In This Together

Family Work in Early Psychosis

Orygen YOUTH Health
Research Centre

EPPIC
Early Psychosis
Prevention and
Intervention
Centre

The EPPIC National Support Program of Orygen Youth Health Research Centre has produced this document as part of its work to support the scaling up of the EPPIC model within headspace, the National Youth Mental Health Foundation, in Australia.

ISBN 978–1–1–920718–32–9

Suggested citation

Crisp K, Creek R, Fraser S, Stavely H, and Woodhead G. *In this together: family work in early psychosis*. Orygen Youth Health Research Centre, 2014.

Acknowledgments

This manual was written by Kingsley Crisp, Rebecca Creek, Sarah Fraser, Heather Stavely and Gina Woodhead, with contributions from Caroline Crlenjak, Ally Hughes, Catharine McNab, Frank Hughes and Liz Burgat.

Disclaimer

This information is provided for general education and information purposes only. It is current as at the date of publication and is intended to be relevant for Victoria, Australia and may not be applicable in other jurisdictions. Any diagnosis and/or treatment decisions in respect of an individual patient should be made based on your professional investigations and opinions in the context of the clinical circumstances of the patient. To the extent permitted by law, Orygen Youth Health Research Centre will not be liable for any loss or damage arising from your use of or reliance on this information. You rely on your own professional skill and judgement in conducting your own health care practice. Orygen Youth Health Research Centre does not endorse or recommend any products, treatments or services referred to in this information.

Orygen Youth Health Research Centre
Locked Bag 10
Parkville Vic 3052
Australia

www.oyh.org.au

In This Together
Family Work in Early Psychosis

Contents

Introduction

About this manual 5

How to use this manual 5

Family work and the EPPIC service culture 6

Part 1

Family work theory and principles of practice

Family work in early psychosis – background and rationale 8

What is 'family'? 8

What is 'family work'? 9

The rationale for family work in early psychosis 9

Overview 9

Family work in the context of psychotic illness 10

Expressed emotion in early psychosis families 11

The effect of family work on psychosis outcomes 13

The benefits of family work for families 13

Family work service considerations 15

Organisation level: systems 15

Clinician level: support and training for family work 15

Service-user level: support for young people and families 17

Implementing a family peer support program for early psychosis 17

The EPPIC approach to family work 18

Overview 18

EPPIC family work conceptual frameworks 19

The three key foci of the EPPIC family work approach 19

The phase model of family needs during early psychosis 20

Phase 1: recognition that 'something's not right' 21

Phase 2: initial contact and getting support 22

Phase 3: towards recovery 23

Phase 4: first relapse and ongoing recovery 24

Addressing family needs during the four phases 26

The EPPIC family work 'pyramid' 26

Part 2

Family work in clinical practice

A stepped approach: the family work pyramid 29

Overview 29

Initial contact: assessment, engagement and orientation to the service 32

Engagement 32

Practical aspects of engagement 34

'I don't want them involved' – information-sharing and confidentiality 35

Assessing the needs of families 39

Peer support from peer support workers and other families 41

Psychoeducation, information sharing and debriefing 42

Explaining symptoms and diagnosis 43

Discussing the future: prognosis and recovery 44

Treatment 45

Regular contact with treating team 46

Recognising early warning signs 47

Specific interventions with treating team (may include specialist family worker) 49

