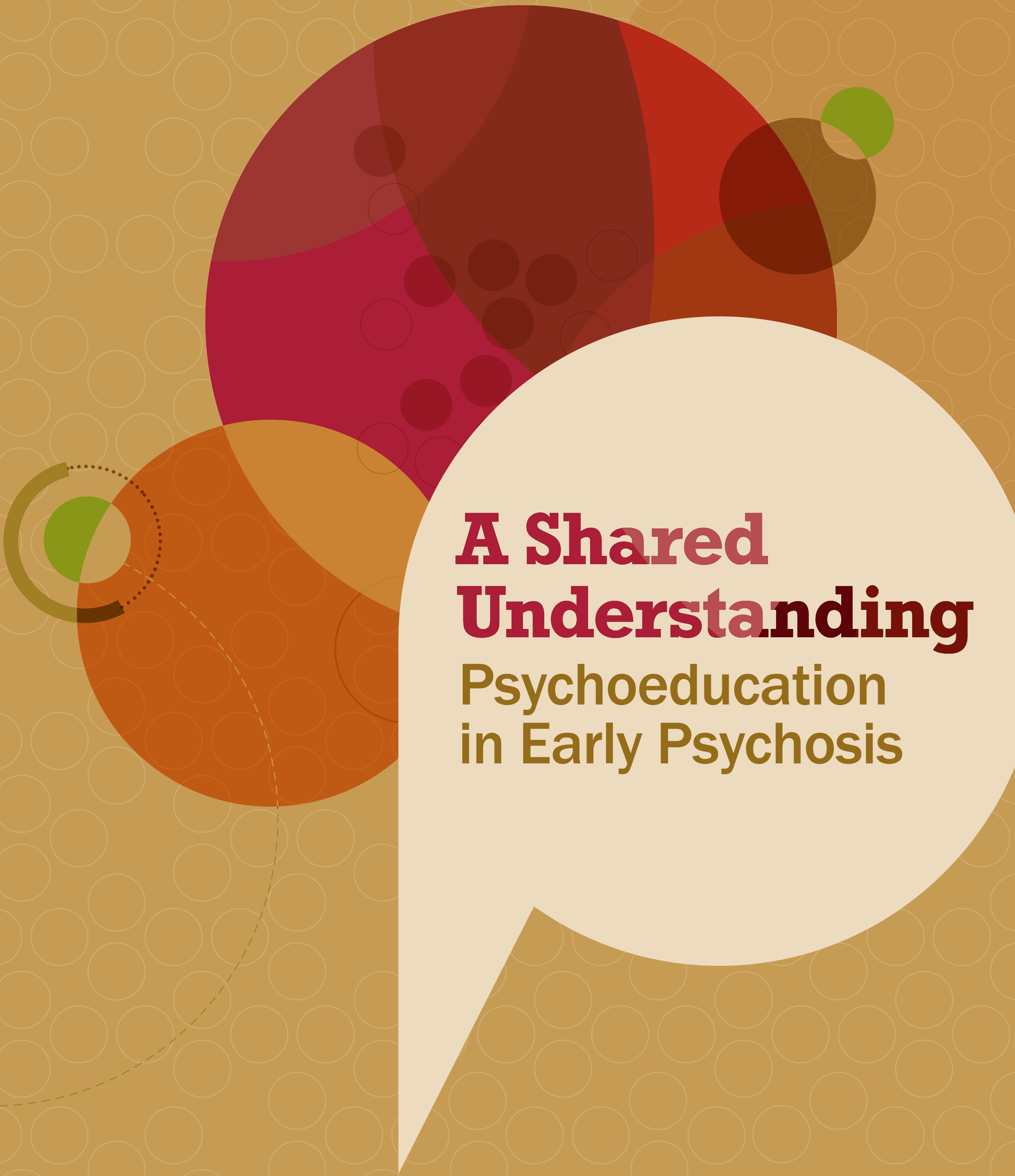

A Shared Understanding

Psychoeducation in Early Psychosis

Orygen
The National Centre of Excellence in Youth Mental Health

EPPIC
Early Psychosis Prevention and Intervention Centre

Special thanks are extended to the clinicians from Orygen Youth Health Clinical Program (OYHCP) who made themselves available to contribute to this resource. OYHCP is the specialist youth mental health service located on the Orygen campus in Melbourne. For more than two decades, OYHCP has been a pioneer in the field of early intervention for emerging and severe mental illness. In that time it has become a world-leader in the development and provision of best-practice mental health care for young people: care founded on clinical expertise and the latest evidence. The integration of OYHCP's wealth of skills, experience and knowledge with Orygen's comprehensive range of research, clinical and knowledge transfer services enables Orygen to sustain a comprehensive academic health sciences centre at the forefront of innovation in youth mental health care.

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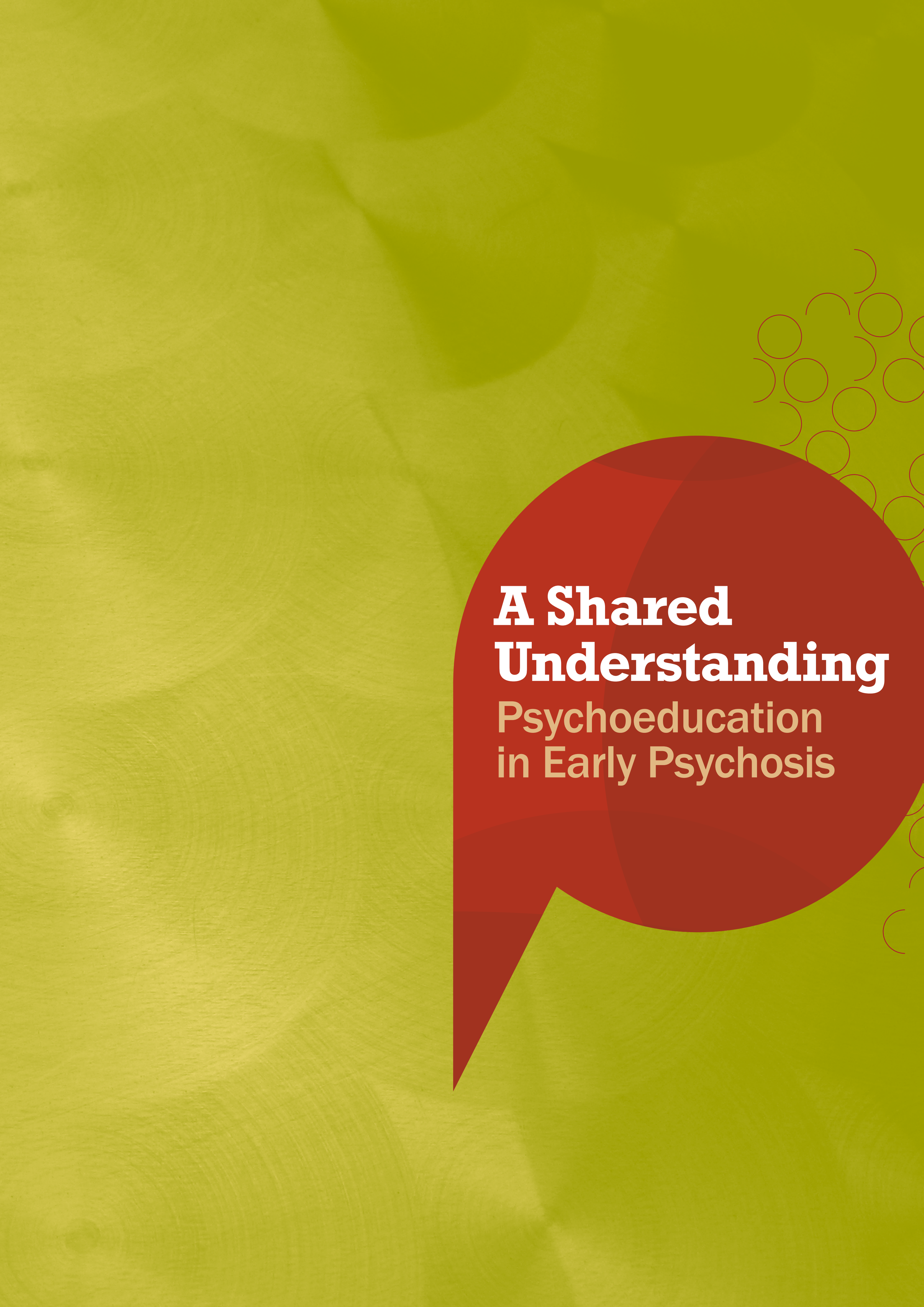

A Shared Understanding

Psychoeducation in Early Psychosis

Contents

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Introduction

Many young people and families arrive at an early psychosis service with little or no previous experience of severe mental illness or the mental health system. Psychoeducation regarding early psychosis and its treatment is therefore a key element of intervention. By developing knowledge and understanding, psychoeducation helps young people and families feel more engaged, reduces stigma, and empowers them in a situation where they are likely to feel helpless. Without this knowledge and understanding, the young person and family will be limited in the extent to which they participate in the young person's treatment and recovery.

It is important to note that, more than simply providing information, psychoeducation seeks to explore and develop the young person's understanding of their experience of psychosis and its treatment. Each individual's experience will be unique, and psychoeducation can only be effective if it is collaborative and responsive to the experience and needs of each young person and their family. This approach to psychoeducation is core to the principles of intervention for early psychosis, and it has two aims: to increase knowledge about psychosis and, by improving insight, to help improve outcomes.

About this manual

A shared understanding: psychoeducation in early psychosis is one of a series of manuals produced as part of the EPPIC National Support Program (ENSP) to support the implementation of the Early Psychosis Prevention and Intervention Centre (EPPIC) Model in early psychosis services. The EPPIC Model is a model of specialised early intervention in psychosis that aims to provide early detection and developmentally appropriate, effective, evidence-based care for young people (aged 12–25 years) at risk of or experiencing a first episode of psychosis. It has been developed from many years' experience within the Orygen Youth Health Clinical Program and further informed by the National Advisory Council on Mental Health's Early Psychosis Feasibility Study (2011), which sought international consensus from early psychosis experts from around the world.

This manual is intended to be a practical guide to psychoeducation interventions for clinicians working with young people and their families in an early psychosis service. It aims to help clinicians develop a collaborative understanding with young people, and their families, of psychosis and its treatment, the impact an episode of psychosis can have on the young person, and the process of recovery.

How to use this manual

This manual is divided into three parts. The first part gives an overview of the rationale for delivering psychoeducation to young people with early psychosis (and their families); the second outlines the principles of effective, collaborative psychoeducation; and the third offers a practical guide to four key topics of psychoeducation for young people and families during their time within an early psychosis service.

Case scenarios are presented throughout the last section to illustrate how the principles apply in clinical practice, and the appendices contain a number of factsheets and worksheets clinicians may copy and use in their day-to-day practice.

Note that this manual provides a guide only to which topics are important to address in psychoeducation sessions and how they might be discussed. Specific content, such as models of psychosis, medical treatment and psychological treatment, can be found in other manuals in this series.

A number of resources that can be used to facilitate psychoeducation for young people and families are provided at the end of this manual. Additional factsheets about psychosis and treatment are available from www.oyh.org.au/factsheets.

Readers are also encouraged to refer to other ENSP manuals that complement this topic, including *Get on board: engaging young people and their families in early psychosis* and *In this together: family work in early psychosis*.

Background and Rationale

Background and rationale

What is psychoeducation?

There are various definitions of psychoeducation. For the purposes of this manual, psychoeducation is defined as a combination of psychological intervention and education for people diagnosed with a mental illness. Psychoeducation in early psychosis aims to: increase young people and their families' understanding of psychosis and other related topics; assist in preventing transition to a first episode of psychosis in young people at ultra high risk of developing psychosis (UHR); and promote recovery for young people experiencing a first episode of psychosis.

It is important that clinicians understand that psychoeducation is a crucial, ongoing part of intervention in early psychosis, and that it involves far more than simply providing young people and families with technical information about psychosis and treatment for symptoms. As well as providing information, psychoeducation endeavours to:

- create a communicative relationship between the young person, family and treating team
- help clinicians understand the young person or family's explanatory models of psychosis and their attitudes towards treatment and recovery
- promote hope and optimism, and help the young person and their family engage with treatment and begin the recovery process
- improve the young person's insight into the disorder, thereby promoting autonomy, self-management and restoring self-esteem
- develop the young person and their family's understanding to improve coping skills and give them a sense of containment about the disorder and decisions about the young person's treatment
- provide 'strategies for wellness'.[1]

Psychoeducation should be a collaborative process where both the young person and the clinician seek to understand psychosis as it is experienced by the young person, and the effect an episode of psychosis has on the young person's life. A range of methods and media can be used to facilitate this process, from face-to-face discussion to online materials; whatever the method, the primary consideration should be to tailor psychoeducation to the individual as much as possible.

> 'A person cannot teach another person directly; a person can only facilitate another's learning.'
>
> Carl Rogers, 1951.

Why is psychoeducation important?

There are two main reasons that psychoeducation for young people and their families is so important: firstly, psychoeducation can improve outcomes for young people who have experienced an episode of psychosis; secondly, the process of psychoeducation increases knowledge and understanding of psychosis, which is crucial to young people and families' being able to make well informed decisions about their treatment and care.

Improving outcomes with psychoeducation

A substantial evidence base supports the efficacy of psychoeducation for families of people with psychosis in improving outcomes, including reducing relapse rates and improving symptoms of psychosis.[2,3]

There are fewer studies of the efficacy of psychoeducation programs for individuals alone; however, those studies that do exist show that psychoeducation:[3,4]

- can help improve adherence to medication
- has a positive effect on relapse rates, including reducing relapses that involve readmission to hospital
- may reduce instances of hospital emergency department admissions
- may improve global functioning, quality of life, sense of well-being and self-esteem.

Psychoeducation is therefore recommended as part of best practice care for early psychosis.[5]

Increasing knowledge and understanding

In addition to improving clinical outcomes, psychoeducation also fulfils the obligation early psychosis services have to inform young people and their families about psychosis and its treatment. As with any serious illness or disorder, a diagnosis of a psychotic disorder can be an unfamiliar and distressing experience. Young people and families will want and need to be provided with clear, accurate and current evidence-based information so they can increase their knowledge and gain a sense of control over their circumstances.

Ninety per cent of young people with early psychosis in one study believed psychoeducation was a helpful intervention,[6] and many families describe a need for information following the onset of an episode of psychosis in a family member.[7] Clinicians should emphasise to young people that it is normal to want to know more about what they are experiencing, and encourage them to ask questions. This will be helped if clinicians actively work to create an environment in which young people and families feel comfortable with asking questions or seeking clarification about information they are given.

> ‘My case manager … made me feel like it was okay to ask questions if I didn’t understand stuff. I felt like we were working together, that it wasn’t just me all on my own. I felt like he had my back.’
>
> Young person
> EPPIC, Orygen Youth Health Clinical Program

Increasing knowledge through psychoeducation is especially important in early psychosis, as most young people and families enter an early psychosis service without any prior experience of mental illness or the mental health system. Often young people and families are fearful and confused about what to expect, and extremely concerned about the young person. They are likely to have little understanding of psychosis, or may have preconceived ideas about psychosis, treatment and recovery (e.g. from the media or experiences of other family members with adult mental health services).

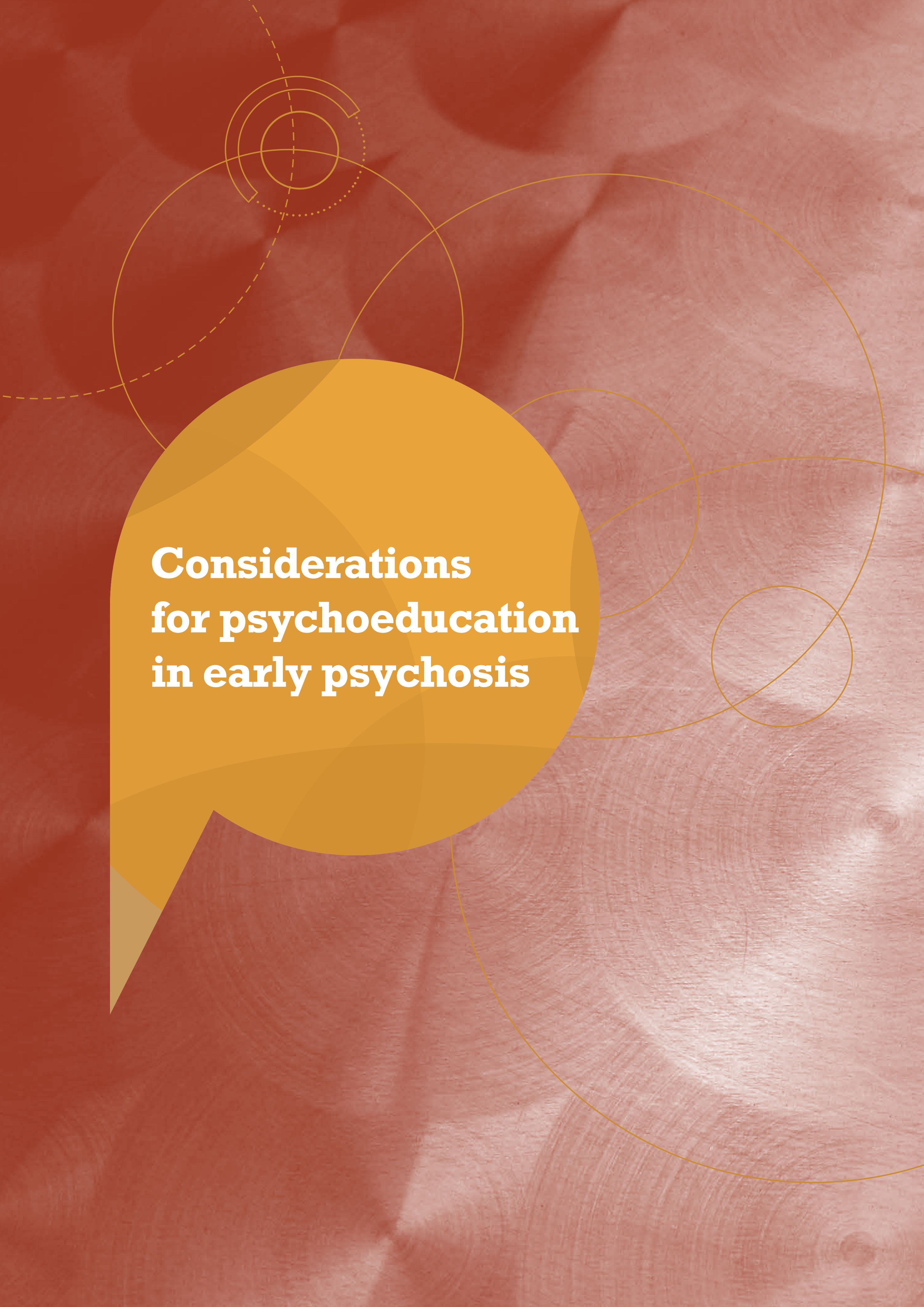
Furthermore, the way information about psychosis is discussed will set the tone and expectations for everything that follows. If psychoeducation is done in a way that reduces stigma right from the beginning, it can be a powerful intervention.

