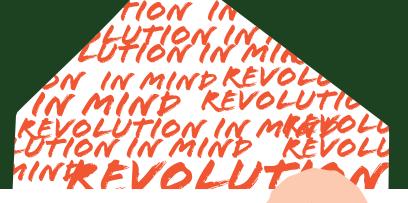
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PROFESSIONALS WORKING WITH YOUNG PEOPLE

### **FACT SHEET**

## SUPPORTING THE FAMILIES OF YOUNG PEOPLE EXPERIENCING PERSONALITY DISORDER

### **AT A GLANCE**

This fact sheet can support you and others working in youth mental health to engage with and support the families of young people who are experiencing personality disorder. It explores:

- · what personality disorder is;
- how to include families in the care of young people living with personality disorder and why it is important; and
- what families can do to support themselves and the young person.

Work through this resource with families to help them understand personality disorder and support them to make sense of their experiences and those of the young person.

This resource brings together evidence from young people and families with lived experience of personality disorder, subject matter experts and research literature.





#### A NOTE ON LANGUAGE:

We use the term families throughout this fact sheet, with an understanding that this includes the friends, partner or others that the young person identifies as important supporters. It is important to work with the young person to understand who is in their family and what role they have, bearing in mind that this may change over time and should be a continuing conversation.

"Family for many people isn't biological family. Chosen family and our friends can sometimes be our main or only supporter."

LIVED EXPERIENCE CONSULTANT, WHO HAS RECOVERED FROM PERSONALITY DISORDER

## WHAT IS PERSONALITY DISORDER?

Personality disorder is a mental health condition where a person's thoughts, feelings, perceptions and behaviours cause them difficulty in adapting or responding to their day-to-day tasks as well as to life's challenges. This leads to enduring difficulties in self-functioning (sense of identity, self-esteem and direction in life) and interpersonal functioning (how they understand other people and form and maintain relationships with them). Consequently, young people living with personality disorder may experience intense emotional reactions and use distress-driven coping strategies. This can lead to difficulties for the young person and those around them.

It is likely that personality disorder develops due to a complex mix of biological, social, environmental and psychological factors.(1) There is no single cause for personality disorder, and its development is often linked to a combination of factors outside of a person's control.

Each person's experience of personality disorder is different and unique. Early intervention, which includes mental healthcare and other practical supports, can ease distress and help young people live meaningful and fulfilling lives.

To learn more about personality disorder, read 'Fact sheet: Supporting young people experiencing personality disorder'.

### ADOLESCENT DEVELOPMENT AND PERSONALITY DISORDER

Adolescence, the period between childhood and early adulthood, is a significant time for growth. During this period, young people progressively take up more adult roles and responsibilities. Some common experiences of adolescence include:

- Navigating setbacks and finding different ways to work towards longer term goals (for example, educational and vocational goals).
- Engaging in new activities, learning about consequences and modifying behaviours.
- Redefining family relationships, placing greater value on peer relationships and beginning to explore intimate partnerships.

Most young people will navigate this period of development without distress and long-standing challenges. However, for young people experiencing personality disorder, this period can be difficult to navigate.

In some instances, families may be told that the experiences of personality disorder are a normal part of adolescence. It is true that adolescence commonly challenges young people in many ways and families might notice episodes of conflict or distress and increased experimentation and risk-taking. While this is the case, it is also important to understand that a young person experiencing personality disorder is likely to struggle significantly more with these challenges, which are likely to have more serious consequences for them than for those without personality disorder.

Personality disorder can also disrupt the development of many non-mental health related aspects of a young person's life. For example, a young person living with personality disorder may disengage from school, which may have longer lasting impacts on their vocational path in adulthood. Delays or disruption to the developmental pathway into adulthood can impact the development of essential life skills.(4) Therefore, it is important to recognise the signs of personality disorder early so that support can help improve a young person's life in the long-term.



## WHY INVOLVING FAMILIES IN MENTAL HEALTHCARE IS IMPORTANT

"The young person sees the clinician for an hour per week... and the carers see them 24/7 to the point where sometimes they sleep on the floor in their bedroom. So, I think one of the things to take away is that carers need to be supported."

