



Clinical practice in early psychosis

Preventing relapse in first episode psychosis

Introduction

Managing and minimising the impact of relapse is an important component of treatment in first episode psychosis (FEP). Between 55–70% of people with FEP will experience a psychotic relapse within 2 years of remission of their initial episode.^{1,2} With each relapse, recovery becomes difficult and prolonged for the young person, and the risk of chronic or persistent symptoms increases.³ Relapse can interfere with a young person's social and vocational development, can negatively affect their long-term outcomes, can also have a significant adverse effect on self-esteem and may increase self-stigma. Furthermore, analyses have indicated treatment for relapses in psychosis costs four times more than care for individuals that do not relapse.⁴

Specialised early psychosis programs that use a comprehensive early intervention approach have lower relapse rates compared with traditional services, and using second generation antipsychotic medication appears to be superior in preventing relapse when compared with first generation antipsychotic medication.⁵ Adherence to medication⁶ and controlling substance use also plays an important role.^{2,7}

Relapse planning combines aspects of psychoeducation, understanding the young person's explanatory model of psychosis, recognising early warning signs of relapse and implementing strategies to manage these. It involves identifying personal strengths and support systems that can help young people to

effectively manage their illness and recovery. Ideally, comprehensive relapse planning can help young people to recognise early warning signs of relapse and prevent a full-threshold relapse of symptoms. However, even if a relapse does occur, good relapse planning can help manage and minimise its impact through: reducing the distress associated with psychotic symptoms, limiting the loss of functioning, reducing the duration of a relapse, preventing loss of optimism around recovery, empowering young people to manage their own mental health, and helping young people achieve a satisfying way of living.

Reducing the duration of relapse has also been shown to be an important factor in minimising functional impairment and loss of brain volume.⁸

This clinical practice point is designed to help clinicians understand:

- relapse and the risk factors for relapse
- the effects of relapse
- strategies used to manage and minimise the risk of relapse.



What is relapse?

Definitions of relapse in mental health vary significantly within the published literature. The definition from the Macquarie Dictionary is 'to fall back into a former state or practice'. The *Pathways of recovery: preventing further episodes of mental illness (monograph)* published by the Commonwealth of Australia defines relapse in a mental health setting as 'a mental state that has previously been diagnosed and the symptoms of which have returned to the point where threshold has again been reached for diagnosis'.⁹

In clinical practice, relapse in psychotic illness is usually defined as an exacerbation of positive psychotic symptoms after a period of remission that triggers a review of the current management plan. In research settings, various definitions of relapse have been used that include admission to hospital or symptom exacerbation objectively measured using different rating scales for specified time periods. A lack of a universally accepted definition of relapse in psychosis has hampered efforts to accurately measure relapse and consequently advancement in this field.¹⁰

Reducing the rates of relapse is a clear goal for early intervention services because relapse has a distressing impact on young people and their families; relapse is also associated with the risk of poorer symptomatic and functional recovery. It is important for clinicians to discuss the possibility of relapse with young people who have experienced a first episode of psychosis. The *Australian Clinical Guidelines for Early Psychosis, 2nd edition* recommends that 'relapse should be discussed with young people and their families along with education regarding early warning signs and the development of a relapse action plan'.¹¹ Preparing for the possibility of relapse and working with young people to reduce the risk of relapse should begin early during treatment and continue throughout a young person's episode of care.

What effect does relapse have on the young person's life?

Most young people who have experienced mental ill-health do not use the term 'relapse' and are more likely to talk about being 'well' or 'unwell'. The language clinicians use to describe relapse is important when engaging young people in a discussion about the possibility of a relapse of their psychotic symptoms. Clinicians should also try to understand what the young person thinks about relapse. The meaning of a relapse can vary from person-to-person – for some, relapse may mean that they've failed, gone backwards and that they might not recover. It is crucial that clinicians explain to young people that a relapse doesn't mean that recovery isn't possible. It is equally important to explain to young people that relapse is common and is part of the process of recovery. Relapse and recovery should be carefully explained to young people and their families using plain language to ensure understanding.

“ For me, when you hear the word relapse and them saying those words, that you are going to relapse, that you're going back there, you don't really believe them. You're not thinking that you could go back there.