> ‘Knowing I could call Stephen’s case manager meant I never felt like I was asking a silly question. I felt validated and respected, and she always asked what my thoughts were. I felt like I was part of the team. That was really important to both me and Stephen.’
>
> Family member
> EPPIC, Orygen Youth Health Clinical Program

Psychoeducation and shared decision-making

Shared decision-making, where the young person is actively engaged in decisions about their treatment, is a core principle of treatment in the EPPIC Model (see *Medical interventions in early psychosis: a practical guide for early psychosis clinicians* for more information). For this process to be truly collaborative, the young person must be well informed about their rights and options regarding treatment.[8] To aid this, psychoeducation should aim to enhance the young person and their family's understanding of psychosis, treatment (including treatment options and the risks of receiving – or not receiving – treatment for psychosis), how psychosis and treatment may affect functioning, and the young person's prospects for recovery.

Ensuring young people are well informed about psychosis and treatment options may have a number of benefits that will optimise the shared decision-making process. These include an improved relationship between clinicians and the young person, better communication between the young person and clinician and a greater sense of autonomy for the young person.[7]



Considerations for psychoeducation in early psychosis

Considerations for psychoeducation in early psychosis

Principles of psychoeducation for early psychosis

Despite the clear benefits that psychoeducation has for a young person's recovery from an episode of psychosis, it is often neglected. In practice, psychoeducation may not be provided often enough to young people and their families, or when it is, not provided effectively.

To guide best practice, a range of core principles for psychoeducation have been developed within the EPPIC Model. Following these principles will help services and clinicians ensure that psychoeducation is effective and engaging for all young people, and their families, in an early psychosis service.

> 'I felt like the case manager was scared about telling me the truth, and that left me feeling scared about asking questions that were worrying me … All I felt I had was Google telling me really horrible stuff that left me feeling like a freak.'
>
> Young person
> EPPIC, Orygen Youth Health Clinical Program

Psychoeducation is everyone's responsibility

Providing effective psychoeducation can be challenging for early psychosis services, and psychoeducation is often not provided, or not provided adequately. For example, Hamann et al. (2005) showed that only 30% of people admitted to an inpatient unit were given psychoeducation about medication by their treating doctor, despite the doctors stating that non-adherence was a concern.[9] Getachew et al. (2009) found that 39% of community mental health services surveyed did not have any psychoeducation program.[10]

At an organisational level, early psychosis services must ensure that there is a service-wide understanding that psychoeducation is crucial and all staff in the service are responsible for its delivery. This includes staff at who work at points of entry to the service, staff in inpatient units, the continuing care team – including doctors, case managers and any other clinicians the young person and family may come in contact with – and family and youth peer support workers.

Clinical staff need to be encouraged to routinely use psychoeducation to collaboratively develop the young person, family and clinical team's understanding of psychosis, treatment and recovery. The expectation should be that psychoeducation is *continually* provided as part of routine care.

This service 'culture' may be difficult to create and maintain: even where psychoeducation is a core part of an early psychosis service's treatment approach, young people may not receive adequate psychoeducation.[1] The management and clinical leadership team therefore has a responsibility to be 'culture carriers', by modelling good practice and promoting the core principles of psychoeducation in early psychosis. Clinical review meetings, supervision and case presentations are all opportunities where the importance of psychoeducation can be discussed with staff.

> 'I think sometimes clinicians feel that bringing up the topic of symptoms or the disorder will upset the young person or their family. But really, we should always be asking young people what they need, what their understanding of what's going on is, instead of waiting for them to ask us.'
>
> Senior clinician
> EPPIC, Orygen Youth Health Clinical Program

Services must also provide adequate support, including resources and infrastructure, for clinicians to effectively deliver psychoeducation. Resources might include:

- factsheets and worksheets
- online access to resources, and a list of accurate, appropriate online resources for young people and families
- resources and technology to facilitate psychoeducation (e.g. computers, tablets, DVDs)
- group programs (coordinator, space, etc.)
- peer-to-peer psychoeducation (see page 17).

Psychoeducation should be tailored to each individual's needs

The aims of psychoeducation are to increase understanding and allow young people and their families to make informed choices about their treatment, recovery and future goals. To do this effectively, psychoeducation must take into account the specific needs of each young person, their family and other supports. As with any other intervention, a case formulation-based approach will be more effective than a 'one-size-fits all' approach.

Clinicians need be open to what the psychoeducational needs of young people are and be guided by each young person. Often what clinicians perceive to be the information needs of a young person are not the same as what the young person in fact wants to know.[11] At other times, the clinician may think they have adequately covered a topic, but the young person feels they have not.[1]

Psychoeducation must also be made relevant to the young person and family's personal circumstances, for example, their cultural background (see page 15), previous experience of mental health services, or explanatory models. A young person may not be responsive to psychoeducation if they feel their explanatory model is contradicted by information presented[12] or if they feel their experience of an episode of psychosis doesn't match the description of psychosis presented, for example, in a standardised 'What is psychosis?' factsheet.

Psychoeducation is collaborative and embraces a shared decision-making approach

Young people, and their families, have the right to be fully informed about their condition and possible treatments. By working collaboratively with each young person to develop an understanding of their experience and situation, clinicians ensure the young person is fully informed in the decisions they make about treatment, including whether they refuse to have treatment.

Psychoeducation is a continuous and evolving process

Rather than a series of 'one off' discussions about discrete topics, psychoeducation should be viewed as a continuous process in which the clinician and the young person develop a shared understanding of psychosis. Psychoeducation should begin from the moment a young person and their family and supports first seek help from an early psychosis service, evolving as the young person moves through treatment and recovery until they leave the service. Often psychoeducation goes hand in hand with the development of the young person's goals for recovery (see the ENSP manual *Keeping on track: functional recovery in early psychosis* for more about functional recovery).

Topics of psychoeducation may need to be revisited, often with a different emphasis, as the young person's experience and understanding changes. For example, psychoeducation about medication in the acute phase of an episode of psychosis may initially focus on providing essential, basic information to the young person, particularly if cognition is affected or the young person is experiencing a high level of distress. As the young person's mental state improves and they enter the early recovery phase, psychoeducation about medication and treatment can continue gradually, with more detail and discussion about important issues such as dose, side effects and length of treatment.

PRACTICE TIP

Always be on the look-out during clinical sessions for opportunities to provide psychoeducation in response to a young person's needs or concerns.

Consider the phase of the episode of psychosis

The phase of an episode of psychosis that the young person is experiencing (see page 31) will greatly impact on how they and their family are coping. It may also affect the level of insight both the young person and family have. Coping and insight in turn may affect to what level young people and families are able to engage with psychoeducation. Psychoeducation therefore needs to be 'matched' to the phase of the episode of psychosis, both in content and in the way that information is delivered.

For example, a young person in the acute phase of an episode of psychosis may not want great detail on vocational recovery programs. This is not to say vocational recovery is not discussed (as in fact emphasising that the ultimate goal of treatment is to help with return to work can help engage the young person), only that what information is provided has to meet their needs at the time.

Similarly, discussing psychosis or antipsychotic medication in depth with young people in the UHR phase may not provide them with the information they need or want to be able to engage in a useful way with the service.

See also 'Building understanding through the different phases', on page 33.

Explanatory models are core to psychoeducation

Understanding each young person's explanatory model for their experiences and why they have become unwell is a crucial part of effective psychoeducation. Incorporating a young person's explanatory model into psychoeducation helps the young person feel understood rather than challenged about their belief system, which is likely to improve their engagement with treatment and the service.

It is also important to understand the family's explanatory model, as this may be different to that of the young person, and indeed may differ between family members.

When developing this understanding, clinicians particularly need to be sensitive to culturally specific explanations for mental illness; however, any explanatory model should be engaged with by clinicians and not dismissed out of hand. If a young person has limited insight, imposing an alternative or 'correct' explanatory model on the young person or family is likely to lead to disengagement from treatment.

At the same time, clinicians do not need to adopt the young person's explanatory model – rather they should acknowledge it and try to negotiate a common ground or goals (see Box 1).

PRACTICE TIP

If someone is experiencing symptoms of psychosis, they can still be given information about their situation. Even when acutely psychotic, young people will understand direct, practical information about their care, and may feel happier to be given this than excluded completely from the information flow.

The following questions may be useful to help clinicians understand the young person or family members' explanatory model.

- What do you think has happened to you/the young person?
- What do you think has caused this?
- Why do you think it started when it did?
- How does what you are experiencing affect you?
- How severe is the problem? How do you know?
- How long do you think it will last?
- What kind of treatment is needed?
- What kind of results do you expect from treatment?

Remember that explanatory models may change as the young person gains more insight into their experience and can be revisited as they recover.

BOX 1 **NEGOTIATING EXPLANATORY MODELS**

Elicit the young person and family's explanatory models.

Communicate the clinical model of psychosis to them in plain language.

Acknowledge and respect the young person's framework and the discrepancies between explanations that may exist.

Look for common goals or common ground.

Find a way to incorporate conventional treatment in the young person's explanatory model.

> 'It can be challenging to find a way to work within someone's explanatory model and to also explain why they have been prescribed medication. It's really important to talk about things like this with other clinicians in the team, with the treating doctor and in supervision. Because you need to be supported to find that balance.'
>
> Clinician
> EPPIC, Orygen Youth Health Clinical Program

Consider preconceptions

Clinicians should explore what the young person's preconceptions or baseline knowledge about mental illness and psychosis are. For example, have they searched for information about psychosis on the internet? Do they have another family member with mental illness (especially psychosis), and what has their experience been of that family member being unwell? Other preconceptions about mental health commonly come from the media or peers of the young person and family, and many people with early psychosis will share the stigma held by the community about psychosis.[13]

It is also important to consider what the young person or family's experience or understanding of mental health services are, or of other services such as justice or child protection services.

> 'My gran has bipolar, and I now have bipolar also, and [being diagnosed] did instantly make me think, "My life's over".'
>
> Young person
> EPPIC, Orygen Youth Health Clinical Program

Consider cultural background

A young person's cultural background may significantly influence how clinicians discuss psychosis and its treatment with them and their families. As always, psychoeducation discussions should be tailored to need and relevancy. Considerations in this instance include:

- What is the young person's cultural background?
- What are some of the conceptualisations of mental illness in that culture? (Consider who and where you can find information about this from, for example, Victorian Transcultural Mental Health, in Victoria).
- How might these affect their understanding of psychosis and treatment?
- What are their expectations of the health care system?
- What influence do cultural or religious leaders (e.g. Indigenous elders or priests) have on the young person and family's understanding of psychosis? Can they play a role in their experience of psychoeducation?
- Does the young person or family require an interpreter?

See also 'Explanatory models are core to psychoeducation', on page 13.

PRACTICE TIP

The best way to learn about a young person's cultural background is to ask them about it. This encourages a two-way flow of information, where the clinician also becomes someone who is learning, which in turn may facilitate psychoeducation and engagement.

Focus on engagement

Ideally, psychoeducation about psychosis and treatment will facilitate the engagement of young people with their treatment and the service. However, in cases where a young person is reluctant to engage, the approach to psychoeducation must focus on establishing and maintaining engagement.

For example, a young person who is recovering and starting to disengage because they feel well may not feel that trying to 'develop an understanding of psychosis' is any longer relevant to them. Rather than focusing on understanding psychosis and the need to maintain treatment, the clinician may need to concentrate instead on keeping the young person engaged with the service. Please refer the ENSP manual *Get on board: engagement in early psychosis* for more about facilitating engagement.

Use plain language

Psychoeducation needs to be comprehensible and accessible to each young person and family. This will be directly affected by the language used by clinicians, and in supporting materials, during psychoeducation. Language should avoid jargon, and ideally will be a reflection of the language used by the young person or family to describe their experiences. Clinicians should also consider whether the young person or family is a speaker of English as a second language.

PRACTICE TIP

Make sure the written materials you use, such as brochures or booklets, have been designed for use by people with early psychosis. Materials designed for people with ongoing or established psychotic disorders may not be appropriate to early psychosis, or they may have a focus or message that unnecessarily worries or demoralises young people with early psychosis.

Consider learning preferences and capacity

A young person's capacity to take in or understand information may be affected by factors such as whether they are experiencing acute psychotic symptoms, their stage of cognitive development, or simply whether the mode of delivery matches their preferred learning style (see Box 2, on page 16).

Some people may prefer to learn visually, and young people in particular may have a preference for online or onscreen educational materials. Online materials may also easier for young people to access. Pictorial representations can also be considered.

Structured, systematic psychoeducation was found useful by people with schizophrenia in one study;[14] for other people, however, this may not be useful or acceptable. Clinicians therefore need to carefully consider what methods will best suit each young person and have multiple modes of delivery available to use.

A proportion of people with early psychosis are likely to have a degree of cognitive impairment, which is often present before the onset of psychotic symptoms.[15,16] Although not every young person will have cognitive difficulties, this possibility is something that clinicians should keep in mind when assessing what style of learning best suits each young person.

Other factors that may affect learning capacity include:

- level of education
- whether the young person has learning or language disorder
- whether the young person has access to resources such as computer or the internet
- the presence of acute symptoms
- the young person's medication, particularly medication with sedative effects.

PRACTICE TIP

Consider carefully the complexity of information you give as part of psychoeducation. Keep verbal information concise and consider what the young person or family members are able to take in. Providing information in key points will make it easier to understand.

BOX 2 **MODE OF DELIVERY**

If services and clinicians are to provide psychoeducation that is meaningful and relevant, they must consider what form information materials take and how they are delivered. It is important that clinicians explore what modes of delivery would suit the young person and their family. This should be done in a way that allows the young person to choose methods that truly reflect their preferences, rather than what they think the clinician wants them to use.

Making the most of written information

Although effective psychoeducation involves more than simply distributing factsheets, the importance of written information in aiding psychoeducation discussions cannot be underestimated. Young people and families are often stressed, especially during the acute phase, and may have difficulty comprehending or remembering information that is only given verbally. Written materials provide a reference and allow young people and families to re-read information at a time that suits them. Providing written information may be as simple as the clinician writing down what is discussed in sessions for the young person to take away with them. Written materials can also help clinicians set an agenda about what they are going to talk about in a session, allowing for clearer communication.[7]

Peer-to-peer psychoeducation is available to both young people and families

Peer-to-peer psychoeducation has been shown to be effective for people with established schizophrenia, and may be acceptable to young people with early psychosis.[17] Hearing the stories of other people who have recovered from an episode of psychosis can be encouraging and normalising for young people.[18]

It is helpful for many young people and families to hear from others who have had similar experiences with early psychosis, including their experience of using the early psychosis service, of treatment options, of recovery and of what comes after. Peer support for young people and families is therefore a core component of early psychosis services, and these programs should include peer-delivered psychoeducation.

See also the ENSP manual *Experience matters: a youth peer support training guide in early psychosis*.

> ‘Hearing other family members talk about their own experience with supporting their young person helped me see the light at the end of the tunnel, and that we aren’t the only ones going through this.’
>
> Family member
> EPPIC, Orygen Youth Health Clinical Program

> ‘It feels like you know it’s possible to come out the other side of having psychosis when you are hearing it from someone who has been through it themselves. You can see they look normal, and that makes you feel more normal and like you want to keep working towards your own goals.’
>
> Young person
> EPPIC, Orygen Youth Health Clinical Program

Include families wherever possible

Families are crucial to the young person’s recovery from an episode of psychosis, and the same psychoeducation principles apply to families as they do to young people.

Psychoeducation appears to have the best effect on outcomes when it is delivered to families as well as young people, with psychoeducation programs for families shown to reduce relapse rates, emergency department visits and negative symptoms.[2,3,19]

Specific psychoeducation about early psychosis for families has been shown to increase family members’ knowledge about psychosis and about specific medications. It may also improve family member attitudes towards early psychosis.[20]

See the next section for more about providing psychoeducation for families.

SUMMARY **THE PRINCIPLES OF EFFECTIVE PSYCHOEDUCATION**

> Psychoeducation is everyone’s responsibility

> Psychoeducation should be tailored to each individual’s needs

> Psychoeducation is a continuous and evolving process

> Consider the phase of early psychosis

> Psychoeducation is collaborative and embraces shared decision-making

> Explanatory models are core to psychoeducation

> Consider preconceptions

> Consider cultural background

> Focus on engagement

> Use plain language

> Consider learning preferences and capacity

> Peer-to-peer psychoeducation is available to both young people and families

> Include families wherever possible

Psychoeducation for families

Ongoing psychoeducation forms a large part of working with families in the EPPIC Model, and is covered in more detail in the ENSP manual *In this together: family work in early psychosis*.

The goal of psychoeducation for families should be to increase a family's understanding of their relative's condition and to help them to relate to the young person appropriately. Along with information about early psychosis, family members may need help with coping, help adjusting to the reality of having a family member with psychosis, information about how to promote functional recovery and reassurance.

Many families also describe a need to learn how to better communicate with the young person and each other – for example, how to avoid blaming the young person when responding to behaviour related to symptoms of psychosis, or how to talk to the young person about psychotic symptoms such as delusions or paranoia.