## JACKIE KNIGHT, LIVED EXPERIENCE WORKER, CARER

It is important for families to be included whenever possible because:

- Families can often share information and insights into what is happening for the young person, what their strengths are and what challenges they are experiencing.
- Families can learn more about personality disorder and how to support the young person.
- Families are usually on their own journey, trying to manage and make sense of their own experiences. Engaging with the young person's care team can connect families to the support they need, for example, family peer support.

Working collaboratively to support young people experiencing personality disorder helps everyone gain new insights about the young person while providing accurate and reliable information about personality disorder. This two-way information sharing can help both clinician and family better support the young person throughout their care journey. Likewise, working collaboratively can help families make sense of their experiences and support their own wellbeing needs. Involving families in this way, balanced with the young person's wishes, can lead to improved outcomes for everyone.

While many young people live with their immediate family, and their parents are often their primary carers and supporters, this may not be the case for everyone. It is important to explore with the young person and their family, what role they play and how they might be involved in their treatment.

# WHAT ARE THE COMMON EXPERIENCES OF SUPPORTING A YOUNG PERSON WITH PERSONALITY DISORDER?

A young person experiencing personality disorder will face challenges in the way they relate to others, including the relationships they have with the people in their family. This can cause conflict and create concern and stress for family members. It's important to remember that a young person does not do this intentionally and is doing their best to navigate relationships, something that doesn't come easily for them. When conflict arises, each person and each family will try to cope the best way they can.

Families may report a range of their own challenges as they support a young person experiencing personality disorder, including:

- · high levels of grief, blame and guilt;
- concern they are not doing enough;
- practical challenges (for example, financial and housing);
- · social isolation;
- feelings of powerlessness;
- · feeling burnt out and hopeless;
- difficulty finding effective and helpful ways to cope;
- little knowledge about personality disorder or mental ill-health generally;
- · negative experiences of parenting; and
- their own mental health challenges, such as depression and anxiety. (5-9)

Feeling overwhelmed or unsure of how best to support a young person is a valid, shared experience for many families. With the right support, families can play a powerful role in a young person's care journey.



## WHAT FAMILY INVOLVEMENT IN MENTAL HEALTHCARE MIGHT LOOK LIKE

How families want to be involved in a young person's care will depend on what the young person and those supporting them want, and what is possible for the clinician or mental health service. Young people with lived experience, families and subject matter experts have highlighted the importance of inviting families into care early, such as:

- early in the assessment phase to share history about the challenges the young person is experiencing;
- at a feedback session where personality disorder is discussed;
- at any further sessions required to ensure a shared understanding about the young person's goals;
- · during treatment planning;
- when the treatment approach is reviewed;
- · at points of crisis planning; and
- during discharge planning.

Working collaboratively as a team will look different for each family and the mental health team. Mental health teams are urged to actively invite families into the mental healthcare of young people and work through what involvement will look like and who is responsible for what, when and how.

Contact between mental health treatment teams and families might include:

- a single phone call or meeting with the clinician or team;
- ongoing contact by phone or in-person meetings with the young person's clinician;
- regular, shared time in appointments (for example, the last 10 minutes of the young person's appointment);
- attending medical reviews;

- family focused appointments (with specific people or the whole family);
- · parenting-focused appointments; and
- attending specific sessions on crisis and safety planning.

### THE GOAL OF INVOLVING FAMILIES

The focus of family involvement will vary considerably for each young person and family. Initial work might focus on who should be involved and how this can be arranged, followed by understanding what each person wants and the capacity for the professional or service to meet their needs.

Common aims of involving families will be to discuss their own support needs and increase their understanding of personality disorder, with topics in family meetings commonly including:

- How personality disorder is being experienced by the young person and how it impacts their life and relationships.
- What the young person wants from mental health support, and what their life goals are.
- What mental health support is being offered and how it might help the young person work towards their goals.
- What it has been like for each person in the family and what other supports are needed.
- How family members can support the young person, which may include discussing ways they have tried to help so far. What has been helpful? What hasn't been helpful? What could be done differently to be more helpful?

In some instances, families may need added supports from other agencies in addition to what can be offered as part of the young person's mental healthcare. For example, professionals might help with a referral to other agencies for help with financial support, housing, substance use treatment, family violence support or mental healthcare for other family members.



## WHAT IF THE YOUNG PERSON REFUSES CONTACT WITH THEIR FAMILY?

Sometimes young people may appear ambivalent or hesitant about including family members. Mental health professionals should explore the young person's concerns, leaving open the possibility of revisiting their decision should the situation change. This is more likely to occur when conflict, disagreement and difficulties exist within the family relationships and is most challenging when the family strongly wants to be involved but the young person doesn't want them involved. Working collaboratively may look different at various stages of care.

