknot.org.au/resources/Publications/Practice-Guidelines
- Borderline personality disorder, SANE Australia
 https://www.sane.org/mental-health-and-illness/facts-and-guides/borderline-personality-disorder
- Spectrum Information for Health Professionals https://www.spectrumbpd.com.au/health-professionals
- BPD Foundation virtual resource library http://bpdfoundation.org.au/virtual-library.php

What the research means for Primary Health Networks

Primary Health Networks (PHNs) can help people living with personality disorder to access support that meets their needs.

Treatment approaches

For many people living with personality disorder, finding regular, evidence-based psychotherapy is key to recovery. Carers may wish to be involved in treatment and could benefit from their own professional support. Referral to a specialist service may be an option, depending on location and availability.

Most research shows the benefits of psychotherapy for people with BPD, but people with other personality disorders can also benefit from psychotherapy.

Existing treatment guidelines and practice resources can help health professionals to assist people in accessing support that meets their needs (see resources below).

"Fifteen years [of trying to access support] and I'm sort of back in the same spot, so it's kind of like... yeah, I don't know, it's very hard for me to say anything positive."

— Lived experience participant

PHNs and support for personality disorder

Long term psychotherapy is usually recommended for people living with personality disorder. Many types of psychotherapy are beneficial and have common elements such as comprehensive risk management, validation and problem-solving.

There are few specialist personality disorder services available in Australia. Treatment may be provided in generalist services, but not all mental health professionals have been trained in evidence-based care for personality disorders. PHNs can address this gap in care by exploring strategies to improve access to evidence-based care.

Improving access to treatments and stepped care approaches for personality disorders aligns with the priorities of the Fifth National Mental Health and Suicide Prevention Plan, as personality disorder is considered a severe and complex mental illness and people living with personality disorder are at increased risk of suicide.

Stepped care and personality disorder

PHNs can identify and address gaps in the stepped care service offerings in their regions for people living with personality disorders. Strategic direction is needed to ensure that people living with personality disorder can access adequate care that matches their needs, wherever their location.

Unless a person is in an emergency or crisis situation, community-based treatment is usually recommended for people living with personality disorder. Many people need intensive and long-term support, and ten sessions of subsidised psychotherapy under the Medicare Benefits Schedule (MBS) Better Access Initiative may not be comprehensive enough to meet their needs.

As well as addressing service gaps, PHNs could also consider ways to help people navigate health services, such as commissioning peer workers for this role.

Coordination and leadership

PHNs play a pivotal role in leading more effective coordination and delivery of support services across Australia. By working closely with local government and health services, PHNs can better deliver support for treating personality disorder at a regional level.

Encouraging services to implement treatment recommendations and adopt traumainformed practice (see guidelines below) may also help to improve outcomes, reduce stigma and validate the experiences of people living with personality disorder.

Through improved coordination, there are also opportunities to increase the capacity of health services. This may include mental health professionals using telehealth to improve access to treatment for people living in rural and remote areas.

What is needed to better support PHNs

Despite the effectiveness of evidence-based treatment, the research found major barriers to getting help for people living with personality disorder. We know from past research that some mental health professionals find this work challenging, and feel they have not been adequately trained.

As part of their research, SANE has made recommendations to streamline treatment pathways and improve treatment access. The NMHC has also funded SANE to undertake exploratory work with PHNs across Australia to identify a model of care with better support options for people with personality disorder.

"[The Project Air and NHMRC guidelines] are both evidencebased, effective ways of treating a personality disorder. Why... haven't they been funded and implemented?"

— Lived experience participant

More information for PHNs

This summary presents key findings from a larger research report by SANE Australia which can be found at https://www.sane.org/pd-report

Other resources that may be helpful for PHNs in relation to personality disorder include:

- Clinical Practice Guidelines for the Management of Borderline Personality Disorder https://www.nhmrc.gov.au/guidelines-publications/mh25
- Treatment Guidelines for Personality Disorders
 https://www.projectairstrategy.org/guidelines/index.html
- Practice guidelines for treatment of complex trauma and trauma informed care and service delivery https://www.blueknot.org.au/resources/Publications/Practice-Guidelines
- SANE Australia Facts and Guides Borderline Personality Disorder https://www.sane.org/mental-health-and-illness/facts-and-guides/borderline-personality-disorder
- The Fifth National Mental Health and Suicide Prevention Plan http://www.health.gov.au/internet/main/publishing.nsf/content/mental-fifth-national-mental-health-plan
- Family, Partner and Carer Intervention Manual for Personality Disorders, Project Air https://projectairstrategy.org/content/groups/public/@web/@ihmri/documents/doc/uow212928.pdf
- Project Air Services Directory
 https://projectairstrategy.org/servicedirectory/index.html
- BPD Foundation virtual resource library http://bpdfoundation.org.au/virtual-library.php