The role of the family in recovery 50

Structured intervention with a specialist family worker 51

Family therapy 54

Common challenges in family work 56

Aggression 56

Non-adherence to treatment 58

Persisting symptoms 60

Substance use 62

Language and culture 64

Abuse 66

Models of family work in FEP 66

OPUS (Denmark) 66

First Episode Psychosis Program (Canada) 67

Meriden (UK) 67

The Lambeth Early Onset and Outreach and Support in South London service 68

Appendices

Questions to help with assessing family need 70

Questions to assess knowledge about psychosis 70

Questions to explore impact of psychosis on families 71

Family work assessment formulation 72

Information sheets for families 74

Positive and negative symptoms 74

What causes psychosis? 75

Phases of psychosis 76

Factors affecting recovery from an episode of psychosis 77

Common early warning signs 78

Creating a positive emotional environment 79

Core skills for effective communication 81

Sample problem-solving model for families 83

References 84

Introduction

The onset of psychosis in a young person can be traumatic for both the young person and their family. Many families experience a first episode of psychosis as a crisis, placing significant strain on the family unit and individual members, which in turn can affect the young person's recovery. Psychosis may signify a disruption of hopes or expectations the family has for the young person, leading them to feel grief and loss for the young person's development and future. Added to this may be the stress of caring for the young person, as the family is usually the primary source of support for them during recovery. Family work – including supports and interventions – therefore needs to form an integral part of any early psychosis service, as part of the recovery process for both the young person and the family.

About this manual

In this together: family work in early psychosis is a manual designed to help early psychosis services incorporate family work into their overall approach to working with early psychosis in young people. It is one of a series of manuals produced as part of the EPPIC National Support Program (ENSP) to help with 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 developed by Orygen Youth Health in Melbourne. Work with family and significant others is one of the 16 core components that make up the EPPIC Model.

Family work can be daunting for some clinicians. Those with little experience or experience in a different service model may see family work as the role of others, such as specialised family workers or family therapists. However, as will be reiterated throughout this manual, family work should be provided at some level by all clinicians working with young people in early psychosis services.

This manual provides an overview of the EPPIC family work approach, which has been developed from international evidence combined with over 20 years' clinical experience in planning, implementing and delivering early psychosis interventions to young people and their families. It offers evidence-based, practical advice for service providers and clinicians to establish and consolidate a family work program in an early psychosis service.

How to use this manual

This manual has been developed as a resource for service providers and all clinicians working in an early psychosis service. The material presented here should be valuable to both clinicians new to family work and those with specialised experience who are not familiar with family work in the early psychosis setting.

The manual consists of two main sections. The first, 'Family work theory and principles of practice' covers the evidence for incorporating family work into early psychosis services and describes the approach to family work that has developed and evolved within the EPPIC program. The second, 'Family work in clinical practice' details how the EPPIC approach to family work can be put into practice in an early psychosis service. Case scenarios and common 'myths' about family work are presented throughout to illustrate real-world challenges and applications of family work.

Service providers should read this manual in conjunction with the *EPPIC Model and Service Implementation Guide* for more detail on how to incorporate family work into an early psychosis service.

It should be noted that for the purposes of this manual, the term 'early psychosis' encompasses both young people who have experienced a first episode of psychosis and those who are at ultra high risk of developing psychosis (UHR). However, as most research and evidence on family work in early psychosis deals specifically with first episode psychosis (FEP), the framework and interventions described will focus on FEP. It is expected that issues and interventions in FEP do, however, apply to UHR families. Further information specific to the UHR population can be found in the manual *A stitch in time: interventions for young people at ultra high risk of psychosis*.

Family work and the EPPIC service culture

As mentioned, the EPPIC Model has been developed from many years' experience within the clinical program at Orygen Youth Health. It is based on current evidence, the experience of other early psychosis programs internationally and shaped by real world considerations. The EPPIC Model 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.

There are a number of core values and principles of practice that inform the EPPIC model of care. Ideally, an early psychosis service should incorporate:[1]

- easily accessible expert care
- a holistic, biopsychosocial approach to clinical interventions
- a comprehensive and integrated service approach
- evidence-based clinical practice
- the presence of youth-friendly culture throughout the service (reflected in staff behaviour and attitudes and decor)
- a spirit of hope and optimism that is pervasive throughout service
- a family-friendly ethos contained in all aspects of service
- a service culture and skills that facilitate culturally sensitive care to all young people and families
- a high level of partnerships with local service providers.