Young person
EPPIC, Orygen Youth Health Clinical Program



Approximately 20% of people with psychotic disorders will only experience one episode of psychosis.⁵

“ Case managers should tell you that there is a chance of relapse and should tell you that your relapse isn't going to be like the first one.

Young person
EPPIC, Orygen Youth Health Clinical Program

What does relapse mean for a young person?

These are young people's perspectives on relapse from EPPIC, Orygen Youth Health Clinical Program.

'Going back to where I started which was a shaky mess - like you know being shy, to not be able go out in public ... that for me scares the bejesus out of me. I wouldn't know what to do'

'It's just a really scary thought that no matter how much work you do, how much you improve, you can always go backwards.'

'My friends were just there and said tell your case manager but then it seems you feel like you are not worth their time you know because I've just gone backwards.'

'I haven't had the term explained to me but I know that it has happened to me several times. My progress is still happening.'

What are the risk factors for relapse?

A number of risk factors for relapse have been identified in the literature. A meta-analysis reported that poor medication adherence or discontinuation in young people with FEP is one of the strongest risk factors for relapse.² This study found the following risk factors for relapse:²

- Poor medication adherence increased the odds by 4-fold
- Substance use increased the odds by 3-fold
- Critical comments from carers increased the odds by 2.3-fold
- Poorer premorbid adjustment increased the odds by 2.2-fold

This meta-analysis found that baseline clinical and demographic variables had limited impact on rates of relapse.² These findings suggest that interventions that target medication adherence and substance use and promote a supportive family environment could be effective at minimising relapse. It is important to note that protective factors are rarely examined in studies, further investigation could indicate that protective factors may have an important role in preventing or predicting relapse in FEP. Protective factors could inform novel interventions targeted at personal strengths, social supports and resilience that could be more effective and more engaging of young people with psychosis.



TIP Clinicians should identify and target protective factors such as enhancing social support to help young people minimise and manage relapse. Strengthening relationships with family, friends and other supports, and enlisting their help when working towards recovery goals and monitoring for early signs of relapse is important for relapse prevention as it is usually family and friends who first notice a change in behaviour. Thorough assessment and collaborative formulation with young people help identify current social supports.

Actively addressing substance use issues is another way to minimise the chances of relapse as a return to regular use of substances can be a trigger for a relapse for some young people. Integrating substance use monitoring into early warning signs and a relapse plan early during treatment will help young people understand how to minimise and manage their relapse by and the impact of substance use.

A prospective study by Alvarez-Jimenez and colleagues aimed to characterise a group of young people with a first episode of psychosis who did not experience another psychotic episode over a follow-up period of 7.5 years and identify predictors of staying well (i.e. not experience a relapse).⁵ Shorter duration of untreated psychosis (< 60 days), faster treatment response and not losing contact with a parent were the strongest independent predictors of young people having a single psychotic episode.⁵ This highlights the importance of services and clinicians moving away from using a one-size-fits-all approach towards individualised interventions for relapse prevention.

Staying well – strategies for minimising the impact and duration of relapse

Relapse planning involves targeting specific risk factors that are unique to each individual to reduce the risk of relapse and the impact it has using a number of strategies and interventions. Strategies clinicians can use to help young people and their families to minimise the impact and duration of relapse in early psychosis are described in this section.

The role of medication

The majority of treatment guidelines in early psychosis advocate continuous treatment with antipsychotic medication for 12 months following a psychotic episode to minimise the risk of relapse, and this approach is supported by existing research evidence. Poor medication adherence is the strongest predictor of relapse, followed by substance misuse and a critical family environment.² In traditional mental health services, discontinuation of antipsychotic medication has resulted in relapse rates of 80–100%.^{12–14} However, the focus on preventing relapse as the primary treatment target in FEP is beginning to be questioned.¹⁵ These days, functional recovery is viewed as the best treatment goal for early psychosis services as it enables young people to live physically healthy and meaningful lives.

Evidence is now emerging that very low-dose antipsychotic medication following a remission in psychotic symptoms is associated with better functional capacity.¹⁶ The onus is on the treating team, including medical staff, to try to find the lowest possible dose of antipsychotic medication to achieve a remission in symptoms and carefully consider maintenance medication. While further research is required to replicate the results from this study, clinicians should aim to minimise antipsychotic dose to minimise side effects and maximise functional recovery for young people. Slight exacerbations in positive symptoms that are of a short duration may be tolerated to help facilitate long-term functional recovery. The risks and benefits of maintenance medication during the recovery phase of FEP should be carefully explained to young people and their families so that they are able to actively participate in decision making about treatment (see ‘Shared decision making’ below). In the context of specialised early intervention services and by providing new targeted psychological interventions, long-term exposure to antipsychotic medication can be reduced. New research is underway to identify who requires medication, how long the medication is required, what the minimal dose is and what interventions can be combined with medication to minimise the risk of relapse and promote recovery.

