YOU’VE BEEN DIAGNOSED WITH BPD - WHAT NOW?

Understanding personality disorder

- You are important. Your diagnosis does not define who you are.
- Recovery is possible, and you can get there.
- Diagnosis can be positive. A diagnosis of personality disorder can be something to work with, and can guide effective treatment.
- Everyone is unique. Many combinations of symptoms make up a personality disorder. Your symptoms may look very different to someone else’s and that is okay.
- Make sure you get the right information from mental health professionals and reliable internet sources. The internet and social media can provide unhelpful information on personality disorders, including some Facebook groups and mental health forums.
- Don’t be afraid to ask questions to mental health professionals.

Living with personality disorder

- Talk to people who support you about what is upsetting you.
- Have information to give others to help them understand your circumstances.
- Find a safe space where you can go when you feel distressed (e.g., a safe space may be a public space where you can sit alone, but still have other people around you).
- If you can, connect with other people who have lived experience of mental illness who have found recovery. It can help to know that someone understands and can validate your experience and provide you support.
- Find activities that make you feel calm or give you positive outcomes. Art therapy, being around nature and spending time with pets can be helpful and help you get through distress.

Seeking treatment

- Mental health professionals should compassionately treat personality disorder. You will connect with someone, but it might take a trial and error process until you find the right one. You have a choice with who you work with.
- Understand the length of care. Find out how long a mental health professional will be able to support you. You have the right to be treated by someone else if you are not comfortable with the time someone is able to provide.
- Know your support boundaries. Ask your therapist whether they can provide support by Skype/Zoom, phone, email or text message.

Your loved ones and support people

- Involve your loved ones and support people in your treatment if you feel you can.
- Encourage your loved ones and support people to seek their own support. This will also help them better understand you, and learn helpful ways of responding.

Reliable websites

https://www.projectairstrategy.org/
https://bpdfoundation.org.au/
https://www.bpdaustralia.org/

THE LIVED EXPERIENCE PROJECT:

The information in these resources was provided by people with lived experience of personality disorder and carers supporting people with personality disorder through two focus groups carried out in May 2019. This set of resources were developed through co-design and consultation with people with lived experience and other peak Consumer and Carer bodies in NSW. This work was funded by the New South Wales Mental Health Commission.
Giving a diagnosis of personality disorder: A guide for mental health professionals

People with personality disorder feel that being diagnosed compassionately can be a positive and helpful experience for their treatment and recovery. When diagnosing someone with a personality disorder, it is important to provide an educated explanation of the disorder, communicate positive ways to move forward, discuss possible treatment options, and offer assurance that recovery is possible. Full comprehensive diagnosis is usually given by a clinical psychologist or psychiatrist. However, this guide is useful for any health professional communicating and educating about the diagnosis.

Before discussing a diagnosis of personality disorder

- Ensure a thorough psychological assessment of personality disorder has been completed.
- Be aware that receiving a diagnosis of personality disorder can come with a range of responses. It can provide a framework for people to understand their experiences, but can bring about self-stigma and concerns about stigmatising responses others, including mental health professionals.
- It is important to discuss the personality disorder diagnosis regardless of expected reaction. Not informing someone of a diagnosis of personality disorder reinforces stigma about the disorder and may prevent appropriate intervention.

Discussing a diagnosis of personality disorder

- Provide factual and credible education on personality disorders and discuss the person’s specific symptoms.
- Set realistic expectations of outcomes. Change is difficult and takes time, but reinforce that recovery is possible.
- Discuss symptoms or conditions that may be comorbid or differentiated from personality disorder including depression, chronic pain, psychosis, substance use disorders, anxiety disorders and eating disorders.
- Discuss treatment options and provide information about services that deliver specific personality disorder treatments, including private psychologists, peer support (where available), telephone support, community mental health services, non-government organisations and support groups.
- Provide crisis strategies that can be used prior to beginning treatment.
- Discuss how carers, family members, and support people can help someone with a personality disorder, and provide information that supports carers, family members, and support persons.

www.projectairstrategy.org

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How to discuss a diagnosis of personality disorder

- Be genuine. Connect as a human being.
- Take time to explain the diagnosis. It may be the first time that the person is hearing about personality disorder.
- Communicate hope that the person can recover.
- Be aware of language. Explain what you mean when using clinical language and avoid stigmatising language.
- Listen to the person’s response to the diagnosis and answer their questions.
- Depending on availability, involve a peer worker or carer to ensure the person feels supported and understands the information provided.
- Discuss the diagnosis openly with the person’s carer, family members or support person if granted permission to do so.
- Provide factsheets and information about personality disorder so they can review and share with the people who are close to them.
- Discuss that the internet does not always provide reliable sources of information. Sometimes the information on non-credible websites can be inaccurate and unhelpful.
- It is useful to go through the criteria to discuss how this makes sense to the person. Further detailed guidelines for discussing a diagnosis are in the Project Air Treatment Guidelines for Personality Disorders (2015, p.17-20).