Other topics of psychoeducation for families include:

- the nature of psychosis, including symptoms and diagnosis
- family members' preconceptions of psychosis and any previous experiences of others with psychosis
- the role and efficacy of medication and other biopsychosocial interventions
- exploring family members' expectations of the treatment and recovery
- the prospects for the young person's recovery
- developing crisis plans with the young person and family
- how to communicate with the young person about their experiences
- training for the family in structured problem-solving techniques
- what services and support are available for both the young person and family members.

> 'One of the most common questions I get asked by families is how they can communicate with the young person about positive symptoms. For example, if they challenge delusional beliefs, it leads to arguments, but if they agree with them, it may reinforce the beliefs. It can be really difficult.'
>
> Senior clinician
> EPPIC, Orygen Youth Health Clinical Program

Psychoeducation focus may differ for families and young people

It is possible that at different stages of a young person's involvement with an early psychosis service, the focus of psychoeducation may need to be different for the family compared with the young person. This may be due to differences in the young person and family members' levels of insight, engagement or coping, or to differences in explanatory models.

For example, during the acute phase, for the young person, it may be most helpful to focus on the symptoms they are experiencing, acknowledge the distress caused by them, and reassure them that the symptoms can be treated – rather than trying to explain what 'psychosis' is. Families, however, may want to learn more about what psychosis is and what causes it, depending on how they are able to cope with that information. What is essential for both is to feel heard, supported and to have access to clear information about early psychosis.

> 'The case manager needs to remind families that this isn't a "short" journey. Recovery can take a while. But they also need to reassure families that there is a plan. Sometimes it feels as if the case manager is treading water, but what they're doing is taking time to build up the young person's trust.'
>
> Family peer support worker
> EPPIC, Orygen Youth Health Clinical Program

Psychoeducation in practice

Psychoeducation in practice

Overview

This section provides more detail of how the principles of psychoeducation can be applied to four key topics of psychoeducation for early psychosis: ‘service information’, ‘understanding psychosis’, ‘treatment’ and ‘wellbeing planning and relapse prevention’. This is not an exhaustive list of psychoeducation topics, but a guide to the most useful and important themes. Briefly, these topics encompass:

- how the early psychosis service works and what young people can expect from it
- what is meant by the term ‘psychosis’, including:
  - the spectrum of psychotic symptoms
  - possible causes or mechanisms of psychosis, particularly the stress–vulnerability model
  - diagnosis, including the concept of diagnostic uncertainty in early psychosis
  - how psychosis may affect the young person’s life
- treatment, including the role of psychosocial treatments, medication and side effects
- recovery, including what this might mean for different people, the fact that it is not a linear or clear-cut process (e.g. psychotic symptoms may remit, but cognitive functioning may remain affected) and that time to recovery may vary from person to person
- what relapse is and how to recognise early warning signs
- creation of wellbeing plans
- living with psychosis, including practical support and information about other organisations or resources that can support the young person
- legal information about rights and responsibilities of the young person, families and the service
- other sources of information and help.

The information a young person or family wants or needs will depend on factors such as the phase of the episode of psychosis and their level of familiarity with mental illness or the mental health system. As always, it is important that the prevailing message of psychoeducation is one of hope, optimism, and expectation of recovery.

Topic 1. Service information

The education of young people and their families about psychosis, treatment, and recovery occurs from the moment the young person is referred to the service. Importantly, this includes orientating the young person and family to the service.

Most young people and families will be naive to mental health services and often bring with them stigma-laden, preconceived ideas of what these services provide. Information related to how and when the various types of services will be delivered is imperative to reduce the confusion often caused by the onset of early psychosis and coming into contact with the mental health care system for the first time.

Service information at initial contact

Generally, at initial contact with an early psychosis service, young people and families should receive information about:

- how the service will support both the young person and family
- how the service works and what sort of interventions are available
- the different treatment settings (outpatient, inpatient, home-based care) and how and why the treatment setting might change for the young person
- the service's business hours, how best to contact people, such as case managers, and out-of-hours contact details. Consider obvious information, such as whether a young person's case manager is part-time, and if so, who to contact in their absence, for example, an interim case manager or duty worker
- the roles of staff in the service (i.e. what a case manager does, how doctors will be involved in care)
- how to communicate their needs to staff
- the young person and the service's legal rights and responsibilities
- family and youth peer support programs.

Psychoeducation about services can be as simple as clinicians remembering to explain who they are when they first meet with young people and families, and talk about what their role is. It can be useful to ask the young person if they know what a case manager is, what a psychiatrist does, etc.

It is important not to overwhelm people with unnecessary information when they are first

LEROY

CASE SCENARIO

Leroy is a 25-year-old male of East Timorese background. He lives with his parents and younger sisters.

Following a breakup with his girlfriend, Cara, Leroy has started withdrawing from his friends and family, spending most of his time drinking beer in his bedroom. After the family move house, Leroy becomes increasingly irritable and distracted, sometimes mumbling under his breath and lighting incense to ward off 'spirits'.

One night, Leroy becomes quite agitated and aggressive, saying that there are spirits in the new house that are trying to take over his body. He insists that they need to move house again, and tells his mother that the spirits are telling him to hurt himself. Leroy's mother calls an ambulance and he is reviewed by the local mental health crisis team. He is admitted to a local inpatient unit, and after being assessed is referred to an early psychosis service.

As a case manager, what are some of the things you would talk about to Leroy when he first arrives at the early psychosis service?

What would you discuss with his family?

While everyone will do things differently, based each individual's need, the following may be good starting points for psychoeducation with Leroy and his family.

- Ask Leroy/his family why they think he is been seen by the service.
- Explain the purpose of the early psychosis service – incorporate Leroy's understanding of why he has been referred to the service into your description.
- Explain who you are, including what a case manager is and the role of the case manager and doctor in the young person's care.
- Start exploring Leroy's goals for recovery.

referred to a service. For example, a young person in crisis may primarily need to know how a service will help them with their immediate problems. (It may, however, help with engagement to mention other aspects of the service, such as group programs or vocational services, that the young person will be able to use to become well again or achieve functional goals.)

PRACTICE TIP

Many young people and families are very confused when they first arrive in an early psychosis service. It can be helpful to draw a diagram for them that shows the different parts of the service that may support the young person and their family, including contact numbers.

Service information during ongoing contact

Service information needs will change as the young person continues their episode of care within the early psychosis service. Following initial orientation, young people and families should be provided with more detailed information about recovery and peer support programs. They may also need information about other services they can access, including housing, financial help, drug and alcohol services and other community programs. Young people and families should also be provided with information about the service's feedback and complaints procedure.

As with all psychoeducation, information may need to be repeated or revisited as needed.

Legal information and advice

Mental health legislation varies between states and territories in Australia. Early psychosis services have the responsibility to ensure that young people and families are fully informed of their legal rights and responsibilities, including what the criteria are for involuntary treatment under relevant legislation (see 'Psychoeducation about involuntary treatment', on page 47).

Services therefore need to be aware of how young people and families can access legal support. Legal information and support for users of mental health services can be accessed through government or specialist legal websites. All clinicians have the responsibility to know the information relevant to their state or territory and must actively support young people and their families to access this.

Advocacy services can also be accessed to support any young person who is unable to advocate on their own behalf or who does not have family who are able to support them. Although advocacy is part of the role of any clinician working in an early psychosis service, it may be useful to involve specific advocacy services, particularly for young people with multiple and complex needs, or where there are many services trying to work together.

The same principles of psychoeducation apply to communicating legal information as for other kinds of information: that is, it should be repeated, be given in clear, plain language, and be available in different formats (e.g. written or on websites).

Addressing concerns about confidentiality

Young people may express concern about the confidentiality of information that they share during sessions with clinicians. It is important that this is addressed early on so the young person feels comfortable about sharing information during psychoeducation.

Services need to have clear guidelines about what information clinicians may discuss with third parties, such as family members, and under what circumstances. It is helpful to explain these guidelines to the young person and explicitly state that the content of discussions is confidential, unless there are extreme circumstances when confidence needs to be broken (e.g. there is high risk to the young person or others).

See the ENSP manual *In this together: family work in early psychosis* for a discussion about information-sharing with young people and families.

PRACTICE TIP

Avoid using acronyms or abbreviations to describe different areas of a service (e.g. MATT, CCT) or aspects of treatment. It's easy to forget that most young people won't know what these mean. Advise young people and families to ask for clarification if abbreviations are used by staff.

Topic 2. Understanding psychosis

Introduction

The concept of ‘psychosis’ is perhaps the most difficult for young people and families to understand and come to terms with. What an episode of psychosis is, what causes it, how it is experienced and whether people recover are some of the likely concerns young people and families will have following diagnosis or referral to an early psychosis service.

Importantly, the meaning that the young person attaches to their experience of an episode of psychosis can have a huge impact on their self-confidence and identity. A young person may struggle to distinguish between the disorder and their identity, so that their perception of self becomes conflated with their experiences of psychosis. For example, rather than individuals seeing themselves as someone who has lived through psychotic experiences, they may identify themselves as being ‘psychotic’ or ‘schizophrenic’.

Whatever the case, exploring what psychosis means and making sense of what has happened to the young person will be a crucial need; developing this understanding is one of the chief roles of psychoeducation in early psychosis.

This section presents some key concepts and topics to introduce during psychoeducation sessions that will help develop the young person and family’s understanding of psychosis. Note that at each phase of an episode of psychosis, the approach to developing this understanding may differ, and the type or level of detail of information discussed may change (see ‘Building understanding through the different phases’, on page 33). However, the overriding principle remains the same: to work with the young person to build an understanding of psychosis that is relevant to them and useful for their recovery.

> ‘[Young people] don’t know much about mental illness. I know heaps about it now, but back then I didn’t know anything. I didn’t know what psychosis was, so how would I know I would recover from it? It sounds pretty scary – the word itself, and all the stigma attached to it.’
>
> Young person
> EPPIC, Orygen Youth Health Clinical Program

Conceptualisations of psychosis

Explaining and exploring what psychosis is may involve a number of conceptualisations or models. There are many ways to do this, and each clinician may have their own methods. It is helpful to share ideas within the clinical team about what methods have worked well with young people. The following are some key concepts that can be useful to explain to young people and families to help them develop their understanding of psychosis.

PRACTICE TIP

One of the most important things clinicians can do when a young person first enters a service is to normalise the experience of an episode of psychosis. Clinicians should stress that the symptoms the young person is experiencing are ‘familiar’ to health care professionals and that staff in the service are experienced in treating them and helping people recover.

Biopsychosocial factors in psychosis

A biopsychosocial framework is used to describe how various biological, psychosocial and social factors can interact to influence the development and progression of mental health problems, including early psychosis. Clinicians can use this framework to discuss with a young person the factors that may be affecting them when they present to an early psychosis service.

It can be used to explain to the young person and family that

- there is not a single cause of the disorder
- causes are unique for each person
- although some factors cannot be changed – such as family history (genetics) or obstetrical complications – other factors that are likely to have a big influence on outcome and prognosis, such as drug use, adherence and management of stress, *are* modifiable
- as well as factors that may cause an episode of psychosis, there are biopsychosocial factors that are protective, and these, and the young person's strengths, need to be considered too.

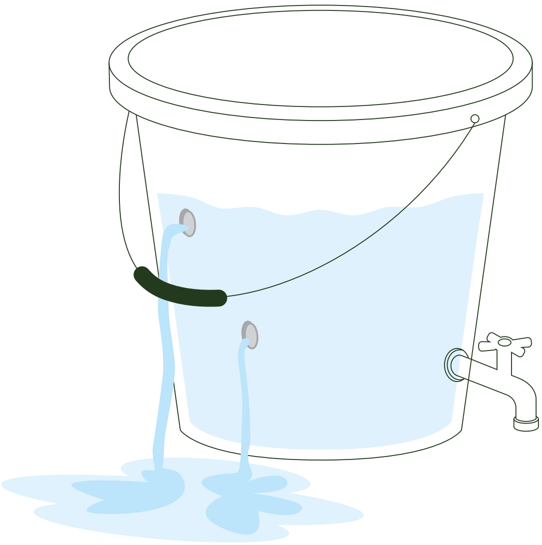
Discussing this framework provides a platform for the young person and clinician to begin developing a treatment plan to target modifiable factors, and ties in with the stress–vulnerability model, discussed next.

The stress–vulnerability model

The stress–vulnerability model of how biopsychosocial factors act to cause and maintain psychosis is a core concept to introduce in psychoeducation. For example, for young people identified as UHR, showing the link between stress and the onset of psychotic symptoms can help explain why it is good for the young person to be seeking help at this stage, and the need to work on reducing stressors, such as personal circumstances or co-occurring conditions.

This link can be represented in a number of ways. A stress 'bucket' is a simple, easy-to-draw analogy clinicians can use to explain the concept and identify with the young person any vulnerabilities or stressors that might have led to the onset of symptoms of psychosis (see Figure 1) and what factors they may need to be aware of to help with recovery and staying well.

FIGURE 1. **THE STRESS BUCKET**



Stressors and vulnerabilities that may have contributed to the young person's episode of psychosis are placed in the bucket until it 'overflows' (the episode of psychosis). Protective factors and treatment are represented by a tap or by putting holes in the bucket, which let the stress out before the bucket overflows.

LEROY

CASE SCENARIO (CONTINUED FROM PAGE 22)

Leroy has begun to get better and has been attending weekly appointments with his case manager, as well as regular appointments with his doctor. His family reports he is not isolating himself so much at home, is not as worried about spirits in the house and has not brought up wanting to move house again.

His case manager has until now been focusing on how Leroy is tolerating his medication and building rapport with both Leroy and his parents. Leroy is attending his third appointment alone. His case manager begins some basic psychoeducation, working with Leroy's understanding of psychosis and exploring his explanatory model.

Case manager (CM): It's great that you're starting to feel more like your old self, Leroy. It's been a really difficult time for you recently, especially going to hospital. Often when people go to hospital, especially when they didn't want to, it can be a really stressful and scary time.

Leroy: Yeah. It was horrible. I don't remember much. But I know I was scared.

CM: Yeah, that sounds really full on. It's no wonder you felt scared. I wonder if it would be okay to talk a bit about it?

Leroy: Yeah, sure.

CM: So first I want to understand what was happening for you at the time. Other young people I speak to say that sometimes it's hard to remember what happened, but can you think back to just before you came to hospital? What sort of things were going on that you think led to you having to come to hospital?

Leroy: I dunno, it just sort of happened slowly. I was having a pretty bad time, and my girlfriend had broken up with me … and then we moved to the new house with the spirits, and at first it was okay, I didn't mind them, but they stopped me sleeping, and it was like I just knew they were trying to get me, like take me over … but no one was listening to me. I got pretty mad, and they made me say some stuff, like I was going to hurt myself if we didn't move … and then, yeah, the ambulance came.

CM: That sounds very stressful, and scary. You say the spirits were telling you to do things and putting thoughts in your head about hurting yourself. I wonder if they are still bothering you?

Leroy: I don't really hear them any more, and I can't feel them like I could before, which is good. But I'm worried they might come back. I really hope they don't. I mean, I'm not sure I really believe in them, but … Yeah, I don't really know what was going on.

CM: Well, some of those things might have felt unusual for you, but other people often have similar experiences when they're under a lot of stress. Maybe I could talk a bit about what I think is going on?

Leroy: Okay

CM: So it sounds like a lot of stressful things were happening, and sometimes stress can really affect our mental health, like, how we think and feel. Is it okay if I draw you something?

Leroy: Yeah.

CM: It's like, we all have a bucket, and the bucket, depending on the person, might be really big, or it might be smaller. Stress can be poured into the bucket, and most of the time we can manage the stress being poured into the bucket. But sometimes the stress gets too much and we find it more and more difficult to manage. Can you think of some things that have been stressful for you?

Leroy: I guess I broke up with Cara, and then I failed one of my exams at TAFE. Then we moved house again.

CM: Yeah, and it sounded like that was really hard.

Leroy: Yeah it was.

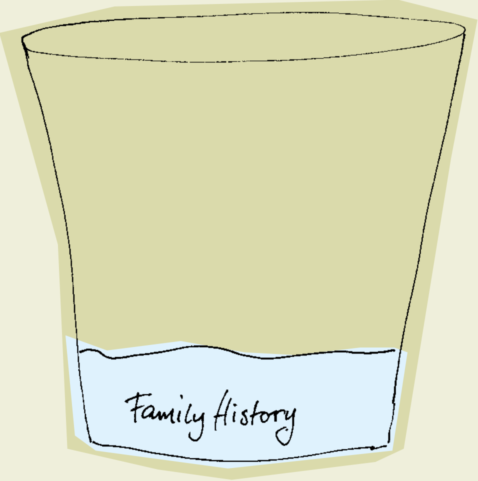
CM: And so if we put those things in the bucket it starts to fill up. Also, some people might already have some things in the bucket, which means it might fill up quicker. Like a family history of mental illness, or if something traumatic has happened to them when they were younger.

Leroy: My aunty has bad depression, and she's been to hospital too. Is that a family history?

LEROY

CASE SCENARIO

CM: Yeah, it is, and most people have a family history of some sort condition, like heart disease or mental illness. And it *might* mean you have some extra stress in your bucket. Like this [adds layer to bucket].



Then there are other things that happen during your life that can add to the stress. Really stressful experiences. Can you think of anything for you?

Leroy: Um, not really.