Clinicians need to balance managing symptoms and preventing relapse with building resilience and empowering young people by focusing on strengths and self-efficacy. Relapse prevention should prioritise functional improvement and long-term recovery.

Provide psychoeducation about psychosis and early warning signs

Young people, their families, friends and other supports require accurate and individualised information about relapse, recovery and relapse prevention as early as possible during treatment. It is important that clinicians provide psychoeducation about relapse and relapse prevention optimistically to young people and their families so that hope for recovery is conveyed. Psychoeducation about staying well, relapse, what can cause it, what can prevent it and how to minimise the impact can help young people and their families feel empowered about reducing the likelihood of relapse.

“ Relapse prevention involves empowering people ... to recognise early warning signs of relapse and develop appropriate response plans.”⁹

The stress–vulnerability model of psychosis can be used to explain how a relapse may occur and how it may be prevented. Each person will have unique factors that may contribute to the risk of relapse, and providing psychoeducation using the model to understand and address these in terms of managing and minimising relapse is important. For more information on psychoeducation, please see the ENSP manual *A shared understanding: psychoeducation in early psychosis*.

“ I didn’t get it [relapse] explained to me, and it felt like I didn’t know that my progress could slip backwards. I wasn’t aware that my health and progress could go back to ten steps, which can be really harsh when it does happen.

Young person
EPPIC, Orygen Youth Health Clinical Program

Identify early warning signs and develop a relapse plan

Often, there is a period of 1–4 weeks of early warning signs that precedes a relapse.¹⁷ Early warning signs are subtle changes in thought, affect and behaviour that occur before frank symptoms of psychosis emerge. Commonly reported symptoms include depressed mood, social withdrawal, sleep disturbance and appetite issues. These symptoms may occur in a predictable manner early during the development of psychosis and are followed by increased emotional disturbance.¹⁷ It is important that young people and their families are aware that fluctuations in mood and thoughts are normal and these are not necessarily early warning signs. But a collection of specific symptoms that persist over time may be a sign of a potential relapse.

Early warning signs vary from person-to-person and a personal set of early warning signs noticed during the development of previous psychotic episodes has been referred to as a ‘relapse signature’.¹⁷ This collection of individual early warning signs provides an opportunity to intervene early and hopefully prevent further deterioration in mental state and functioning. When early warning signs are noticed, people need to know how to respond effectively – this requires having a relapse plan. Clinicians should work with young people and their families to consider what particular early warning signs are relevant to the young person and develop a relapse plan that describes how the early warning signs will be managed. Recognising sensitive and specific early warning signs for each young person and developing a relapse plan in a hopeful way can help the young person and their family understand their: risk factors for relapse, early warning signs to monitor and coping strategies that need to be implemented. Clinicians can use checklists of common early warning signs to help young people identify their own individual early warning signs (see Box 1).

BOX 1. Common early warning signs

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

Relapse plans can cover a number of topics or themes including managing stress, reducing substance use and maintaining a healthy lifestyle. Relapse plans will include an action of things the young person can do to manage their early warning signs and the people who can support them to do this, including their case manager or GP. It is important that clinicians collaborate with young people and their families to identify their specific early warning signs and coping responses so that the overall relapse plan is meaningful for those involved and can be implemented when required.

Tools to identify early warning signs: a timeline and cards

Using a timeline can help young people connect their episode of psychosis with events or feelings that may have indicated that they were unwell. Signs and symptoms can be categorised into: early, middle, late warning signs and placed on the timeline in the appropriate order. Significant events can be used as anchors on the timeline. Timelines can be a useful way of looking back and using specific time points to understand early warning signs of a relapse. Common early warning signs can be listed on cards and young people can place these at appropriate intervals on the timeline. Additional cards can be made and used as required.