Serious disagreement about family member involvement will require careful negotiation with all parties. The age of the young person, their living situation and how capable they are of making decisions for themselves are all factors to consider. Both the young person's wishes and the family's need for support should be taken seriously. Usually, a compromise can be found where family members can be supported in a way that is tolerable to the young person. Sometimes it is possible for families to receive support that is distanced from the clinical team, for example, from a family peer worker who does not know the young person or via referral to external organisations for support.

## WHAT OTHER SUPPORTS ARE THERE FOR FAMILIES OUTSIDE THE YOUNG PERSON'S MENTAL HEALTH TEAM?

Many families report how valuable it is for them to talk to others with lived experience of caring for a young person living with personality disorder. Family members report that hearing about the experiences of others helps them to feel less alone and provides ideas about possible ways to respond and communicate effectively. It also reinforces that everyone's experience is unique.

"Access to peer workers and care consultants is really important when you're engaging in care."

JACKIE KNIGHT, LIVED EXPERIENCE WORKER, CARER

While family peer workers are a welcome resource for many families, they are not always available where the young person is receiving care. Some agencies or local government services run support groups for carers of young people with mental ill-health, and sometimes there are specific groups for carers of young people living with personality disorder.

Families can access a range of support services to increase their understanding of the experiences of personality disorder or for emotional and social support.

Families can talk with the young person's mental healthcare team to explore what might work for them and their needs.

## WHAT CAN FAMILIES DO TO SUPPORT THEMSELVES AND THE YOUNG PERSON?

There is no single way to support a young person experiencing personality disorder, and everyone's experiences are unique and varied. However, there are some things, explored below, that families have found helpful when supporting a young person living with personality disorder.

## LEARNING MORE ABOUT PERSONALITY DISORDER

Learning more about personality disorder helps families make sense of what the young person is experiencing. As with any youth mental health topic, the quality and accuracy of information (psychoeducation) will vary. This is particularly the case when looking online where misinformation and stigma are common. It is, therefore, worthwhile going to reputable sources, such as specialist youth mental health websites (listed at the end of this fact sheet). If the young person is receiving mental healthcare, their clinicians should be able to provide useful and specific information relevant to the young person, their family and situation.

"I went to a fantastic psychoeducation workshop on personality disorder and that was life changing."

JACKIE KNIGHT, LIVED EXPERIENCE WORKER, CARER

Many families already feel burnt out and frustrated by the time the young person enters mental healthcare. Improving understanding about personality disorder helps families remain compassionate and empathetic towards the young person when they are expressing their distress in challenging ways.(10)

Learning about personality disorder in a straightforward and open way reduces stigma and anxiety. It also helps to build consistency so everyone can work more effectively together to support the young person. Understanding what is typical for the young person at their point in development, and discussing with professionals what might be the most helpful way to manage specific issues that arise also improves outcomes.(9)

"Learning about self-harm and suicidality was important because every time my son cut himself or swallowed a whole lot of pills, it was stressful but knowing the thinking behind that... made me not feel so guilty."

ANONYMOUS, LIVED EXPERIENCE WORKER, CARER



## CONTINUING TO FIND WAYS TO SHOW LOVE AND SUPPORT

When anyone feels stressed, it can be hard to remember and acknowledge good things. The same applies for families supporting a young person experiencing personality disorder. We can all cope better when reminded that others care about us. It is important for families to find ways to notice the small things that the young person says or does that are positive. The young person is more than their experiences and families are best placed to know their strengths, which can help them feel supported and less alone. Families can do this by:

- commenting on something the young person did that was positive;
- commenting on something they like about the young person;
- · noticing that they are trying; and
- remembering to tell the young person that they love and care about them.

Families can provide a strong message of support by recognising and acknowledging that the young person is doing the best they can.

## ENCOURAGING POSITIVE COMMUNICATION AND ROLE MODELLING RELATIONSHIPS

How family members communicate with young people and model relationships can play a big part in supporting them to develop skills in establishing and navigating their own relationships. This includes:

- Talking about difficult topics when everyone is calm rather than when people are fired up.
- Trying to listen carefully and repeating back what they have heard to check understanding.
- Noticing and naming emotions before moving on to try and problem-solve.
- Encouraging the young person to build their decision-making skills.