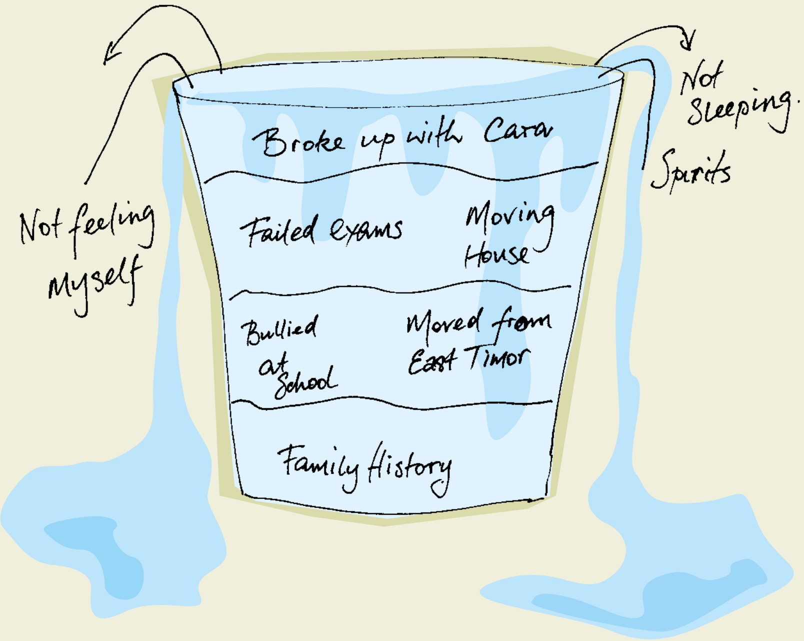
CM: What about when you moved to Australia from East Timor? I guess things might not have been very safe there, or it was stressful to move countries?

Leroy: Yeah ... actually, I didn't really want to move. I didn't like it to start with. No-one really liked me at my first school.

CM: Okay, that was a big change in your life, so it sounds like those things could go in the bucket too?

Leroy: Yeah, being bullied and moving and missing my friends and family.

CM: So there's a lot of stress here, and you can see how your bucket is getting pretty full. And see, when the bucket gets full it overflows, and that's when people start to get unwell. Like for you, you weren't sleeping and started not feeling like yourself. And you know what? This overflow could be any mental health problem. Depression or anxiety. In your case we think it might be psychosis. Is this a word you've heard before?



Symptoms diagram

Psychoeducation about symptoms of psychosis may help reassure the young person and family that what they're experiencing is treatable, without minimising their distress or concern. Done sensitively, and working with the young person's explanatory model in mind, exploring symptoms is an important component of informing the young person about their condition and helping them develop a greater level of insight.

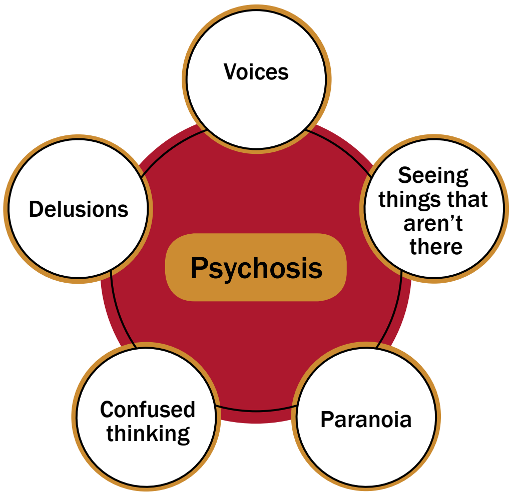
Language use is particularly important to consider: it is unlikely that using medical terminology to describe symptoms will be helpful for most people; rather, use plain language that relates to the young person's experience of symptoms and reflects their own language for these experiences.

Resource 1 can be used to explain the different symptoms of psychosis.

> 'Movies are a good way of explaining psychosis – for example, The Truman Show, where you might feel that everything around you is staged and that there are cameras everywhere.'
>
> Clinician
> EPPIC, Orygen Youth Health Clinical Program

A symptoms diagram, such as Figure 2, can be used to explore with the young person what they have experienced. It can be useful for the young person to put a label on their experience, and this process will also help their case manager to get a better understanding of the young person's symptoms. This can lead on to a discussion about how symptoms are often overlapping in different disorders, which is why clinicians initially use the general terms 'early psychosis' or 'first episode of psychosis' to describe the young person's experiences or symptoms.

FIGURE 2. **SYMPTOMS DIAGRAM**



Ask the young person to describe some of the things they experienced when they were becoming unwell. Were there things that friends or family told them they noticed? You may also add other things that you are aware of as a clinician, but be sure to check with the young person whether these are things that they remember or that your observations feel accurate to them. This helps to build a shared understanding of the episode of psychosis.

It can be important to explain the distinction between positive and negative symptoms, including why positive symptoms are called 'positive' when they are usually not in fact enjoyable or helpful experiences. Negative symptoms in particular can be difficult for young people and families to recognise and cope with, often misconstrued by the young person's family as laziness. They are also harder to treat than positive ones and therefore are often the last to resolve. Resource 2 can be used to help guide discussion about negative and positive symptoms.

> 'I remember the moment I was told that I was experiencing symptoms of psychosis … I'm like, "Oh so … there is a reason for this; the world isn't actually out to get me, and no-one's filming me".'
>
> Young person
> EPPIC, Orygen Youth Health Clinical Program

LEROY

CASE SCENARIO (CONTINUED FROM PAGE 27)

Leroy attends another session with his case manager.

CM: So Leroy, we talked a bit last time about the stress bucket and what might have caused your experiences. I mentioned psychosis and I just wanted to check what you've heard about it, or what you know already.

Leroy: I know it's not good.

CM: [smiles] It's not great, but it's maybe not as bad as you think. Often young people we work with have ideas from TV or movies about psychosis. But actually, psychosis is just a term we use for symptoms that might be caused by a whole range of mental health problems.

Leroy: What kind of symptoms?

CM: Well, for some people it can be hearing things that other people can't hear; this can be voices, or other noises. Is it okay if I draw it?

Leroy: Yeah, okay.

CM: Great [draws circle with voices written in it]. Other symptoms can be seeing things that aren't there, even though they feel really real, or holding beliefs about things that other people don't believe.

Leroy: You mean when I could hear the spirits and believed they were going to hurt my family if I didn't do what they said?

CM: Exactly. And then some people feel really worried about their safety, or about what other people might do to them … like they feel paranoid.

Leroy: Yeah, that was how I felt.

CM: And people can find that their thinking is confused, or not as clear as it normally would be [draws more circles with 'paranoia', 'seeing things', 'unusual thoughts' and 'confused thinking'].

Leroy: Yeah. I felt like people didn't understand what I was trying to tell them. And I also felt really annoyed with people, especially my sister, like she was trying to make me feel confused or trick me.

CM: That would have felt horrible and really confusing for you. Can you think of any other things that might go on here?

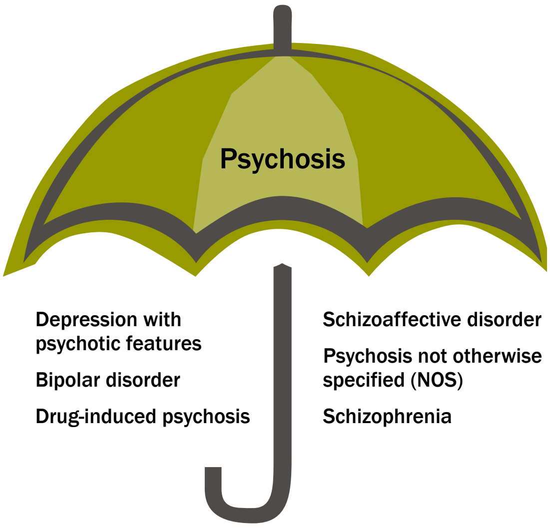
Leroy: I didn't want to sleep. I just was awake all the time. And I was really angry and shouting a lot. I don't normally do that.

CM: [Adds these to the circle] Yeah, these can be other symptoms people experience when they have an episode of psychosis. Do you think there might be other things that maybe your mum, or dad or sister noticed as well …?

The umbrella

The umbrella is a simple drawing that can be used to explain to young people and families that 'psychosis' is a general term, and a range of disorders come under this 'umbrella'. Clinicians use the terms 'psychosis', 'early psychosis' and 'first episode of psychosis' because the young person hasn't experienced these kinds of symptoms before and it can take time to work it out whether the young person has one of the disorders in the picture. Emphasise, however, that it is possible treat the symptoms of psychosis the meantime.

FIGURE 3. **THE 'UMBRELLA' OF PSYCHOTIC DISORDERS**



LEROY

CASE SCENARIO (CONTINUED FROM PAGE 29)

CM: Hi Leroy, I wanted to check in about what we talked about last week about psychosis. I wondered what you thought about what we spoke about?

Leroy: it was good to know that the things I had wasn't me being crazy. I know I wasn't being myself, but it was good to know that it's got a name and that the things that felt really scary are things that you guys know how to treat.

CM: [smiles] Yeah, that would feel reassuring I imagine. I wondered if you asked your family about it?

Leroy: Yeah, they thought it made sense. I drew it for them [smiles]. So they could understand.

CM: That's great. It helps sometimes to do that. Hey, I wondered if there were things that left you with more questions?

Leroy: Um, yeah. I was on the internet looking up psychosis. And there was all this stuff about schizophrenia. Is that what I have? Is that what psychosis is?

CM: That's a really good question. Do you mind if I draw something? You know I like drawing stuff!

Leroy: That's cool.

CM: Psychosis is what we call an 'umbrella' term [draws umbrella] for all these conditions. It's like when we talk about someone having a 'fever'. That's the symptom, but it might be caused by lots of different conditions.

Leroy: So what do I have?

CM: Well at the moment, it's too early to say if you'll have one of these conditions. It often takes time to work out which of these conditions you might have, so right now it's about treating the symptoms of psychosis so that you can be doing what you want to be doing, like getting back to TAFE, hanging out with your friends. The good thing is that you use the same type of medication to treat all these conditions. Like the one you are taking now.

Leroy: How long will it be till you know which one I have?

CM: It depends. Some people only have one episode of psychosis, then they recover and the never have another one again. Other people may take longer to recover, and need to keep coming in to the service, and that's when it might become clearer that they have one of these conditions under the umbrella.

The phases model

Clinicians can use the phases model of early psychosis (Figure 4) to illustrate to the young person and their family the possible course of the episode of psychosis, including the expected outcomes. This would usually be done in retrospect, once a young person has recovered from the acute phase of an episode of psychosis. It is important to explain that the time spent in each phase is different for everyone and that there is no ‘set’ progression through the phases. For example, some people may remain longer in the acute phase before moving into recovery, and not everyone will necessarily experience the incomplete recovery phase.

The phases model can also be useful to introduce the idea of the prodrome and begin discussions about early warning signs (see page 49).

Understanding diagnosis

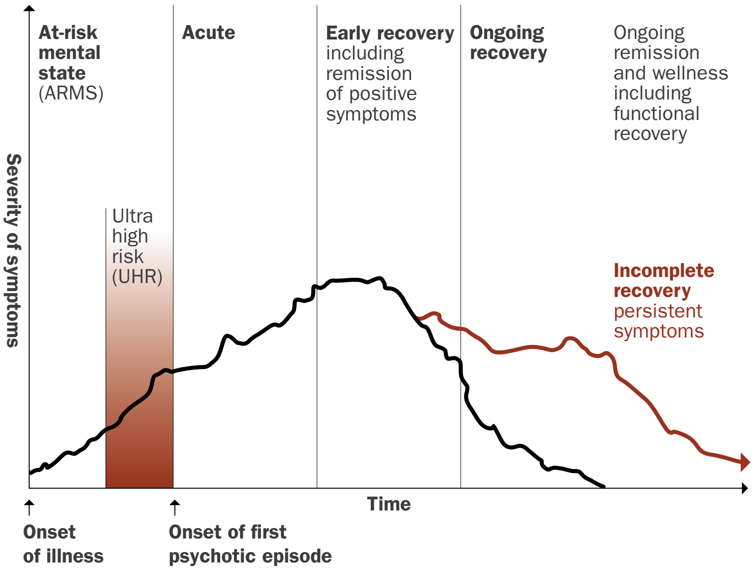
Diagnosis presents a few problems in terms of early psychosis. Because of the difficulty with classifications, and because many diagnoses have quite negative connotations, clinicians understandably are reluctant to place too much emphasis on the young person’s diagnosis. Although diagnostic categories should not be emphasised unduly, it is important that clinicians demonstrate to the young person and their family that the symptoms the young person is experiencing are recognisable, that they know what is affecting the young person – and that they can give it a name. Receiving a diagnosis may be a relief for the young person, as it acknowledges that something is not right and gives them something to ‘hold on to’ as they navigate the mental health system, treatment and management of their symptoms.

> ‘In my case I was so desperate to understand what was going on, it actually really worked for me to have a diagnosis.’
>
> Young person
> EPPIC, Orygen Youth Health Clinical Program

When discussing diagnosis, clinicians should be clear with a young person and their family about what the young person’s working diagnosis is, but at the same time emphasise the ‘working’ part of this, to acknowledge that often symptoms change over time and the overall clinical picture may be different to what it is currently thought to be. This requires open, ongoing discussion to ensure that young people and families do not feel like the diagnosis is being arbitrarily changed at a later point or that somehow the treating team got it wrong.

Terms such as ‘early psychosis’, ‘acute episode of psychosis’ or ‘first episode of psychosis’ convey this initially, and more specific diagnoses can be discussed over the course of the young person’s treatment. It may, however, be particularly important

FIGURE 4. **THE PHASES MODEL OF EARLY PSYCHOSIS**



to address concerns about whether having had an episode of psychosis means the young person has schizophrenia. This can be clarified by explaining the overlapping nature of the different symptoms of psychotic disorders and also being realistic about the fact that there are a small number of people who do go on to develop schizophrenia. However, emphasise that with good support and treatment, recovery and managing this will be possible. See also 'Incomplete recovery' on page 37.

> 'Families and young people often get really worried when they see the young person has been prescribed medication to treat "schizophrenia". It's important to talk about what a diagnosis means, that treatments are often similar for different disorders – and also that the diagnosis might change.'
>
> Senior clinician
> EPPIC, Orygen Youth Health Clinical Program

JAY

CASE SCENARIO

Jay is an 18-year-old Aboriginal man who has been seeing his case manager for several weeks after an acute episode of psychosis that required admission to an inpatient unit. There has been more general psychoeducation since meeting his treating team.

Jay: Hey um. I know we said we would talk about the work stuff today … But I um, I read this thing. It really freaked me out.

CM: No worries Jay, that sounds a bit full on. What freaked you out?

Jay: I um, was looking online, you know, about psychosis … and there was all this stuff on there about schizophrenia. I was like, Holy moly. Do I have schizophrenia?! It freaked me out.

CM: I imagine that would have been really freaky. And I wonder if it made you worried about like what happened with your uncle with schizophrenia?

Jay: [long pause] Yeah, 'cos he was in hospital all the time. And would just do really crazy things and say crazy things that scared everyone.

CM: It sounds like it would be good to talk more about this?

Jay: Um, nah …

CM: Okay, that's okay. Sometimes people want to ask questions and at other times they just want to sit and think things over a bit. Do you think that's a bit like you?

Jay: Yeah … I don't like talking that much [long pause] … I like listening though.

CM: [Smiles] I think you're a pretty good listener. Hey, I thought of you the other day when I was watching a really short video. It sort of covers what we were just talking about. I wondered if we could watch it together. I might write down some thoughts, maybe you could too if you want … but no pressure.

Jay: Yeah, that sounds cool. Yeah, and maybe I could show it to my mum too [smiles].

Common myths about psychosis

There can be considerable stigma attached to terms such as ‘schizophrenia’ and ‘psychotic’, and concerns about these and other terms may be raised by the young person or their family. It is therefore important to talk about what psychosis *isn’t* and address some common misperceptions about it.

Psychosis isn’t ‘split personality’

This term is often used in the media, TV or movies, and may be confused with psychosis because it denotes that the person might experience something that is distinctly different from their usual self, or behave in a way that is very out of character.

You’re not ‘crazy’ or violent

Many perceptions in society are that people with psychosis are out of control, particularly, that they are violent. Words such as ‘crazy’, ‘psychotic’, ‘schizo’ and ‘psycho’ have connotations of someone being out of control, and may be particularly concerning for the young person or their family.

You’re not ‘insane’

Although the word ‘insanity’ denotes severe mental illness, it is not a psychiatric diagnosis or term. The ‘insanity’ or ‘mental impairment’ defence is used legally to argue that someone is too mentally ill to be held responsible for a crime they have committed.

You’re not a psychopath

The word ‘psychosis’ sounds similar to ‘psychopath’, and some people may confuse the two terms. It is important to explain that psychopathy is a separate diagnosable disorder where people lack sympathy and are indifferent to their own violent or criminal behaviour. Young people may need to be reassured that very few people with psychosis are likely to do bad things or harm other people. This discussion may need to be balanced with some of the realistic risks that the young person may present with.

This disorder is treatable and is not a life sentence

It is important to be clear that the young person won’t necessarily have services in their life or have to take medication forever (although a small group might). Likewise, some family members, in particular parents, may feel that they are now responsible for looking after the young person for the rest of their lives; however, although a high level of support might be needed initially, the usual trajectory is that the young person recovers and learns to manage their circumstances by themselves.

> ‘I can’t really tell people about it – they get this mental image of a person wearing a hockey mask with a chain saw, so…’
>
> Young person
> EPPIC, Orygen Youth Health Clinical Program

Co-occurring psychiatric conditions

Co-morbidity of some kind is likely for most young people presenting with early psychosis. Most commonly, depression, anxiety, personality disorders or substance use are a concern. It is important not only to discuss these as discrete conditions during psychoeducation, but also discuss how these might impact on recovery.

Distinguishing between problems or symptoms related to psychosis and those related to other conditions is also important so that treatment plans can be effectively developed with young people and their families. It is also useful to explain that some symptoms are attributable to more than one disorder, but treatment may be quite different depending on which disorder is the cause. For example, low mood will be treated differently if it is related to psychosis than if it is related to depression.

Building understanding through the different phases

At each phase of an episode of psychosis, the young person and family’s understanding of psychosis will need to be built upon to reflect their changing circumstances and address any issues that arise as they move through the period of treatment. In this section we consider how the approach to psychoeducation about psychosis may change at the different phases.

Explaining the at-risk mental state

For more about the definition of the at-risk mental state, UHR and interventions in this phase, refer to the ENSP manual *A stitch in time: interventions for young people at ultra high risk of psychosis*.

As with at every phase of psychosis, it is important to be clear with young people considered to be at risk of experiencing an episode of psychosis about the reasons they have been referred to an early psychosis service. However, this must be balanced with the need to engage the young person and their family and to build rapport. Young people in this phase have often been referred because of other mental health difficulties, such as depression or anxiety, that they are more concerned about than their risk of experiencing an episode of psychosis. Thus, discussing psychotic symptoms and the concept of the at-risk mental state needs to be done thoughtfully so that the young person does not become alarmed or disengage because they feel these concepts are not relevant to them.