What to do following a diagnosis of personality disorder

- Direct people to recovery stories. Eg. Project Air Strategy – Personal Journeys www.projectairstrategy.org/mpapersonaljourneys
- Book in a follow-up appointment.
- Provide referrals to appropriate services as discussed with the person, and follow up.
- With consent, communicate with the next treating professional to provide continuity of care.

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Supporting Carers: Guide for health professionals

Supporting a person with personality disorder can be challenging at times, particularly when the individual is experiencing crisis. It is important for mental health professionals to also support carers in their caring role. Note, in this guide the term ‘carer’ may be used to denote someone who provides care, support and assistance for an individual with personality disorder. Carers may be a partner, parent or child, other family member (including chosen family), or friend.

Understand and respect the rights of carers
Carers have rights, including the right to:

- Privacy and confidentiality
- Be recognised by health professionals as a contributor to the health of the person being cared for.
- Be heard and treated with respect.
- Complain about provided services and appeal against unfavourable decisions.

It is important for health professionals to be familiar with the Carer Recognition Act 2010 (https://www.legislation.nsw.gov.au/#/view/act/2010/20/whole).

What do carers need from health professionals?

- To be informed about and included in the treatment that the individual they are caring for is receiving, and provided with information at all stages of the treatment process.
- To be provided with accurate and written education about personality disorder and how they can help the person they support, including electronic resources.
- To be supported in finding appropriate services for the person they support, and to be provided with accurate information about the services so that they can make an informed decision with the person they are supporting (e.g. provide a list of private psychologists that have experience treating personality disorder).
- To be provided with information on helpful and unhelpful strategies in their interactions with the person they support.
- To be encouraged and supported to receive their own support, including counselling, support groups and helplines.

Interacting with carers

- It may be the first time that a carer is hearing information about personality disorders. Be patient and open to questions. Carers also depend on mental health professionals to provide them with information.
- Discuss with the individual with personality disorder who they want involved in their treatment, and discuss the benefits of
communication between mental health professionals and carers. Carer involvement can help protect the safety of the individual with personality disorder, the carer/s, family members and other support people.

- If given permission, include carers in treatment consultations. Carers can provide their perspective of the person they support to aid treatment.
- Make regular contact with carers to ensure that they are supported.
- Encourage self-care and mental health support for carers, and make referrals where necessary.
- Use clinical judgement to recognise unhelpful carer behaviours, and address these sensitively.

What do health professionals need to understand about being a carer?

- Being a carer is often a 24/7 role. It can be very stressful, and many are doing the best they can.
- Supporting someone with personality disorder can have an impact on family members, including emotional and financial challenges.
- Carers often experience guilt. Adopt a non-judgemental and de-stigmatising approach to supporting carers.

For downloadable carer resources, go to:

- https://www.projectairstrategy.org/mpafactsheets/index.html

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Guide for first responders and health professionals in the hospital setting: Providing support for people living with personality disorders

Often people with personality disorder access care through emergency and hospital presentation. These steps outline best practice for health professionals to ensure people with personality disorders and their carers, family members and support persons receive appropriate and compassionate care.

General principles for compassionate responding

- Understand that mental health problems are as significant as physical health problems, and treat them appropriately.
- Respectfully inform the person that you are there to help and speak in a calm manner. Providing a positive experience at these stages can help the person feel safe.
- Understand the person is experiencing genuine distress and respect their rights to access health services, regardless of their history.
- Provide adequate medical care without judgement, and use respectful, non-judgemental language. Avoid phrases such as “attention seeking”, replacing them with terms such as “needing support”.
- Never refer to self-harm as “superficial”. Recognise that self-harm is often an attempt to regulate emotion.
- Engage in professional development and education relating to understanding personality disorder and other complex mental health problems.

First responders: Police and ambulance

- Explain what you are doing, why you are doing it, and what will happen next. Include carers or support people in these discussions where appropriate.
- Provide medical care for self-harm in the same way you would for someone who is injured in other ways.

- Report any inappropriate behavior (eg. excessive force) from other first responders to the relevant governing body.

Emergency department

- Sitting in an emergency department can be distressing for people. Try to reduce waiting times, and ask if anything can be done to help them feel safe while they wait (eg. a person may request that health professionals regularly check on their feelings of safety).
- People with physical wounds should be given privacy, and their wounds immediately triaged.
- Try to reduce distress by explaining what to expect and describing the emergency department process to persons and their carer (if appropriate).
When a diagnosis is known and has been communicated with the person, provide written information about the diagnosis.

Upon leaving the Emergency Department, provide persons with tools and options about what to do next (e.g., referrals and education about services and supports) and how to manage their distress. When appropriate, include carers in these discussions.