Working with families is integral to these principles of practice. An early psychosis service that is youth- and family-friendly must make supporting the family – whoever that might be – a priority. This is best achieved by ensuring a culture within the service that supports and enables all clinicians to carry out family work. Empathy for what a young person and their family is going through needs to be part of service culture right from the beginning of setting up a service. This will require a dedicated, specialist family worker who can be the overseer and 'culture carrier' of the family work approach in the service.

Attributes of a team culture that enables family work include:

- an assumption that family and friends are involved from first point of contact with the service and throughout the episode of care
- a collaborative approach, with strong recognition of family as part of the treating team
- awareness among all clinicians that it is part of their role to work with families (not just that of specialist family workers). This includes case managers, family peer support workers, psychiatrists and other members of the multidisciplinary team.

It is important regarding the last point that clinicians are encouraged and supported to work with families, as many may feel reluctant to do so, for a number of reasons. These might include: it has not been the clinician's role historically to carry out family work (e.g. as a practitioner coming in from another mental health service); a clinician does not feel they have the skills for working with families; or, they consider family work to be a discrete part of care that is used only for crisis assessment or dealing with the most distressed families.

PART 1

Family work theory and principles of practice

> ‘I think it’s important that they mention that ‘family’ doesn’t necessarily have to be your parents, that it can be close friends or anyone else really. My case manager only ever suggested to me to get my parents involved, but I didn’t really want that, so I didn’t.’
>
> – Young person
> EPPIC, Orygen Youth Health Clinical Program

Family work in early psychosis – background and rationale

What is ‘family’?

There are many different types and configurations of families. Who a young person depends upon for support, and who they count as ‘family’ will vary; it is therefore important that services and clinicians acknowledge that a ‘family’ may encompass a range of relationships, not only the immediate family. Family may include, for example, extended family, partners or significant others, children, close friends, housemates and other guardians or carers. Note that it does not include formal supports of the young person, such as Department of Human Services case support workers.

All family may be included in family work, but is important to understand and acknowledge the particular role and experiences of the people who are a young person’s primary support during recovery from a first episode of psychosis. Alongside this, clinicians need to identify who the young person sees as their key support – and be aware that this may be different to who the key people providing care in fact are. Both may, however, need to be provided with support. For example, a young person living at home with her parents might view her partner as her key support; however, her parents may play a significant role in her care while she lives at home.

What is ‘family work’?

The term ‘family work’ is used as a way to reduce the stigma that may be attached to terms such as ‘therapy’ by young people and families. It includes family support or interventions that can be carried out by any member of a clinical team, and follows the general principle of attending to the needs of the family to help them both support the young person and cope with the impact of having a family member develop a serious mental illness. Family work should be considered routine clinical care, and it is important to note that clinicians do not need to be family therapists to provide a level of family work.

The majority of evidence for effective family work in psychosis is provided by studies of structured family behavioural therapy or cognitive-behavioural therapy interventions (see page 13). However, family therapy approaches, such as narrative, systemic, solution-focused or other therapies, may be useful and can be provided to families with need for therapy beyond the impact of the psychosis. It is expected that only small number of families will require family therapy, which can be provided by clinicians within a service, depending on training and experience, or through referral to an external service. See also ‘Family therapy’ on page 54.

Myth

You have to be a ‘family worker’ to do family work.

Not true. All members of the clinical team can and should be involved in family work at different levels. Talking to family members, listening to concerns and providing information all constitute ‘family work’.

The rationale for family work in early psychosis

Overview

Early approaches to working with families of people with psychosis were informed by flawed theories of the role of families in psychotic illness.[2,3] These theories focused on ‘blaming’ the families of people with psychosis not just for the onset of the disorder, but also for hindering recovery and contributing to relapse – using terms such as ‘schizophrenogenic’ mothers and ‘marital schisms’.