PRACTICE TIP

It can be helpful to review what you have covered at the end of each session, especially regarding psychoeducation. Ask the young person if they can identify three 'take home messages' from the session.

Use of language is particularly important, and the tension between helping the young person avoid transitioning to an episode of psychosis and potentially stigmatising the young person needs to be kept in mind, especially as transitioning is not an inevitable outcome. For example, the term 'schizophrenia' has quite negative connotations, and telling someone that they are 'at risk' of developing this disorder could cause unnecessary anxiety and possibly disengagement.

It can be helpful to explain what 'at-risk' means by using the dimensional model of psychosis (see Figure 5). This model explains symptoms of psychosis as something that everyone can experience, and they exist on a continuum of experience, from 'normal' to 'severe'. Use the young person's own experiences as an example (see case study 'Liana').

A good way to begin psychoeducation is by asking the young person why they think they have been referred to the early psychosis service. This understanding should be incorporated into clinician's explanations of the at-risk mental state and the purpose of the early psychosis service. For example, if a young person cites difficulty with school or studies as the reason for their referral, exploring the reasons for this difficulty may lead to discussion about specific symptoms related to mental health difficulties, including the at-risk/UHR phase.

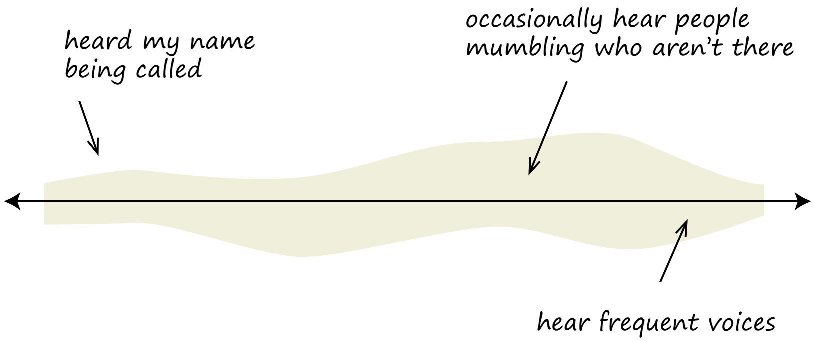
The focus may then change to the young person's goals: what these are and how their unusual experiences might be getting in the way of their leading a normal, healthy life. Clinicians can explain that one of the purposes of the service is to make sure their experiences don't get any worse; however, they can also work on any other things that are worrying them, such as needing to improve their studies.

IMPORTANT MESSAGES ABOUT THE AT-RISK MENTAL STATE

> The at-risk mental state is not a diagnosis.

> Symptoms of psychosis can occur in people without a diagnosed mental illness.

FIGURE 5. **SYMPTOMS OF PSYCHOSIS EXIST ON A CONTINUUM OF HUMAN EXPERIENCE**



LIANA

CASE SCENARIO

Liana has been referred to an early psychosis service because she has been quite depressed and having trouble attending school. She has also reported feeling occasionally that someone is watching her on the way to school, and says that it's not just the depression making her skip school sometimes, but also because people at school sometimes seem to be reading her thoughts.

CM: Our job is to support you to feel better in yourself. This means we want to focus on what you feel will help you to get things back on track … it would also be good to keep checking in on the other experiences you described. Like feeling people can hear your thoughts at times.

Liana: Yeah. I know it makes me sound weird …

CM: Actually, those type of experiences you mention are really common, and can happen to any of us. See? Like this [draws continuum]. Some people at times, when things are more stressful, hear unusual noises or a mumbling. Or they may see shadows moving out of the corner of their eye. They don't bother most people, but if they get in the way of you doing normal things, that's when maybe you need help with dealing with them.

Liana: Okay. Yeah – it's only sometimes. But when it happens, it really freaks me out.

CM: That's good that it's only sometimes. I wondered if it's okay if we keep it in mind that you've had these weird [using Liana's words] experiences and if I check in with you later about how they are going? Linda [Liana's doctor] may also want to check in with you about these, if that's okay? It's just about making sure those thoughts don't get in the way of you getting back to school.

Liana: Yeah, okay.

CM: Meanwhile, we'll also keep working together to get you back to school and feeling better. Most people we see find the weird experiences tend to stop happening once other things in their life feel a bit more under control.

PRACTICE TIP

Remember the importance of pacing and repeating psychoeducation to allow people to properly understand information.

Understanding psychosis in the acute phase

The acute phase of an episode of psychosis, whether it is an initial acute episode or an acute episode following a relapse, is a time of intense distress for young people and families. Young people and families will require a great deal of information about what is happening and what can be done. At the same time, it is easy for them to become overwhelmed by the experience and all the new information they are being presented with.

Psychoeducation for understanding psychosis in this phase will therefore explore the young person's initial understanding of their experiences and address stigma and misperceptions. It needs to be concise and clear, focusing on the message that the young person's condition is treatable.

If the young person is acutely unwell, more detailed information may be needed by the family compared with the young person, in which case it is essential to provide support, reassurance and acknowledge the young person's distress and confusion about what is happening.

IMPORTANT MESSAGES DURING THE ACUTE PHASE

> Help is available.

> The young person and family's current distress will decrease – it's going to get better.

> Recovery is to be expected.

> No-one is to blame for the onset of the episode.

> The young person needs to minimise stress and over-stimulation (refer to the stress–vulnerability model).

> Agitation, unusual beliefs and behaviours are part of the episode of psychosis.

> It's not helpful for family members to argue with the young person about unusual beliefs or try to convince them they are wrong.

> Family members should avoid confrontation and criticism of the young person, unless to prevent harmful or disruptive behaviour.

Understanding psychosis during early recovery

As a young person starts to recover from an episode of psychosis, clinicians can begin to focus on trying to get a clearer sense of their understanding of psychosis. This may include exploring:

- the young person and family members' explanatory models
- their preconceptions about psychosis, including preconceptions about treatment, expectations for recovery and stigma
- any previous experience they have of psychosis, or serious mental illness, and treatment.

Psychoeducation should then build on this understanding to make sure the young person is as well informed as possible about psychosis and how it has affected or may affect them. Aims of psychoeducation in recovery include:

- enhance the young person and family's understanding of the nature and causes of psychosis
- provide information on the relationship between mood disorder and psychosis, if relevant
- reduce any fear or distress caused by the episode of psychosis
- reduce or remove feelings of shame or stigma
- encourage feelings of optimism and expectation of good things
- foster a sense of mastery over the individual's experience of psychosis
- develop an understanding of the need to manage stress, in the context of the stress–vulnerability model.

IMPORTANT MESSAGES DURING THE EARLY RECOVERY PHASE

> The pace of recovery is individual.

> The journey of recovery is not linear.

> Recovery means different things for different people.

> Recovery is about doing things that are important to the young person (functional recovery) as well as managing symptoms.

> The young person is much more than their experience of psychosis.

Late recovery

There are particular challenges for young people and families in the late recovery phase. Most young people will have experienced a remission of positive symptoms of the episode of psychosis; however, some may experience ongoing negative symptoms, which appear more prominent once the positive symptoms have reduced or resolved. Psychoeducation for the young person and the family is important in this phase to help them understand the impact of negative symptoms, especially on motivation and cognitive functioning (see Resource 2).

Clinicians should maintain a message of optimism that the negative symptoms will reduce and likely resolve with time, and a focus on functional recovery and more practical interventions is important.

Late recovery is also a time to begin working on relapse prevention and identification of early warning signs. This will be addressed later in this manual in 'Wellbeing planning and relapse prevention' on page 49.

It is important to be mindful that people in the recovery phase are more likely to have depressive episodes, and the period immediately following discharge from a service is associated with the highest suicide risk.[21,22] Psychoeducation may therefore need to address this increased risk and higlight the need for families to be aware of risk factors. It may also cover the presentation of disorders such as depression and the need for associated treatment.

IMPORTANT MESSAGES IN THE LATE RECOVERY PHASE

Topics of psychoeducation may include:

- what would it mean to the young person, or family, to have a relapse?
- factors that promote or hinder recovery and staying well
- coming to terms with the experience of an episode of psychosis and treatment
- difficulties young people may face in staying well, such as
  - it can take a while to recover, and this is different for everyone
  - lowered self-esteem (from stigma, loss of sense of self)
  - social anxiety
  - post-psychotic depression
- resources to help the young person to stay well and continue to recover – e.g. vocational and other services
- goal-setting.

Incomplete recovery

It's important to start talking about the possibility of incomplete recovery early on in treatment, although clinicians may prefer to talk about 'managing ongoing symptoms' rather than use the term 'incomplete recovery' when discussing this concept with young people and their families.

Clinicians should maintain realistic optimism about the young person's outcomes in this phase. It may be that the young person has an ongoing condition, but this can viewed in the same way as physical conditions such as diabetes or asthma. Like these ongoing conditions, psychosis can be managed with the right treatment and access to support; it may require lifestyle changes, but that doesn't mean the young person cannot live a normal and fulfilling life.

Psychoeducation during incomplete recovery might focus on helping the young person and family gain an understanding of what might be hindering a complete recovery, how to manage symptoms, or the importance of interventions that assist with getting on with life despite ongoing illness.

Specific topics include:

- revisiting the stress–vulnerability model to develop an understanding of the modifiable factors that might lead to an incomplete recovery, such as drug use or stress
- treatment options and approaches
- persisting positive, negative and cognitive symptoms
- the role of additional services
- revisiting diagnosis and what it means (and what it doesn't)
- explicitly addressing the stigma associated with having a diagnosed psychiatric condition
- structured discussions of early warning signs and relapse prevention plans.

IMPORTANT MESSAGES ABOUT INCOMPLETE RECOVERY

> A fulfilling life is possible despite ongoing mental health problems.

> Recovery is a non-linear process: the young person will continue to improve with time.

> A diagnosis is just a label for meeting certain criteria; it does not determine prognosis.

> Functional recovery is likely, even with persisting symptoms.

JAY

CASE SCENARIO (CONTINUED FROM PAGE 32)

Despite commencing antipsychotic medication, Jay continues to experience positive and negative symptoms of psychosis. Seven months after his referral to the early psychosis service, his mum, Jenny, attends an appointment with him, wanting to know what Jay's diagnosis is. Jay asks his case manager why he still continues to have voices.

CM: Jay, remember a few months ago we were talking about the 'umbrella of psychosis' and all the different types of diagnoses that fit under it?

Jay: Yeah I remember. You said something like, psychosis can be a lot of different things, that it can become lots of different things over time.

CM: Yeah, that's right. We talked about how we use 'psychosis' as a term because it's not always clear in the beginning what kind of psychosis you might have. We use the term as an 'umbrella' to cover a lot of different diagnoses … with me so far?

Jay: So psychosis isn't a diagnosis?

CM: That's right – 'psychosis' itself isn't a diagnosis, but there are different diagnoses that all sit under that umbrella.

Jenny: So does that mean that you don't know what Jay's diagnosis is?

CM: That's a really good question. In the early stages it's really difficult to tell, because each diagnosis has different criteria. Sometimes in the beginning, not enough of the criteria can be met to apply a clear diagnosis … but we still treat the symptoms in the same way. We had talked previously together about schizophreniform psychosis being Jay's initial diagnosis. Do you both remember?

Jay: Yeah.

Jenny: Yes, that was a few months ago now. Has that changed?

CM: Remember we talked about that diagnosis being limited to six months?

Jenny: Oh yeah. But Jay's been sick for longer than six months now, so what does that mean?

CM: Well, according to the criteria that we use, it means that Jay meets the criteria for a diagnosis of schizophrenia. Jay, I know you read some stuff online a while ago about schizophrenia that worried you. Jenny, have you heard of schizophrenia before?

Jenny: Yeah. Jay's uncle has schizophrenia.

CM: So we can all be on the same page … can I ask both of you to tell me what you understand or know about schizophrenia?

Jay: I dunno … I think it means you're dangerous, or a 'schizo'. You know? Or multiple personality. Like Uncle Michael … he's crazy.

Jenny: Jay I don't think it means you're dangerous. You're not dangerous, honey. But does it mean that Jay's going to be sick for the rest of his life? His uncle isn't a very well man.

CM: I just want to reassure you, Jay, that having schizophrenia doesn't mean you are dangerous or a 'schizo' and you don't have multiple personalities. As far as I can see, you only have one personality, and it's a good one!

But because your symptoms have gone on for longer than six months, it means that there is more chance of you having a relapse in the future, and that it now looks like a condition that you will probably have to manage over the longer term. Diagnoses are categories that are designed to help us decide what treatments will be most effective to help you recover. When your uncle became unwell for the first time, he was probably around the same age as you, right?

Jenny: I think he was about twenty-two. So maybe thirty years ago. He had a lot of the same kinds of symptoms that Jay had initially … that's what gets me worried.

CM: I know it can be worrying to see the same symptoms in family members, especially if they haven't fully recovered. I guess though, Uncle Michael probably didn't have access to specialised treatment when he was young, like you do Jay. The treatments that we have for psychosis and schizophrenia are much better now than they were thirty years ago.

Jay: Yeah?

JAY

CASE SCENARIO

CM: Yep. [To both] Can you see any differences between Jay and Uncle Michael? [The case manager asks this because she knows from a previous conversation with Jenny that Jay's uncle has not worked since becoming unwell.]

Jenny: Well, Uncle Michael never worked after he got sick. He went to hospital for a year, then came home to live with Mum and Dad. He only moved out of home when Mum and Dad went to the nursing home a few years ago.

CM: Right. How is that different to you Jay?

Jay: Well I'm working … and I'm planning on moving out at the end of the year, when I save enough money.

CM: Yeah that's a pretty big difference isn't it? You've really continued to get on with your life despite some challenging symptoms from time to time.

Jay: Yeah, since I got that job my confidence is better. I feel like my life is just getting going again, you know? Don't think about the voices so much.

Jenny: I agree, he's been much happier in himself, and more motivated too.

CM: Well it's down to all the hard work that you've both been putting in to Jay's recovery! You know recovery is different for every person, so you can't really compare one person's recovery with the next. Everyone has their own individual path, but what's important is that we keep working together to help you achieve what you want out of life.

Jenny: Do you think he'll get married?

Jay: Mum!! I don't want to get married!

CM: Well in any case Jay, if you wanted to get married at some point in the future there is no reason why you couldn't! I guess my main message is that even if you need to manage this condition, there's no reason you can't get on with life and do all the things that you hope to do, like focusing on your career and having relationships. I think it would be good for us to keep this discussion on the agenda for the next few appointments … I'd just like to keep checking in with you both about any questions or concerns you have about this new diagnosis. Would that be okay?

Jenny: I think I would find that helpful. It's hard to know what to ask right now.

Jay: Umm, yeah … but I don't want to talk about it too much.

CM: Great, I'll check in, and you guys tell me when and what you want to talk about. How does that sound?

Topic 3. Psychoeducation about treatment

Introduction

The involvement of people in decision-making regarding their own medical treatment, including consideration of their preferences, is becoming increasingly recognised as best practice in all areas of health care.[23] It is a core principle of the EPPIC model that treatment is collaborative.

If young people are to navigate a shared-decision-making approach to their own treatment, they must be well informed about what treatment involves and what their options are. Psychoeducation therefore has crucial role to play in informing young people, by making knowledge about treatment accessible and relevant to the young person.

It is important to talk about the range of options for treatment and the rationale for each. With reference again to the stress–vulnerability model, explain that the approach to a young person's treatment is holistic. It may include psychological (talking) therapies, social programs and medication.

Psychoeducation about psychosocial interventions

Psychosocial interventions should be presented to the young person and family as part of a holistic approach that includes medication for the treatment of psychosis. It can be explained that psychosocial interventions are offered to all young people and families, and a collaborative process is needed to work out what interventions will best address the young person's goals and preferences.

It is important to convey that most psychosocial interventions, such as certain psychological therapies, family work, vocational interventions and educational interventions, have an established evidence base in working with people who have experienced an episode of psychosis. The aim is to have a holistic approach to treatment that addresses all the young person and family's needs. The stress–vulnerability model is a good way to explore how psychosocial interventions may assist in recovery from psychosis.

For more information about psychosocial interventions, please refer to the ENSP manuals *Psychological interventions: why, how and when to use in early psychosis* and *Keeping on track: functional recovery in early psychosis*.

LIANA

CASE SCENARIO (CONTINUED FROM PAGE 35)

CM: It seems like we have a good sense about how the unusual symptoms you've been experiencing have affected you, what with feeling worried about other people and also with how you are managing at school.

Liana: Yeah. It's like there is so much going on, and I don't know how to, um, turn it down … I mean the stress.

CM: That's a good way of putting it. Kind of like when you have a saucepan on the stove with the heat turned up high, and it starts to boil over, like all the stress is boiling over.

Liana: Yeah, and it spills all over the place.

CM: I wonder how we could stop the stress boiling over…

Liana: Hmmm. Turn the stove off [smiles].

CM: Good point! That would help. I wonder what things you are doing or could do to turn the heat down? Or like how when we talked about the stress bucket – how could we turn the tap on or put holes in the bucket to reduce the likelihood of the water spilling out over the top?

Psychoeducation about medical treatment

Treatment for a first episode of psychosis will involve the initiation of an ongoing medication regimen for the person being treated, using psychotropic medications that can cause substantial side effects. For young people, this can be a particularly difficult and even frightening process. It is unlikely they have had much experience of having to take medicine on a daily, ongoing basis, or of meeting regularly with a doctor. Furthermore, there can be significant stigma attached to antipsychotic medication.

This section covers how to deliver psychoeducation about a number of key areas related to medical treatment of early psychosis. Although medical practitioners have more knowledge about medication, non-medical clinicians should also be involved in delivering psychoeducation about medical treatments. To do this effectively, it is clearly necessary that they have an understanding of the medications that might be used to treat psychosis. It is especially important that the messages that young people and their family receive from the treating doctor and clinician are consistent. Information about what antipsychotic medications are, how they work and what side effects they might cause can be found in the ENSP manual *Medical interventions in early psychosis: a practical guide for early psychosis clinicians*. Medical practitioners may find it helpful to refer to the ENSP manual *Medical management in early psychosis: a guide for medical practitioners*.