Engaging families in relapse prevention work

The importance of working with young people, their family, friends and other supports to develop and implement strategies that can reduce the effects of a relapse cannot be understated. Relapse planning supports young people (and their families) to feel confident about recognising and responding to a relapse, which ultimately allows them to effectively manage their own mental health.

Family, friends and other supports will often be the first to notice when a young person has a change in their mental state that signals a possible relapse. Therefore it is important that family, friends and other supports are involved in discussions about early warning signs and strategies that need to be implemented to help manage a relapse. Families, friends and other supports can provide a wealth of information about the young person's premorbid functioning and the development of psychosis. They need to be helped to recognise early warning signs and need to know what to do when these appear. It is vital that clinicians involve families and other supports in the development of relapse plans, which can include recommendations about what they can do to help the young person.

When talking to families, friends and supports about early warning signs, clinicians should be optimistic and ensure that there is balance between increasing their awareness of early warning signs and causing unnecessary anxiety. Questions clinicians can ask family, friends and supports, include:

- What first made you realise something was 'not quite right'?
- Which signs did you notice first?
- When did you know something was definitely wrong?
- What was going on when these changes were happening?
- Who first noticed these changes?

For more information about working with families and early warning signs, please see the manual *In this together: family work in early psychosis*.

“ I definitely found the more info they [my family] had about early warning signs, the more they could pick up on. They were more nurturing – they couldn't stop it, but they knew what was going on.’

Young person
EPPIC, Orygen Youth Health Clinical Program

Build coping strategies, resilience and strengths to help young people manage relapse

It is important that clinicians help young people to identify and enhance coping strategies and help them develop new ways to effectively manage stress and symptom exacerbation. Coping strategies can empower young people to manage their own mental health and minimise the impact of a relapse.

Identifying individual strengths is now emerging as an important focus within the field of positive psychology and is promising for young people with early psychosis. Focusing on individual strengths and how to use these when trying to control re-emerging symptoms and maintain or enhance functional recovery is a powerful tool clinicians can use when working with young people. Using a strengths-based approach in relapse prevention work is important:¹⁸ individuals are guided and encouraged to identify, discuss and use key personal strengths to enhance self-esteem,¹⁹ nurture social functioning¹⁹ and reduce depression.¹⁸ This approach is based on the novel positive psychology model that proposes that psychosocial interventions should aim to build strengths, meaning and purpose and relieve symptoms.^{18,19}

The role of protective factors such as strong social support in reducing the risk and impact of relapse and facilitating recovery broadly can't be underestimated. Together these can have lasting effects in terms of managing relapse. Helping young people develop or enhance their social connectedness and recognise the importance of supportive relationships in maintaining wellness is an important responsibility for early psychosis clinicians.

The overall treatment goal in psychosis is to improve functional capacity and to help young people live meaningful lives. This requires focusing on social and vocational functioning. Significant components in treatment clinicians can use to reduce relapse and improve recovery include helping young people to:

- act early
- learn how to cope with symptom exacerbation
- recognise and use their strengths
- develop or maintain supportive interpersonal relationships
- maintain social and occupational functioning.

“ Relapse prevention requires identifying risk and protective factors for mental health and implementing interventions that enhance protective factors and eliminate or reduce the impact of factors.⁹

Shared decision making is a model to use when making decisions about treatment

Shared decision making is an important part of working with young people to manage and treat their psychosis. It involves a clinician and a young person collaborating in a deliberate way to discuss decisions about the young person's treatment. Shared decision making is especially important when working with young people around their concerns about medication and relapse. Many young people have concerns about the side effects of medication (e.g. it makes them sleepy and they are unable to function properly at work or school) and may want to discontinue medication. The issues around appropriate treatment during the recovery phase of early psychosis are complicated and involve balancing the risk of relapse with improving functional recovery beyond the first few years following the illness onset (see 'The role of medication' on page 4).

Shared decision making involves providing young people and their families with all the relevant information to enable them to make informed decisions about their mental health and treatment. It engages young people and their families in the decision-making process about their treatment and helps them consider their preferences in terms of medication and relapse which in turn can help improve adherence to medication. The role of the clinician is to provide the young person with whatever they need to make an informed decision about their mental health treatment options. Please see the clinical practice point *Shared decision making*.

“ I felt like everyone would be really disappointed in me, but then you realise the ones that really matter don't care that you have relapsed. That they are just care about you and your wellbeing.

Young person
EPPIC, Orygen Youth Health Clinical Program

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