Contemporary theories of family intervention have moved away from 'treating' the family to working with them to offer support to both the family and their relative with psychosis. This change of focus is important in two ways: firstly, it removes stigma from the family (i.e. of being a family that 'produced' the psychosis), and secondly, it recognises that family interventions also need to meet the family's needs, as they too may be experiencing trauma from the onset of an episode of psychosis in a loved one.

There is a clear rationale for family work in early psychosis, which is presented in the following sections. Briefly, because the young person exists within a wider family system, and because family will be a major source of support for many young people presenting with early psychosis, engaging and supporting the family throughout their family member's treatment will benefit both the family and the young person.

Family work in the context of psychotic illness

The stress–vulnerability model of psychosis aetiology

The stress–vulnerability model of psychosis posits that psychosis does not arise from underlying biological factors alone, but develops from external stressors interacting with a biological vulnerability. The disorder can change, responding to environmental psychological and social circumstances.[4] A biopsychosocial framework is used to describe how various factors can interact to influence the disorder's development and progression.

Biological factors include genetics, physiology, biochemistry – in particular neuronal biochemistry – and general physical constitution. Psychological factors encompass the legacy of adverse events in early development, and emotional and cognitive responses to interactions with others. Social factors include the family and friendship system and the individual's socioeconomic and sociocultural background.

A number of biological, psychological and social contexts are relevant to young people experiencing a first episode of psychosis.

- Biologically, they may have recently gone through puberty, with associated neurological development; they may be experimenting with or using alcohol or other drugs.
- Psychologically, they are progressing through the developmental stage of individuation and beginning long-term vocational and social aspirations.
- Socially, the peer group can still be a source of social norms and self-esteem, or it might be lessening in influence.

In terms of a young person's relationship with their family, the onset of psychosis might be occurring in the context of the young person's changing place in the family's structure. This change may be reflected in, for example, greater self-reliance, rebelliousness toward parents as alternative values are adopted, or even a closer identification with adult figures in the family as the young person begins to work toward vocational goals. The advent of psychotic symptoms in a family member may therefore significantly affect development of relationships within the family.

Expressed emotion in early psychosis families

The concept of expressed emotion in families of people with established psychotic disorders, and its impact on illness, has been the subject of fairly extensive research since the 1950s. Expressed emotion (EE) refers to three characteristic ways family members might comment when talking about the person with psychosis and their perceptions of their relationship with them. The three characteristics are ‘criticism’ (commenting on annoying behaviour), ‘hostility’ (critical or rejecting comments about the person) and ‘emotional over-involvement’ (self-sacrificing behaviour, over-identification with the person).

There is strong evidence for a link between high EE in families of people with psychosis and rates of relapse.[2] Family intervention to reduce EE in families has therefore become a key focus of family work with people with established psychoses, such as schizophrenia. However, it is important to be aware that EE has a different relevance in the early psychosis context. For example, ‘over’ involvement might in fact be developmentally appropriate in family members of young people going through adolescence (see case scenario ‘Athena’). Families dealing with a first episode of psychosis will be distressed, bewildered and not necessarily behaving as they normally do. EE may therefore be a response to stress (‘state’), and not characteristic of the family’s usual pattern of interaction (‘trait’). Furthermore, the link between EE and relapse is less well established in FEP. In fact, one study of intervention to reduce EE in FEP families showed it may increase risk of relapse in families with low EE, where it’s possible the extra intervention increases stress in the family.[5] In this study, ‘[families] reported that a focus on behavioural family interventions prevented an opportunity to deal with feelings of grief and loss surrounding the onset of psychotic illness in a son or daughter’.[2] Similarly, families of people with bipolar disorder were found by Miklowitz and Goldstein (1997) to perceive structured intervention as irritating and unhelpful.[6] It is also worth noting that high-EE family members’ causal attributions regarding psychosis have been shown to be more predictive of relapse than has the level of EE.[7]

This is not to say that EE has no relevance to FEP families. A percentage of young people with FEP will go on to develop a more established condition, where the evidence for the negative impact of EE is clearer.[4] Besides this, regardless of how the disorder may progress in the future, some families with FEP may find interventions to reduce their distress and improve communication useful.