PRACTICE TIP

Even if a young person has been in the service a while, don't assume what they already know: it's important to always cover the basics and reiterate these messages.

AIMS OF PSYCHOEDUCATION ABOUT MEDICAL TREATMENT

> Provide information about the effects and role of medication in the recovery process.

> Nurture a positive attitude to medication.

> Develop the young person and family's capacity to ask questions of appropriate staff and to negotiate about medication.

> Develop the young person's ability to monitor and report on side effects.

> Empower the young person and incorporate their perspective into their own treatment.

What does medical treatment involve?

The types of medical treatment the young person may need to receive, and why, should be discussed. This includes antipsychotic medication, antidepressants, mood stabilisers and sedatives. It is important to explain that all medications have a brand name and a generic name (e.g. Panadol and paracetamol), and that *all* medications have potential side effects. In addition, the need for baseline and ongoing physical health screening and investigations should be clearly explained to young people and their family.

A 'start low, go slow' approach is taken to medication dosage to reduce the chance of the young person's experiencing undue side effects (see the ENSP manual *Medical management in early psychosis: a guide for medical practitioners*); explaining this to the young person and family may help address any concerns about medication and side effects.

Some family members or young people will wish to know how medication works, and clinicians may find it useful to refer to the ENSP manual *Medical interventions in early psychosis: a practical guide for early psychosis clinicians* for biological explanations of how medication is thought to work. Box 3 presents the dopamine hypothesis of psychosis aetiology, which may be used to explain the current thinking about how antipsychotic medication works.

If a biological explanation is not the best one to use with a young person, the treating team may decide to simply explain the range of intended effects of medication using clear and simple language.

This may include a brief explanation that it isn't fully understood how antipsychotic medication works, but many studies have shown that they can improve symptoms and functioning for many people. In the context of the stress–vulnerability model of psychosis, taking medication can be an important part of reducing some of the (biological) vulnerabilities (or putting a few holes in the young person's stress 'bucket'), which is why it's an important part of treatment options.

BOX 3 **THE DOPAMINE HYPOTHESIS**

Explaining psychosis using the dopamine hypothesis may appeal to some young people or family members who want a biological explanation for their experience, and may help provide a rationale for taking medication.

How much detail is needed, or even whether this is useful, will depend on the young person and their explanatory model. The hypothesis can be explained simply in the following way:

- Dopamine is a chemical in the brain that has a role in motor (movement) control, motivation, arousal, cognition and reward.
- When anyone has a novel experience, dopamine can be released in the brain.
- Sometimes, for example as an effect of certain drugs, dopamine can be released out of context. This can lead to someone thinking that something mundane actually has some special relevance or important meaning (e.g. something that's on the TV, or the way someone looks at you).
- It is thought that in some people with positive psychotic symptoms there is an excess of dopamine activity in the brain, which leads them to interpret events in a way they wouldn't usually.
- Antipsychotic medication is thought to work by blocking dopamine activity, which helps people to stop interpreting events in unusual ways.

LEROY

CASE SCENARIO LEROY (CONTINUED FROM PAGE 30)

Leroy: How does this medication work anyway? I don't feel like it's actually changed anything. I mean, I'm the same as I was before…

CM: Okay, let's talk about it a bit more. Do you remember a while ago we were talking about some of the things that you experienced when things weren't quite right – can you remember what they were?

Leroy: Um, yeah, I was really confused, like my thoughts were all jumbled up a lot of the time … and I had that thing where I thought that the spirits were out to get me.

CM: Yeah that's right. We talked about that being part of your experience of psychosis, didn't we? Would you like to know how we think medication helps with that stuff?

Leroy: Yeah, okay.

CM: Well, we think that when those symptoms or experiences are happening, there is an imbalance in the chemicals in your body, in your brain specifically. They can get out of whack for all kinds of reasons – stress, drugs or a combination of lots of different things. You with me so far?

Leroy: Yep.

CM: Okay, so we think that medicine is one thing that can help bring those chemicals back into balance, along with all the other things that we're doing together.

Leroy: So medication got rid of the spirits?

CM: Well maybe it made you notice them less. But reducing stress in your life and stopping smoking dope definitely helped too. What do you think about that?

Leroy: Sounds alright.

How do we decide what medication to use?

A simple table of the common antipsychotic drugs, their side effects and potency can be used to discuss the pros and cons of each and help with shared decision-making. It is important to emphasise to the young person that the aim is to find a balance between the benefits of a medication and its potential side effects. While discussing medications, clinicians should take care to explain:

- that it is alright if the side effects of one medication aren't tolerable, and it is possible to change to a different medication if this is the case
- that sometimes people need to trial a couple of different medications to find the one that is effective and tolerable for them
- that the medication dose can change once the young person is well, and that the aim is to find the lowest dose that will maintain their wellbeing
- that it is difficult to say how long they may need to take medication (it is tempting for clinicians to say to someone who is acutely unwell that it will only be a few months; however, they need to be realistic about how long it may take the young person to recover)
- that there is conflicting evidence about what is the ideal time to remain on medication once their symptoms have gone away. It will therefore probably be the young person's choice to discontinue medication once they are well again (see 'Discontinuing medication', on page 44).

Medication adherence

Non-adherence to medication is a significant contributing factor to non-response to treatment and relapse. Many young people will not be fully adherent to medication within the first 6 months of taking treatment.[24]

Young people are more likely to adhere to a medication regimen if they perceive it to be beneficial. Psychoeducation about medication therefore should explain:

- the benefits of taking medication to reduce symptoms and also prevent them returning
- that the time it takes for medication to work can depend on a number of things, such as how long the young person was unwell before they first received treatment
- that if the young person has problems with side effects, it's possible to change the dosage or type of medication (rather than simply stopping taking it)
- that medications are designed to be taken in a particular way, for example daily or twice-daily, to have the desired effect. It's therefore important to take them as prescribed, or they probably won't work as well.

It is crucial that the young person is supported so that they feel able to discuss any worries they may have about medications or side effects to allay any concerns that may affect adherence.

Long-acting injectable (LAI) medication

Voluntary use of LAIs can help adherence and also may have a steadier effect. LAIs should therefore be offered early as an option alongside oral medications. Young people are usually commenced on oral medications so that their dose can be titrated slowly and medication switched rapidly if needed; however, once an effective medication and dose has been found, young people should be given psychoeducation about the use of LAI medications. Psychoeducation about this kind of medication might cover:

- plasma steady-state: LAIs mean the young person may be able to receive a lower and more effective dose
- the convenience of not needing to remember medication every day
- the convenience of not needing to take medication to a friend's house or if the young person goes away for a few days
- there is less risk of running out of medication unexpectedly
- there is less risk of forgetting doses.

Discontinuing medication

It is likely to be the young person who initiates the process of discontinuing medication, and a desire to come off medication should always be taken seriously by clinicians. The young person should be encouraged to talk about their concerns with medication or their reasons for wanting to stop taking it. Brushing them off may mean they simply stop taking their medication, feeling they have not been listened to.

Psychoeducation about discontinuation of medication should include an explanation of the conflicting evidence about what is the ideal time to remain on medication once someone has recovered from symptoms of psychosis. Guidelines recommend at least 1–2 years, and some studies cite high relapse rates following discontinuation; however, another, recent, study found improved functioning in the longer term if medication was discontinued.[25] Please see the ENSP manual *Medical management in early psychosis: a guide for medical practitioners* for a discussion of this subject.

Psychoeducation should also cover:

- when is the best time to discontinue medication (e.g. it's better not to discontinue medication just before important or potentially stressful events, such as school exams or starting a new job)
- the pros and cons of discontinuing medication, which can be discussed in the same way as when the young person is commencing medication
- the risk of relapse, but with an emphasis that it is up to the young person to decide about taking that risk
- developing a relapse management plan, including work on the young person's early warning signs for an episode of psychosis (see page 49)
- the possibility that the young person may need to start taking medication again if early warning signs emerge, but with emphasis that this is not a failure on the young person's part.

LEROY

CASE SCENARIO (CONTINUED FROM PAGE 43)

Leroy: So, how long do I have to take the tablets for?

CM: Well, to have the best recovery from symptoms, it's recommended that people keep taking medication for while after the symptoms all resolve, actually for about twelve months after this, which I know sounds like a long time. Some people choose to stay on the medication for longer than this, especially if it took them a long time to get well again.

Leroy: Oh … so it sounds like I should stay on it for a while longer?

CM: Well, that's what would be good to discuss. Because now that your symptoms have resolved, we can maybe start talking with the doctor about when might be a good time to think about reducing it.

Leroy: Yeah, okay. I don't like taking it, but I'm a bit scared to stop.

CM: Okay, so I think it would be good to make sure that when you feel more ready we can start talking about reducing the medication. We can see how things go and make sure you feel supported. And if we are all talking about it, and if we all keep an eye on how things are going, we can get in quickly if some of the early warning signs start to appear.

Leroy: Okay. Sounds like a plan.

Side effects

The side effects of antipsychotic medication can be substantial, and they are often a major reason for the young person's not adhering to medication.

Common side effects can include:

- sedation
- weight gain (increased appetite and decreased metabolism)
- other metabolic effects
- hormonal and sexual side effects
- menstrual cycle dysregulation
- movement disorders (extrapyramidal side effects)
- cognitive side effects
- anticholinergic effects.

For more information see the ENSP manual *Medical management in early psychosis: a guide for medical practitioners*.

Side effects should be discussed with the young person from the very beginning of treatment, as part of the shared decision-making process. It is important that this psychoeducation process empowers the young person to feel able to:

- monitor any side effects that they experience
- ask questions of clinicians about side effects
- raise side effects that they experience with clinicians
- negotiate about medication (e.g. to ask for their medication to be reviewed if they are unhappy with its side effects).

In addition to common side effects, young people and their families should be informed about potentially serious but rare side effects, such as dystonic reactions and neuroleptic malignant syndrome. Explaining this in a non-alarming and informative way is important so the young person and family can monitor and report any adverse events early.

Young people should be made aware of the possible interactions between their medication and other drugs they may be using. For example, it is particularly important to inform young people taking clozapine about the effect smoking tobacco has on this drug's potency.

Physical health

One of the more concerning side effects of antipsychotic medication is its effect on metabolism. Young people prescribed medication with particularly significant metabolic effects should be given clear information about the possible effects of these medications and strategies to manage them.

Monitoring physical health

One of the key functions of psychoeducation about physical health is to empower the young person and family to manage their own physical health and to take an active role in monitoring the effects of medication on their physical health. It is the responsibility of the treating team to ensure the young person is monitored correctly; however, the young person and family should be made aware of what should be happening and need to be empowered to follow up or remind clinical staff if they think they are not being monitored properly.

More information about metabolic monitoring requirements can be found in the ENSP manual *Medical management in early psychosis: a guide for medical practitioners*.

Diet and exercise interventions

The importance of a healthy diet and exercise for young people experiencing an episode of psychosis cannot be overemphasised. It is not enough to only explain the need for this: young people should be provided with strategies for how eat well and exercise.

Encourage the young person to think about how keeping the body healthy also helps keep the mind healthy.

Regarding diet, psychoeducation should discuss simple strategies such as drinking water instead of soft drinks and snacking on healthy food such as fruit. It is also useful to make the young person aware of how some antipsychotic medications can affect appetite, for example by increasing food cravings.[26]

It is often hard for young people to maintain a balanced diet, especially if they are experiencing financial strain. However, actively assisting young people to think about what they eat, and considering 'harm minimisation' strategies, can help young people change their diet. For example, ask the young person about reducing the amount of caffeinated drinks they may consume in a day, or review what they might eat usually in one day and ask them to think about other options that fit the same price range.

Some young people may benefit from being referred to a dietitian or exercise physiologist, but even the use of generic tools such as mobile phone apps to encourage exercise can be effective in motivating people.

Further information about interventions to improve diet and exercise and help manage weight gain can be found in the ENSP manuals *Keeping on track: functional recovery in early psychosis* and *Medical management in early psychosis: a guide for medical practitioners*. Resources 6 and 7 provide some strategies for healthy eating and promoting exercise.

> 'What's the point of me, you know, being well and then putting on 20 kilos and then getting really depressed over my own size?'
>
> Young person
> EPPIC, Orygen Youth Health Clinical Program

Sexual dysfunction and sexual side effects

Sexual dysfunction is common among people with established psychotic disorder, and has been shown to be prevalent in people identified as UHR for psychosis.[27] It can be present as part of the disorder and can also be caused or exacerbated by antipsychotic medication. Additionally, it may be related to psychological issues or stigma stemming from the young person's diagnosis, such as low self-esteem, reduced self-confidence or relationship problems.[28]

Sexual dysfunction can have a significant impact on young people's lives, but it is often under-reported, and can be a difficult subject to broach for both the young person and clinicians. Considering both its significant impact and the reluctance of young people to bring it up, it is crucial that clinicians are not embarrassed to ask specifically about any sexual problems the young person might be experiencing. It is also hugely beneficial to explain that these kind of problems are common and can be addressed. For many young people it is a relief to find out that what they are experiencing is common and to be given the opportunity to discuss it.

> 'Often clinicians are more embarrassed than young people to talk about sexual side effects. We're comfortable with asking someone if they've tried to kill themselves, but not if they're having any sexual problems.'
>
> Senior clinician
> EPPIC, Orygen Youth Health Clinical Program

JAY

CASE SCENARIO (CONTINUED FROM PAGE 39)

Jay has switched medications and is starting to respond to the new treatment. In his next appointment, his case manager checks in to see if he is having any side effects as a result of the switch.

CM: Hi Jay. So it sounds like the new medication is really helping with some things, which is really good to hear. I'm really pleased that you feel the voices aren't bothering you as much. But I know for lots of people there can be side effects, things like nausea, headaches, and even people feel like they have trouble ejaculating or even getting an erection. They can be really unpleasant, but not permanent. So I just want to make sure that you aren't getting these, or if you are, see what we can do about them.

Jay: Yeah, I feel sleepy, but it's not too bad, and is starting to wear off. But … yeah, I can't seem to get an erection since I started the medication. It hasn't bothered me too much, cos I haven't really felt like horny … but yeah, I kind of want to have sex.

CM: Of course you do. Unfortunately a common side effect of the meds can be that people find they can't get an erection. But it's definitely not permanent, and as soon as people come off medication, things go back to normal. It's important to know that stress is also something that can really impact on how much people feel like sex too. So it's really important to not be too hard on yourself.

Jay: Okay. Good. I was a bit worried I was never going to have sex again.

CM: You definitely will! It's important that we talk with your doctor about it too, and keep an eye on how much it continues to worry you. If it turns out the negatives are outweighing the positives with how this medication is affecting your life at the moment, if you are feeling worse off with these side effects, then we need to perhaps think about another medication that might suit you better.

Jay: Cool. I think I just want to stay with it. I'm just glad it's not permanent. And yeah, I want to chat with the doctor about it too.

PRACTICE TIP

Consider keeping a checklist with the young person of psychoeducation topics that you have discussed. This can be a reference for both you and the young person and help you see whether any areas, such as sexual side effects, are being neglected.

Sexual health

Psychoeducation about sexual health is important, as young people often experiment with sexual relationships in adolescence and early adulthood. Information about safe sex, preventing STIs and the need for regular testing as should be included as part of broader education about physical health and side effects.

Psychoeducation about involuntary treatment

Involuntary treatment can be traumatic for the young person and their family, particularly if it involves other services such as the police. It risks the young person's disengaging from the service after the order period has finished, and may negatively impact on the young person's relationship with their family and members of their treating team.[29]

At the same time, some young people may afterwards reflect positively on their involuntary treatment, feeling that it was necessary and beneficial to their mental health,[29] and it can be used as an opportunity to engage young people in community follow-up.

Involuntary treatment therefore needs to be managed to minimise risks and ensure the most benefit is gained from the experience for the young person. To aid this, a chance for reflection and psychoeducation about involuntary treatment should always be offered to young people who have experienced involuntary treatment.

At the time of admission, it is important that clinicians explain to the young person why they are being treated involuntarily. There are usually two reasons that involuntary treatment may be ordered: where there is a need to provide a safe environment for the young person or others (risk to self or others) or if treatment is needed that cannot be provided safely or effectively in the young person's own environment.

Information needs to be provided simply and clearly and should include:

- the reason for involuntary treatment. For example, it is done after much consideration, usually because the young person or someone else needs to be safe or the young person is acutely unwell and needs medication to help with recovery
- under what authority the young person is being treated (mental health legislation)
- what their legal rights are (see Box 4)
- an explanation of the role of the Mental Health Tribunal, including:
  - it is an independent tribunal
  - one of its purposes is to determine whether criteria for involuntary treatment apply to an individual
  - it provides legal support
- the aim of involuntary treatment: to improve the young person's mental health and to engage them in their recovery process
- an explanation that the overriding principle of involuntary treatment is to have the shortest period in the least restrictive environment.

It is just as crucial that psychoeducation is provided about the experience *after* the involuntary treatment period has ended. As mentioned, involuntary treatment may have a negative effect on the young person's family relationships. It may also impact on their relationship with their case manager and treating doctor. Talking about the experience with the young person and again explaining why they had to be involuntarily treated may reduce the risk of trauma caused by the treatment and the risk of disengagement from treatment.

Furthermore, psychoeducation is needed to address any stigma the young person may have attached to themselves because of the need for involuntary treatment. For example, O'Donoghue et al. (2010) found that one third of people treated involuntarily feared that it would negatively affect their employment prospects.[29]

BOX 4 **COMMUNICATING LEGAL RIGHTS REGARDING INVOLUNTARY TREATMENT**

- Relevant state or territory legislation will guide the minimum standard of information that is given to a young person who is receiving involuntary treatment. However, it is good practice to provide as much information as possible to the young person and their family. This includes the reasons the treating team has decided to commence involuntary treatment, specifically in relation to the young person's individual circumstances.
- Information needs to be conveyed using the principles of psychoeducation.
- Care should be taken to avoid involuntary treatment being perceived as a punitive measure. This can be aided by clearly explaining the young person's rights and communicating the treating team's intention to continue working collaboratively with the young person and their supports. Even when young people are being treated involuntarily and are reluctant to engage, they should continue to be encouraged to collaborate about their treatment plan.
- The treating team needs to actively support the young person to engage in any legal hearings in relation to involuntary status and actively support the young person to engage in the process of appeals or hearings, including support to gain legal representation.
- Legal status should be continually discussed with the young person, with the clear aim of moving towards voluntary engagement with the service.