## RESPONDING TO THE YOUNG PERSON IN CRISIS

Young people experiencing personality disorder may engage in behaviours that can be dangerous and confusing to those around them. Their coping strategies can seem extreme and not very effective. The most concerning of these are when a young person is thinking or talking about suicide or is intentionally harming themselves. It is important to understand that young people often do this to deal with strong emotions or situations that they feel unable to manage in any other way. It is also important to know that self-harm, such as cutting or burning, can help a person feel a bit better in the short-term even though it is ineffective in the long-term. Understanding why the young person engages in self-harm can help families remain compassionate and supportive in encouraging them to seek help.

It is important to discuss with families what to do in these circumstances. Mental health teams can work with young people to develop alternative coping strategies. While this can take some time, in the interim, mental health teams, young people and families can collaborate to develop safety plans. This usually includes the names and numbers of people to call and what to do in an emergency, as well as information about early warning signs and any other strategies that might help to reduce the young person's distress. With early intervention and support, young people can learn to care for themselves more effectively, reducing suicidal and self-harm thinking over time.

### EMPHASISING THE IMPORTANCE OF SELF-CARE

Caring for someone with personality disorder can require lots of time and energy. During times of crisis, families may need to give a lot more of their energy to the young person. Families should therefore care for their own wellbeing to make sure they have energy available when they need it and to reduce the risk of feeling burnt out or wanting to give up.

The people supporting the young person are also significant role models. While it is understandable for families to focus a lot on the young person, especially at times of crisis, it is important to balance support with caring for themselves. When family members value looking after their own health and wellbeing, it demonstrates the importance of this attribute to everyone, including the young person. Family members can talk about the things they love to do, such as spending time in nature or playing with the family dog, and demonstrate making time to do so. Engaging in healthy stress management strategies is good for everyone.

#### TAKE HOME MESSAGE

It is important to involve families in the mental healthcare of young people experiencing personality disorder, when and where appropriate. This can have positive outcomes for both the young person and the family. How families want to be involved in a young person's care will depend on what the young person and those supporting them want, and what is possible for the mental healthcare team. One of the aims of involving families will be to discuss their own support needs as they may experience a range of their own challenges. It is helpful to offer support to the family too and emphasise the value of self-care.



#### **RELATED RESOURCES**

- · Videos. Personality disorder and young people.
- Fact sheet. Supporting young people experiencing personality disorder.

#### **FURTHER INFORMATION**

- Australian BPD Foundation. www.bpdfoundation.org.au
- National Education Alliance for Borderline Personality Disorder Australia (NEABPD-Australia).
   www.bpdaustralia.org
- · Project Air. www.uow.edu.au/project-air
- Spectrum. Specialising in Personality Disorders and Complex Trauma. www.spectrumbpd.com.au

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#### **CONTRIBUTORS**

- Associate Professor Louise McCutcheon, Principal Psychology Educator and Senior Program Manager, Helping Young People Early (HYPE) Service Development, Orygen Specialist Program
- Desirée Smith, Registered Nurse, Team Leader Workforce Development, Knowledge Translation, Orygen
- Professor Andrew Chanen, Chief of Clinical Practice, Head, Personality Disorder Research, Orygen and Professorial Fellow, Centre For Youth Mental Health, The University of Melbourne
- Sian Lloyd, Director Workforce Development and Service Implementation, Knowledge Translation, Orygen
- Zoe Nikakis, Project Officer, Knowledge Translation, Orygen

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- Ben McKechnie, Clinical Psychologist, Clinical Stream Leader, Helping Young People Early (HYPE), Orygen Specialist Program
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- · Jo Veltkamp, Registered Nurse, Eastern Health
- · Laksha Alahkoon, Research Assistant, Orygen
- Lived experience consultant, who has recovered from personality disorder
- · Susan, Family/Carer Consultant, Orygen

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IF YOU'D LIKE MORE INFORMATION ABOUT ORYGEN, PLEASE CALL +61 3 9966 9100 OR SEND AN EMAIL TO INFO@ORYGEN.ORG.AU

ORYGEN.ORG.AU

ORYGEN LTD

35 POPLAR ROAD PARKVILLE VIC 3052 AUSTRALIA

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