However, the concept of EE does need to be used with caution in FEP families, as it can have quite negative connotations regarding the role of the family in relapse. Although it may describe a relevant and difficult situation for the young person and the family, it should not be used to label families seen to be ‘difficult’, thereby undermining and disregarding the level of distress and grief being experienced within the family.

Importantly, the concept of EE does not help identify any needs of the family, when in fact the priority when a family arrives at a service should be to meet their immediate needs. Depending on how they have come to the service, they might be confused and stressed after a long trip through the healthcare system. They may have received little, or have had little chance to ask for, information about the illness, treatment or prognosis; they may have the wrong information. All these factors can leave a family in a heightened state of distress, which impacts on how they respond to the young person, the disorder and behaviours caused by the disorder.

The immediate role of family work is therefore to create a space for caring, non-blaming and respectful communication. It should provide the family with clear and accurate information, reassurance about the illness, realistic expectations for prognosis, opportunity to express feelings associated with the onset of psychosis and access to peer support. This essential information will need to be reinforced and repeated throughout the episode of care, as, similar to people in crisis, family members often find new information difficult to process and retain.

It may be that these first interventions are all the family needs, and that simply providing information, support and an opportunity to express fears or emotions to an empathic listener will in itself lower EE in families without additional interventions.

The immediate role of family work is to create a space for caring, non-blaming and respectful communication: to debrief the family and offer information, empathy and support.

CASE SCENARIO **ATHENA**

Athena is 21 years old and currently completing an Advanced Diploma in Administration. She lives with her parents and older sister, Rita, in inner-city Melbourne. Athena's parents, George and Melina, moved to Australia from Greece before she was born, and are both now retired.

Athena recently experienced a first episode of psychosis, and began treatment in an EPPIC service. Athena has made one serious suicide attempt, and in a separate incident sustained serious injuries after jumping from a moving car to get away from her ex-employer, who she was afraid was attempting to kill her.

Athena sees her case manager weekly and has fortnightly appointments with her psychiatrist. George drives her to all her appointments, and meets with her case manager after all her appointments. Athena's parents want to be involved in all decision-making regarding her medication, and Melina and George both attend the first half of each of her psychiatrist appointments.

Recently, Athena has become increasingly paranoid and more preoccupied with trying to understand the 'signs' that her ex-employer is 'out to get her'. She reads the newspaper every day from cover to cover, where she finds these hidden signs. She is also becoming increasingly irritable and agitated, and her family has observed her pacing the hallway at home.

Athena's parents have expressed concern that she is experiencing a relapse, and are concerned about her safety, saying she has been talking about how there is 'no point' and she should 'get in first' before her ex-employer tries to hurt her. Athena's case manager has noticed that Athena is increasingly guarded about her mental state, appears to be increasingly preoccupied and hyper-vigilant in sessions and has trouble following the conversation. He is also concerned that she is experiencing a relapse, with auditory hallucinations.

CASE SCENARIO **ATHENA** (continued)

George and Melina, the case manager and Athena's treating doctor meet to discuss their concerns about Athena's deteriorating mental state. Her treating team believes the risk of Athena's acting on her thoughts of suicide is increasing and that closer monitoring is required by the EPPIC community treatment and crisis response team, her treating team and her family. The local inpatient unit is informed that Athena may require a short-term admission to maintain her safety and provide extra support, as her parents are currently struggling to continue caring for her at home due to her increasing suicide risk and deteriorating mental state.

Athena's situation – living at home and with the substantial involvement of her parents in care – is not unusual for young people at EPPIC. Despite her age, because she is still living at home, she requires considerable support from her parents during the recovery process from a first episode of psychosis.