Topic 4. Wellbeing planning and relapse prevention

Introduction

A young person and their family should begin receiving information about relapse prevention and wellbeing planning as early as possible in treatment, in keeping with the overarching message of realistic optimism for recovery. How much psychoeducation needs to focus on this topic at different stages of treatment should be gauged by clinicians, but often young people and families will find talking about the young person's future 'after' an episode of psychosis reassuring. Psychoeducation about relapse should be given optimistically; however, given the high relapse rates among people with FEP, it is important to avoid giving an unrealistic impression that relapse will not occur.[5]

> 'It's a fine balance getting the pitch right with young people and families about realistic optimism for the future. You don't want people to feel so anxious about a possible relapse that they are too scared to live their life … but you want to be honest and to prepare them for the possibility of an ongoing condition.'
>
> Senior clinician
> EPPIC, Orygen Youth Health Clinical Program

Relapse prevention

Relapse prevention requires a team-based approach and must be supported by the family and young person. Psychoeducation about staying well, relapse, what can cause it, what can prevent it, and how to minimise the impact if a relapse does occur, can help ensure young people and families feel engaged and empowered about reducing the likelihood of relapse. Typically, psychoeducation about relapse should begin in the early recovery phase, when the young person's mental state has stabilised and they have developed trust and rapport with the treating team. Discussions about relapse may, however, be had earlier with family members, depending on their needs.

Using the stress–vulnerability model to explain how relapse may occur and how it may be prevented is an effective technique. It is essential that the family is involved, as they can play a significant role in recognising early warning signs of a possible relapse of symptoms of psychosis.

There are a number of factors that affect the likelihood of relapse, such as substance use, adherence to medication and stress. Each person will have individual factors that may contribute to the risk of relapse, and psychoeducation using the stress–vulnerability model and shared formulation to address these in the context of relapse prevention is important.

Early warning signs

Commonly there is a period of 1 to 4 weeks preceding a relapse of symptoms of psychosis when the young person may experience a number of 'early warning signs' that they may be about to experience a relapse.[30] If these signs are recognised in time, the young person or clinicians may be able to intervene to reduce further deterioration in the young person's mental state or, if a relapse does occur, reduce its impact on their functioning (vocational, educational and social).

It is important to start discussions about early warning signs in the early recovery phase. General early warning signs include depression, anxiety and low-level psychotic symptoms. However, each young person will have their own particular early warning signs that signal they are at risk of becoming unwell again. A timeline can help connect the young person's first episode of psychosis to any events or feelings that might have indicated that they were unwell (see Figure 6). These may then be identified as possible early warning signs of a relapse.

LEROY

CASE SCENARIO (CONTINUED FROM PAGE 45)

Leroy has started back at his TAFE course, but with his first round of assessment coming up, he confides to his case manager that he is worried that he will not cope well with the pressure.

CM: Hi Leroy, you look a bit tired today. How's everything going?

Leroy: Yeah – I haven't been sleeping so well. I'm really worried about it, and also with all the stress from TAFE … I'm worried about getting unwell again.

CM: Okay. It sounds like it would be good to talk about some ways to decrease the stress.

Leroy: Yeah.

CM: You know how we have talked about the stress bucket, and how it can get full and overflow? It's also important to remember that there are ways to decrease the stress as well and bring that level down. Is it okay for me to draw it again?

Leroy: Yep.

CM: We all need to have things in our lives that help us to manage the stress in the bucket. Like, things that can decrease the stress. These are things that put some holes in the bucket, so the stress is released before the bucket overflows.

Leroy: Or like a tap..? Like you can use different things that help to turn the tap on so that you release some of the water …

CM: Yeah, just like that … I like that image! So if you're worried about getting unwell again because of stress from TAFE, what kind of holes could we put in, or what could help turn the tap on?

Leroy: I think things like, making sure I am hanging out with people – my friends.

CM: That's a good one. It also sounds like sleep is important so that you feel well rested and able to function as well as you can.

Leroy: Yeah. Sure.

CM: What about if you try to avoid things or situations you know are stressful for you.

Leroy: Yeah. Like, I can't stand when there are lots of people in the room, or too much noise.

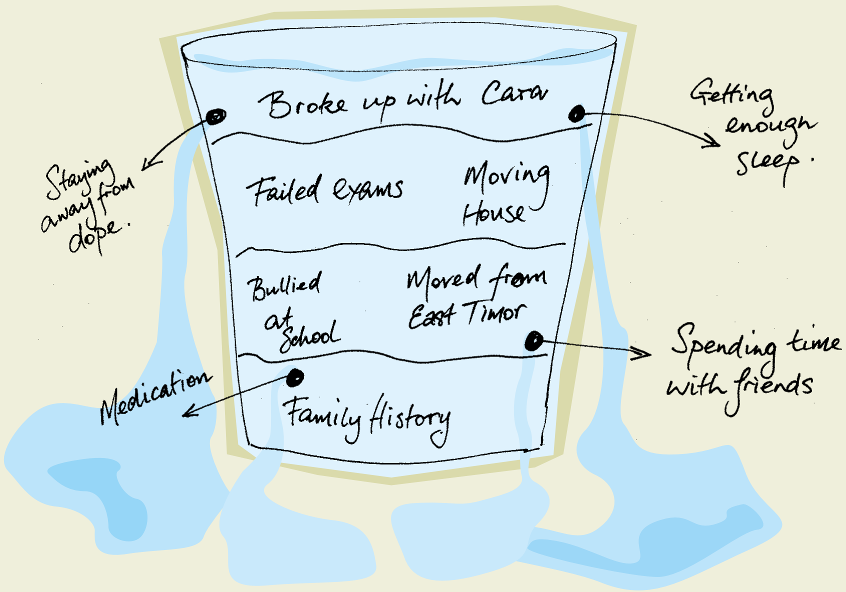
CM: So maybe finding a quiet place helps turn the tap on?

Leroy: [Nods]. I also think probably staying away from smoking dope has helped.

CM: Yeah. I think so. I wondered also if medication could be helpful?

Leroy: Yeah. It's been good to help me with clearing up my thoughts and get rid of the spirits.

CM: And you know, maybe you could even talk to your teachers at TAFE and see what your options are if you *do* feel like the assessment's too stressful.



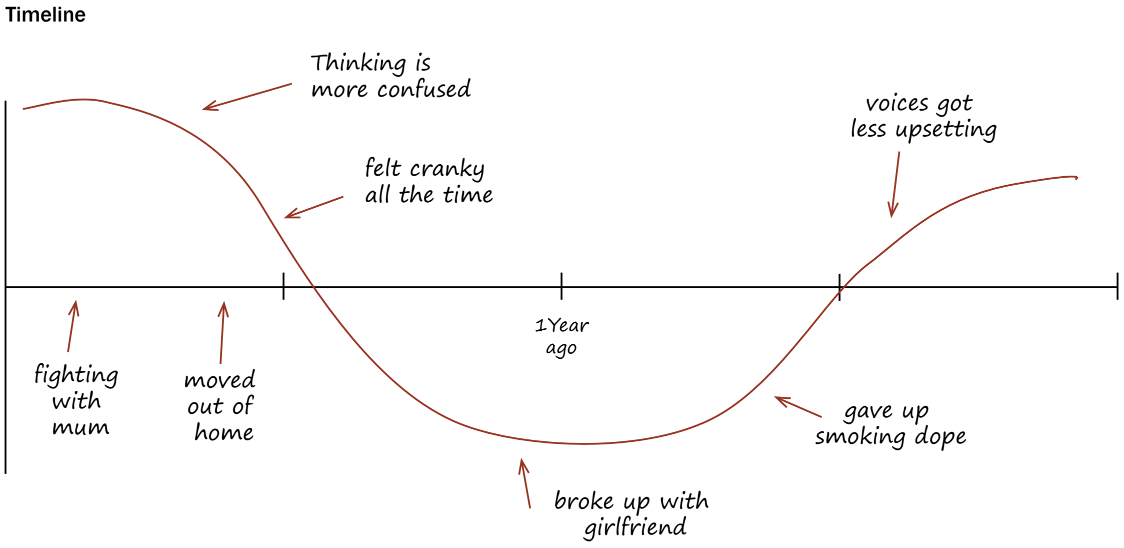
Talking to the young person's family about early warning signs is particularly important, as they are often the first people to notice when the young person is starting to decline.

Initially, it is often difficult for young people to identify their own individual early warning signs. A helpful way do this is to discuss common warning signs that other young people experience. Using a checklist, such as that shown in Resource 3, can help prompt the young person to remember their own experiences from when they previously became unwell. This checklist may describe generic experiences that can be elaborated upon with the young person to define their specific experiences, using a template such as Resource 4. It can be helpful to do this exercise with a family member or a close friend or partner (someone the young person feels they can trust). Explore how these signs relate to several domains, including:

- changes in thinking
- changes in emotions
- changes in behaviour.

Often young people or family members become anxious that any change of this kind in the young person is a sign of relapse. It is therefore important to explain that fluctuations in mood, thoughts or feelings are normal and that these are not necessarily early warning signs. Although the young person and family should be alert to early warning signs, they should try not to become hyper-vigilant or fearful of relapse.

FIGURE 6. **USING TIMELINES**



Timelines can be a useful tool to work out what someone's possible early warning signs or triggers for a relapse are. A timeline allows clinicians and the young person to look back and link specific events or feelings, such as seasons, exam stress or birthdays, to the first episode of psychosis. Some helpful prompts are: What were you doing around x time? Were there any special occasions happening (birthdays, exams, family events)? What was the weather like?

JAY

CASE SCENARIO (CONTINUED FROM PAGE 47)

Jay continues to improve, and he and his case manager begin to explore what his early warning signs might be for another relapse.

CM: Jay, I know when we first met, back when you first got really sick, there were problems you experienced before the voices got really bad. I wonder if it's something we need to monitor, just in case you do begin to get unwell again, so we know it might be happening and can get in more quickly?

Jay: Yeah. I know I get tetchier, you know, like agitated. It's more something that my mates notice. And yeah, my sister. She reckons I'm cranky.

CM: So it sounds like feeling particularly cranky is an early warning sign for you.

Jay: Yeah, but it's like I don't notice that it's maybe the start of things getting a bit worse. I just feel like itchy on the inside, like everything gets under my skin. It's not til people are a bit more like, 'Jay, what's your problem? Why are you so cranky?' That's what I notice: other people start telling me I'm being irritable.

CM: Okay. So you mentioned about how it feels itchy. I wonder if we could think more about that feeling. Because that might be a good indicator for you to you notice earlier, rather than other people telling you your being cranky. If we can tease it out … what do you think?

Jay: Okay.

Developing a wellbeing plan

A wellbeing plan aims to help the young person, family and treating team understand what the young person's individual risk factors for relapse are, what their protective factors are, identify early warning signs that might signal they are deteriorating in mental state and decide what actions they can take to respond to them. As the title of the plan indicates, the focus should be on the young person's wellbeing, rather than on preventing a relapse as such.

Developing this plan should be a collaborative process between the clinician, the young person and their family. It should be done in a realistic but non-alarming way – the aim should be to 'hope for the best, plan for the worst'.

A wellbeing plan may cover subjects such as:

- sleep hygiene (see Resource 8)
- managing stress
- reducing substance use
- keeping healthy.

Please see Resource 5 for a template wellbeing plan.

The most important aspect of a wellbeing plan is to begin reconnecting the young person with their sense of identity, their life, interests and future outside of world of psychosis and treatment. The disruption that an episode of psychosis causes to the young person's developmental trajectory can cause real distress and a sense of loss about who they are, how they define themselves and their future.

Developing a wellbeing plan is in itself a form of psychoeducation. For the plan to be meaningful to the young person, it should focus on the young person identifying their likes, hopes and also their strengths. By working on what they see as their main goals to work towards to have the life they want, a wellbeing plan helps the young person reconnect with the meaning in their lives, their friends, family and work and study goals.

Resources

Symptoms of psychosis

SYMPTOM	WHAT THIS MEANS	EXAMPLE
Hallucinations	Hearing, seeing, feeling, or smelling something that is not there	Hearing voices that no one else can hear, or seeing things that aren't there
Delusions (false beliefs) or ideas of reference	Having a strong belief that is firmly held despite contrary evidence, or believing that the world or objects are referring to you in some way	Being convinced from the way cars are parked outside your house that you are being watched by the police Believing that a television show is about your life
Confused thinking	Difficulty with thinking clearly and expressing oneself clearly Problems with concentration, memory, or reasoning	Your speech seems jumbled or doesn't make sense to others Your thoughts seem to speed up or slow down You have trouble concentrating on things like homework or have trouble remembering things
Changed feelings	When your emotions change for no apparent reason	Feeling strange and cut off from the world Having mood swings (feeling unusually excited or depressed) Feeling like your emotions are dampened, or not showing much emotion
Changed behaviour	Behaving differently from how you normally behave	Becoming extremely active or lethargic Laughing inappropriately Becoming angry or upset for no obvious reason
Negative symptoms	Lack of energy, motivation, pleasure, or emotional expressiveness	Things you used to enjoy don't bring the same pleasure Difficulty feeling motivated or following through with things People say that they can't read your facial expressions
Depression	Extreme feelings of sadness that might affect your appetite, sleep, or energy levels	Loss of interest in activities you used to enjoy Feeling sad a lot Sleeping too much Feeling tired and having low energy Not eating enough, or eating too much
Anxiety	Feeling nervous, scared or worried	Avoiding a situation or experience because of fear Constant worry or concern Difficulty concentrating Physical symptoms, such as heart palpitations, perspiration, trembling or shortness of breath

Positive and negative symptoms

Positive symptoms are when there is too much of certain types of thinking or behaviour. They are often described as things that are ‘added’ to someone’s personality or usual characteristics, such as confused thinking or paranoia. For example:

‘The police have bugged my house and are following me.’

‘I can hear voices of people talking to me, but no-one’s there.’

Negative symptoms are when there is not enough of certain aspects of a person’s usual functioning. They can be described as parts of someone’s personality being ‘taken away’ from them, and can include withdrawal, lethargy, low interest, poor motivation, low energy, increased need for rest and sleep, lack of emotional expressiveness, slowness in thinking and speech. For example:

‘I feel flat and I don’t know what I feel sometimes.’

‘I can’t think of things to say; my mind just goes blank.’

‘I find it hard to get motivated to do the usual day-to-day things.’

‘I feel low in energy a lot of the time.’

‘I’ve lost a fair bit of interest in seeing my friends lately.’

Negative symptoms can be a feature of a range of psychological disorders, such as psychosis and depression. It is harder to notice if someone is experiencing negative symptoms, as to the people around them, it may just look like someone is not taking care of themselves or is just lazy.

Positive symptoms are most marked during the acute phase of an episode of psychosis. Negative symptoms can be present during the at-risk (early), acute, and recovery phases.

Most people affected by psychosis will experience both positive and negative symptoms to some extent.

Adapted from *Family work for relapse prevention in early psychosis: a cognitive-behavioural approach* (Orygen Youth Health, 2012).

Common early warning signs

☐ Preoccupied with things
☐ Feeling depressed or low
☐ Difficulty concentrating
☐ Others have difficulty following what I am saying
☐ Feeling as if my thoughts might not be my own
☐ Feeling as if I am being watched
☐ Feeling useless or helpless
☐ Feeling confused or puzzled
☐ Feeling stubborn
☐ Feeling very excited
☐ Feeling forgetful or ‘far away’
☐ Being open and explicit about sexual matters
☐ My speech comes out jumbled and full of odd words
☐ Sleep has been restless or unsettled
☐ Behaving oddly for no reason
☐ Feeling unable to cope
☐ Not feeling like eating
☐ Feeling like playing tricks or pranks
☐ Feeling quiet and withdrawn
☐ Talking or smiling to myself
☐ Not bothered about appearance or hygiene
☐ Feeling violent
☐ Thinking I could be someone else
☐ Feeling dissatisfied with myself
☐ Having aches and pains
☐ Losing my temper easily
☐ Having no interest in things
☐ Feeling as if I am being laughed at or talked about
☐ Feeling tired or lacking energy
☐ Movements seem slow
☐ Feeling as if my thoughts might be controlled
☐ Feeling aggressive or pushy
☐ Feeling irritable or quick tempered
☐ Feeling tense, afraid or anxious
☐ Feeling very energetic or needing little sleep
☐ Feeling very talkative or outgoing
☐ Feeling very confident or extremely happy
☐ Having the urge to spend a lot of money
☐ Feeling over-assertive or having no regard for authority
☐ New ideas are constantly coming into my mind
☐ Feeling that I am not safe
☐ Not wanting to be alone
☐ Taking on more than I can handle
☐ Feeling restless
☐ Not wanting to get out of bed
☐ Feeling that I want to hurt myself
☐ Thinking that the radio or TV are referring specifically to me
☐ Thinking that food or drink has been tampered with
☐ Having difficulty focusing or concentrating
☐ Thinking that I can communicate with spirits or people who have passed away
☐ Having difficulty getting to work, school or leisure activities
☐ Thinking people can read my thoughts
☐ Having difficulty managing everyday tasks
☐ Hearing people talking when nobody is there

Early warning signs

Think about your first experience of psychosis…

What was the **first** change you noticed? Were there changes in:

- Mood and emotions
- Thoughts and ideas
- How you felt in your body (physical sensations, energy, sleep)
- Your behaviour
- How you were functioning at school, work, socially, health and hygiene

What was happening for you at that time?