There are helpful factsheets on the Project Air Strategy website – use them and refer people to them. [www.projectairstrategy.org](http://www.projectairstrategy.org)

### Inpatient services

- Provide crisis skills training and other therapeutic opportunities, including adjunct therapies where available.
- Write the discharge summary in collaboration with the person, confirm their medical contact details are correct, and ensure they have a copy before they leave.
- Before discharge provide treatment options and referral when appropriate.
- Ask the person how they want to be supported after their hospital discharge. For example, they may prefer a home visit, phone call or text message, or contact from a mental health professional.
- Ensure that discharge summaries are provided to all health professionals involved in the person’s care.
- Where appropriate, use the “Find a Service” Directory and let people know how to find it. [www.projectairstrategy.org/servicedirectory](http://www.projectairstrategy.org/servicedirectory)

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Providing care for people with personality disorder

- Understand that change can be difficult and takes time. It is likely treatment may extend beyond the 10 session Mental Health Care Plan Medicare model.
- Clearly explain and discuss treatment approaches and plan with the person and involve carers where applicable. Invite them to ask any questions about treatment options and approach.
- Encourage self-determination. Locus of control is on the person with personality disorder (even if at times, they ask you to take control). Try to keep people responsible and engaged with their recovery plans and goals.
- Listen to what the person is saying with curiosity and be attentive in the moment.
- Provide a safe space within treatment for the person to express distressing emotions.
- Be responsible, consistent and accountable with your communication. This will strengthen rapport, increase trust and decrease distress.
- Continue to learn from people with lived experience about how to better work with personality disorder.
- Individualise treatment by engaging with the person you are working with, discuss their goals openly and focus on what works for them. Encourage human connection by allowing and inviting questions.
- When a person is not benefiting from treatment, discuss the issues, focus on strengths and explore other treatment options together. If a person stops attending therapy, reach out to reconnect and let them know they are safe to ask for a referral to another professional.
- Engage in professional development to further understanding and education of personality disorder and other complex mental health problems.

Encouraging person centered care

- Consider that people may have more than one mental health diagnosis and many also have physical health and other social concerns (i.e. homelessness, domestic or family violence). Discuss these concerns and provide appropriate treatment for co-morbid conditions, and refer to specialised services when suitable.
- Encourage opportunities for the person you are working with to be in contact with or aware of other people with lived experience, particularly those who are well on their journey to recovery (i.e.. peer workers where available).
• Encourage holistic care with a range of modalities such as physical exercise, peer support, art therapy, and pet therapy, and where possible provide therapy in the natural environment. Unfortunately, these options are not always available to all, but be aware of the services available within your area.
• Encourage the person to recognise when they are not feeling safe, and support them to identify a safe space outside of therapy (e.g. a place where they can decrease distress and feel safe).
• Where appropriate and with consent, include carers, family members and other support people in treatment consultations.
• Encourage and support the person to connect to community (i.e. LGBTIQA+) and cultural groups (i.e. first nations people).

Communicating with people who have personality disorder

• Communicate that recovery is achievable.
• Be genuine and communicate that you want to support the person to help themselves.
• Recognise that reaching out for help can be difficult. Validate their efforts when they attend sessions.
• Understand that when a person is experiencing crisis, they are in immense pain. Be empathetic, and do not use stigmatising labels such as “attention seeking” or “manipulative”
• Work with people in a way that respects their intellectual capacity.
• Understand that most people with personality disorder have difficulties with trust. Validate this experience and be authentic while building rapport.
• Use carefully considered language (eg. Avoid telling people that they are not ‘unwell enough’ to access services). Admit and apologise if you have said something ‘wrong’ – repairing these ruptures may be a part of the therapy process.
• Let the person know that you may not be able to meet all needs at all moments because you are a human being. Be open to having rupture and repair conversations.
• Inform the person about the amount of time you will be able to provide support and discuss your experience regarding personality disorder. Allow them to decide whether they are comfortable being supported by a particular professional or if they would prefer another professional.
• Be clear about the cost of sessions and discuss options (eg. medicare, ATAPS, victims support). Understand that private psychology sessions may increase financial strain and consider accommodating. Ask the person if they would prefer completing payment before sessions begin to reduce anxiety.
• Offer flexibility for therapy sessions. For example offer to provide virtual sessions for when the person is out of area, or offer to provide support over phone, text message or email when they are too distressed to attend. Be open and clear about how this will be costed, and the boundaries around this type of support.
• Provide information that people can read and use at home.

Communicating with other health professionals

• Encourage continuity of care and multidisciplinary treatment, and be open and willing to working with a range of other health professionals.
• With permission, share information between health professionals and services to support quality and trauma informed care. For example, read previous case notes before a meeting so that distressing questions are not repeated.
• Contact the persons primary provider (if applicable) to understand how best to help them.