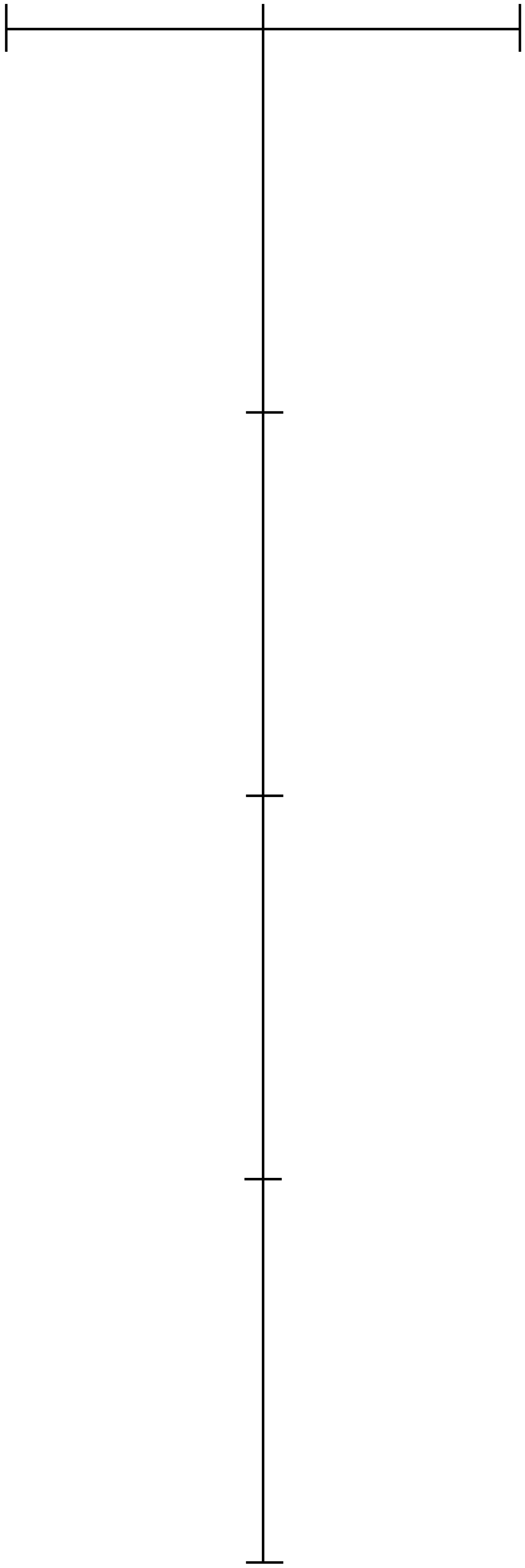
- What were you doing and where? (e.g. on holidays, doing exams, at home)
- Were there any events or special occasions happening? (e.g. birthday, Christmas)
- What was going on in the world? (e.g. there was a natural disaster on news, it was the AFL finals, the election)
- What season was it/what was the weather like?
- Were there any changes in your relationships?

What was the **last** change you noticed?

What was happening for you at the time?

What are any other changes you noticed?
What was happening for you at these times?
Put them in order on the timeline.

Timeline



My wellbeing plan

Name: Date:

Things I can do regularly that help me manage stress and look after myself:

Situations that may act as 'stress triggers' for me are:

Things I can do that help me to cope with 'stress triggers' are:

Early warning signs that I should take notice of are:

Thoughts

Feelings and physical sensations

Behaviour

Steps I can take if I notice these signs:

What I would like my friends and/or family to say or do if they notice these signs:

People who can support me:

Family

Friends

Case manager Phone

Psychiatrist Phone

GP Phone

The importance of healthy eating

Eating healthily helps

Staying healthy is important for everyone, but it can be hard if someone has a mental health problem. Older children and adolescents need to make sure they eat enough nutritious foods to grow and develop normally. Australian dietary guidelines recommend a wide variety of nutritious foods and drinking plenty of water.

Depending on body size and activity level, teenagers 12–18 years old should eat on average each day: 5–11 servings of cereals (bread, rice, pasta, noodles), 4 servings of vegetables, 3 servings of fruit, 3 servings of milk, yogurt or cheese and 1 serving of lean meat, fish, poultry, nuts or legumes. They should have no more than 1–3 extra foods (cake, biscuits, chocolate, soft drink, ice-cream, jam, honey, pizza, potato chips).

A serving size is, for example:

- 2 slices of bread
- 1 cup cooked rice or pasta
- 1 cup breakfast cereal
- 1 medium potato
- ½ cup broccoli
- 1 medium-sized apple
- 20 grapes
- 4 dried apricots
- ½ cup fruit juice
- 2 slices of cheese
- 200 g (small carton) of yogurt
- 1 cup of almonds
- a piece of chicken or meat the size of the palm of your hand
- 2 small eggs
- 1/3 cup of lentils
- 1 medium piece of cake
- 3–4 sweet biscuits
- half a chocolate bar
- 1 tablespoon jam or honey
- 30 g potato chips
- 1 slice of pizza
- 1 can of soft drink.

Food safety is also important. You can keep your food safe from bacteria by washing your hands well before preparing food, making sure kitchen equipment is clean and returning food to the refrigerator as soon as you have finished rather than leaving it out on the bench.

> While healthy eating can be tricky, it is worth it. It reduces the risk of other physical health problems and can help with improving energy levels, getting a good night's sleep and feeling good about yourself. Your brain will work better if you feed it right.

Tips for healthy eating

> Breakfast is important; if you are rushed, or don't feel like something substantial, try having a glass of milk or a piece of fruit.

> Keep your snacks healthy and plan what and when you eat.

> If you can't avoid fast food, try to make healthy choices, such as felafel wraps, rice paper rolls, stir fried vegies and salad sandwiches. Have salad instead of chips, avoid extras like garlic bread or soft drink and say no to upsizing.

> Eat slowly and wait 10 minutes before having a second helping to be sure you are still hungry.

> Eat home-cooked meals. You can make your own healthy pizza using pita bread as a base and topping it with veggies and lean meat – and go easy on the cheese!

> Be aware of what you are drinking. Soft drinks can add a lot of sugar to your diet. Always have a water bottle with you (try adding lemon or lime if you want a bit of flavour) that you can refill, and reduce sugar in your tea and coffee.

> Alcohol and some drugs can stimulate your appetite and lead you to eat more than you need to. Alcohol also contains lots of kilojoules, which can lead to weight gain.

> Try not to shop at the supermarket when you are hungry; take a list with you to avoid impulse purchases.

> Read the labels on food and check the number of servings, kilojoules, fats and sugar. Be aware that some low-fat foods have high levels of sugar in them.

The importance of being active

Why exercise?

Being physically active is important for staying healthy, not only physically but mentally too. It can be difficult to stay active at the best of times, but when you're not well, it's even harder. Symptoms of some mental illnesses include lower energy, problems with motivation, loss of enjoyment in activities, and problems with sleep. Some people can feel like their medication affects their energy levels too.

It can be difficult to find the energy or motivation to do things, but it's usually the case that the less you do, the worse you feel. Even though it's difficult, physical activity (even in small doses) can have a big impact on how you think and feel.

Being physically active can…

- …give your mood a boost
- …increase your energy levels
- …help with getting a good night's sleep
- …provide a distraction from your thoughts and worries
- …help increase your concentration
- …help with getting out and socialising when done with others
- …help with maintaining your physical health
- …help you feel and look great (increases your self-esteem)
- …give you a sense of achievement, especially if you would like to increase your fitness or just feel better
- …change levels of chemicals in your brain (e.g. serotonin, endorphins and stress hormones), making you feel better
- …help reduce your stress levels and help you feel less irritable or frustrated.

Tips for getting active

Everyday things…

> Take the stairs instead.

> Ride or walk instead of taking public transport or driving.

> Park at the far end of the supermarket

> Time your daily walks to and from the train station – can you go faster?

> Put on some music for a 10-minute dance!

Enjoy what you do

Think about the sort of physical activity you might enjoy or used to (e.g. running, playing sport, walking, swimming). Doing things that are enjoyable may increase your chances of actually doing them, and they will give your mood a boost. Steer away from things you don't like (e.g. don't go to the gym if you've never liked going).

Don't fly solo

Involve someone else like a friend or family member. This can make being active more enjoyable and is an easy excuse to socialise. If lack of motivation gets in the way sometimes, involving someone else can help you stick at it. Doing exercise classes or team sports can provide social environments for your physical activity.

Start small

Some is always better than none. If you aren't used to very much physical activity, start with small, low intensity activities. While it might be difficult at first, it's important to stick with it – you'll be amazed at how much easier it gets and how good you feel. It might be helpful to aim to do something for a set amount of time rather than aiming for an amount of something (e.g. try walking for 30 minutes rather than trying to run a total of 5 km).

Set achievable goals

If you are beginning to get back into being active or thinking of doing so, setting goals can be a good starting point. This gives you something to work towards and can help motivate you. Try to make your goals achievable (aiming to run a marathon in your first week might not be a good idea!). A sense of achievement from reaching your physical activity goals can make you feel good and help motivate you.

Make a plan

Plan what you would like to do and when you can do it. Plan your physical activity around the things you need to do during the day (school, work etc.). It can be good to involve a friend or family member, as they can help motivate you (it's always better doing things with someone else!). Try writing your plan down: this may help you stick with it.

Building up

Start small but always try to build up the amount of activity you do. Try increasing the amount of time you exercise during the day (aim for 30–60 mins) or the number of days in the week you exercise.

The importance of good sleep

Sleep helps

Good sleep helps us to feel fresh, focused and good during the day. We all know what it's like after a bad night's sleep. As well as feeling lousy, lack of sleep can affect your physical and mental health, learning, memory and concentration, your activity levels, emotions and relationships.

Are you always tired, or more so than usual? Napping all the time, or feeling like you need to? Feeling annoyed and irritable more than usual? Feeling less energetic? Having trouble concentrating or remembering things?

You might not be getting enough good sleep. So what **helps** and what **prevents** good sleep?

Things that can prevent good sleep

Caffeine

Try to stay off caffeine (coffee, cola, strong tea) in the afternoon or evening. It's a stimulant and hangs around in your system for a while and can make it difficult to get to sleep.

Exercise or strenuous activity right before bed

Exercise increases your attention and arousal and if done too close to bedtime, makes it difficult to fall asleep. Exercise is excellent and good for your physical and mental health but do it earlier in the day.

Nicotine and alcohol

Tobacco is a stimulant and may make it difficult to sleep. Alcohol is a depressant and makes you drowsy but won't help you sleep. The sleep you do get will be disrupted and you will likely wake feeling lousy.

Napping during the day

This can mess up your body clock and make it harder to sleep at night. If you do nap, only do it if you're tired, and keep it short.

Weekend sleep-ins

This sounds outrageous – but sleeping in to catch up on sleep can throw your body clock out and the effects may last for days, making it harder to return to your normal sleep cycle when the school or work week resumes.

Thinking and worrying about falling sleep

This will actually make it harder to sleep. If you find you haven't fallen asleep after being in bed for 20 minutes or so, don't stress about it, get up and try something relaxing like reading or progressive muscle relaxation. Get back into bed only when you feel more relaxed. Don't worry if you have to repeat this a couple of times. This can also help if you find yourself waking during the night and have difficulty getting back to sleep.

Too much stress

There are some things you can do to help clear your mind before trying to sleep – write things down, talk things over with someone you trust, do something you find relaxing or ask your clinician about progressive muscle relaxation, or even problem-solving skills.

Things that can help with getting good sleep

A warm bath or shower before bed

This can help you relax and feel sleepy, but allow some time between your bath/shower and bed, as it's harder to fall asleep when your body temperature is high.

Physical activity during the day:

Being active (e.g. exercising) during the day can help you feel good and sets you up for a good night's sleep.

A warm drink like milk or chamomile tea

Milk contains amino acids and these can make you drowsy. The tea will help you relax and feel ready to sleep.

Associating your bed with sleep

Only use your bed for sleeping: try not to do other activities like reading, homework or watching TV in bed. Train yourself to associate your bed only with sleep.

Having consistent 'sleep' and 'wake' times

Try to keep the time you go to bed and the time you get up each morning consistent throughout the week. Avoid sleeping in on days when you don't feel like getting out of bed. Getting up at a good time (even when you still feel tired) will make it easier to fall asleep at night. This also helps get your body clock into rhythm, so sleep will feel more natural.

A room that is quiet, dark and cool

Make sure your room is quite, dark and cool. This gives you the best chance of falling asleep and might stop you waking during the night.

Trying some relaxing activities to wind down before bed

Try reading a book, listening to some relaxing music or ask someone for a massage. Ask your clinician about some relaxation techniques that can be practised before bed – like progressive muscle relaxation.

References

1. Swadi H, Bobier C, Price L et al. Lessons from an audit of psychoeducation at an older adolescent inpatient unit. *Australasian Psychiatry* 2010; 18: 53-56.
2. Murray-Swank AB and Dixon L. Family psychoeducation as an evidence-based practice. *CNS Spectr* 2004; 9: 905-12.
3. Calvo A, Moreno M, Ruiz-Sancho A et al. Intervention for adolescents with early-onset psychosis and their families: a randomized controlled trial. *J Am Acad Child Adolesc Psychiatry* 2014; 53: 688-96.
4. Xia J, Merinder LB and Belgamwar MR. Psychoeducation for schizophrenia. *Cochrane Database of Systematic Reviews* 2011; 6: DOI: 10.1002/14651858.CD002831.pub2.
5. Early Psychosis Guidelines Writing Group. *Australian Clinical Guidelines for Early Psychosis, 2nd edition*. Orygen Youth Health, Melbourne. 2010;
6. Welsh P and Tiffin PA. Assessing adolescent preference in the treatment of first-episode psychosis and psychosis risk. *Early Interv Psychiatry* 2014; 8: 281-5.
7. Timms P, Ramsay R and Byfield R. Using written information in clinical work with patients and carers. *Advances in Psychiatric Treatment* 2008; 14: 441-451.
8. Mistler LA and Drake RE. Shared decision making in antipsychotic management. *J Psychiatr Pract* 2008; 14: 333-44.
9. Hamann J, Mischo C, Langer B et al. Physicians' and patients' involvement in relapse prevention with antipsychotics in schizophrenia. *Psychiatr Serv* 2005; 56: 1448-50.
10. Getachew H, Dimic S and Priebe S. Is psychoeducation routinely provided in the UK? Survey of community mental health teams. *Psychiatric Bulletin* 2009; 33: 102-103.
11. Burlingame GM, Ridge N, Matsuno J et al. Educational needs of inpatients with severe and persistent mental illness: a partial replication. *J Psychosoc Nurs Ment Health* Serv 2006; 44: 38-43.
12. Kilkku N, Munnukka T and Lehtinen K. From information to knowledge: the meaning of information-giving to patients who had experienced first-episode psychosis. *J Psychiatr Ment Health Nurs* 2003; 10: 57-64.
13. McGorry PD. Psychoeducation in first-episode psychosis: a therapeutic process. *Psychiatry* 1995; 58: 313-28.
14. Hatonen H, Suhonen R, Warro H et al. Patients' perceptions of patient education on psychiatric inpatient wards: a qualitative study. *J Psychiatr Ment Health Nurs* 2010; 17: 335-41.
15. Davidson M, Galderisi S, Weiser M et al. Cognitive effects of antipsychotic drugs in first-episode schizophrenia and schizophreniform disorder: a randomized, open-label clinical trial (EUFEST). *Am J Psychiatry* 2009; 166: 675-82.
16. Robles O, Zabala A, Bombin I et al. Cognitive efficacy of quetiapine and olanzapine in early-onset first-episode psychosis. *Schizophr Bull* 2011; 37: 405-15.
17. Rummel-Kluge C, Hansen W, Helbig A et al. Peer-to-peer pyschoeducation in schizophrenia: a new approach. *J Clin Psychiatry* 2005; 66: 1580–85.
18. Schrank B, Sibitz I, Unger A et al. How patients with schizophrenia use the internet: qualitative study. *J Med Internet Res* 2010; 12: e70.
19. Rummel-Kluge C and Kissling W. Psychoeducation in schizophrenia: new developments and approaches in the field. *Curr Opin Psychiatry* 2008; 21: 168–72.
20. McWilliams S, Egan P, Jackson D et al. Caregiver psychoeducation for first-episode psychosis. *European Psychiatry* 2009; 25: 33-38.
21. Power PJ and McGowan S. *Suicide Risk Management in Early Intervention*. Early intervention in psychosis IRIS network 2011.
22. Hunt IM, Kapur N, Webb R et al. Suicide in recently discharged psychiatric patients: a case-control study. *Psychol Med* 2009; 39: 443-9.

23. Simmons M, Hetrick S and Jorm AF. Shared decision-making: benefits, barriers and current opportunities for application. *Australas Psychiatry* 2010; 18: 394–7.

24. Rabinovitch M, Bechard-Evans L, Schmitz N et al. Early predictors of nonadherence to antipsychotic therapy in first-episode psychosis. *Can J Psychiatry* 2009; 54: 28-35.

25. Wunderink L, Nieboer RM, Wiersma D et al. Recovery in remitted first-episode psychosis at 7 years of follow-up of an early dose reduction/discontinuation or maintenance treatment strategy: long-term follow-up of a 2-year randomized clinical trial. *JAMA Psychiatry* 2013; 70: 913-20.

26. Kluge M, Schuld A, Himmerich H et al. Clozapine and olanzapine are associated with food craving and binge eating: results from a randomized double-blind study. *J Clin Psychopharmacol* 2007; 27: 662–6.

27. Marques TR, Smith S, Bonaccorso S et al. Sexual dysfunction in people with prodromal or first-episode psychosis. *Br J Psychiatry* 2012; 201: 131-6.

28. de Boer MK, Castelein S, Wiersma D et al. The Facts About Sexual (Dys)function in Schizophrenia: An Overview of Clinically Relevant Findings. *Schizophr Bull* 2015; 41: 674-86.

29. O'Donoghue B, Lyne J, Hill M et al. Involuntary admission from the patients' perspective. *Soc Psychiatry Psychiatr Epidemiol* 2010; 45: 631-8.

30. Birchwood M, Spencer E and McGovern D. Schizophrenia: early warning signs. *Adv Psychiatr Treat* 2000; 6: 93–101.

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