The effect of family work on psychosis outcomes

A 2010 Cochrane review showed that family intervention in people with schizophrenia may decrease their frequency of relapse, reduce hospital admissions and encourage compliance with medication, although the authors concluded that further research needs to be done in this area.[8] Nonetheless, the association with reduced relapse is strong enough that family work is recommended as part of best practice care for schizophrenia.[9,10]

Studies of family work in families with early psychosis are more limited; however, interventions with a family work component have been shown to reduce risk of relapse in the short-term[11,12] and reduce negative symptoms, minor psychotic episodes and stabilise positive symptoms,[13] although the latter study did not show reduction in relapse rates. Studies are currently under way to examine the impact of family intervention on transition from the UHR state to FEP, and whether it can improve symptoms or functioning in the UHR population.[14]

Whether or not family work has a direct effect on relapse rates, a strong incentive for prioritising family work is the value brought by the family as partners in the extended treating team. Clinicians should see family work as an 'investment' in the young person's care: by collaborating with families and engaging them early on, clinicians can lay foundations of trust and respect that may improve outcomes for the young person, for example by the family being a 'treatment ally' if a young person is non-adherent to treatment.[15]

The benefits of family work for families

Aside from the effect family work may have on a young person's recovery from FEP, further rationale for family work is provided by the benefits it has for the family itself. The evidence for the role family work plays in helping families cope with a first episode of psychosis is more conclusive.

Families of people with schizophrenia report feelings of being burdened, stressed, anxious and depressed.[16] The stigma of mental illness that may be experienced by the young person is also felt by the family,[17] and many relatives experience significant personal distress during an episode of psychosis.[18,19] According to research conducted with parents, grandparents and siblings of young people at Orygen Youth Health, the most important issues for families of young people with mental illness are the need for information and the need for emotional support.[20]

From the 1990s, research into the effectiveness of family work in FEP families began to examine not just its effect on relapse rates but also the effect on family members.[16] Family work ranging from basic interventions to more involved cognitive-behavioural therapy (CBT) has been shown to reduce perceived stress in families regarding their relative's negative symptoms and increase perceived opportunities to make a positive contribution to the care of their relative.[21,22] It can also improve family members' experience of caring for a relative and may reduce psychological stress.[23]

> 'They talked to my parents about things that could happen, like that I could attempt to kill myself or self-harm, and what to do if that does happen – whether to call 000 or whether to get a bandaid. Which was good, because it made my family – Mum especially, she's a worry wart – feel more comfortable.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

It should therefore be viewed as a clear responsibility of an early psychosis service to support families as they come to terms with their family member's illness and their role in supporting them. Services must recognise that families have rights and recovery needs of their own, and that the trajectory of recovery for a family may not be the same as that for the young person.

Myth

Family work is only for families that have identified issues or problems.

Not true. Some level of family work can be helpful for every family who accesses an early psychosis service.

Family work service considerations

Although family work can be of substantial benefit to both young person and families in early psychosis, it is often not prioritised and may get left out of routine practice in services. There are three levels at which family work must be supported within an early psychosis service and where barriers may be found to implementing family work in practice: the organisation level, the clinician level and the service-user level.

Organisation level: systems

The challenge of implementing family work at an organisational level will be to ensure family work is central to all areas of the service. It is vital that staffing and workplace structures are optimised for family work to be developed and supported in the service. See the *EPPIC Model and Service Implementation Guide* for the core components of the EPPIC approach to family work and associated standards and guidelines.

Employing a specialist family worker is key to embedding family work in the culture of the service. The specialist family worker should form part of the continuing care team, which allows them to be seen as part of the treating team, attend clinical reviews and work directly with case managers. Although tempting, services should avoid allowing or requiring the specialist family worker to become a direct case manager. This is important to ensure that they have time to oversee the family work program and to provide support, consultation, training and education.

Clinician level: support and training for family work

Fadden (2009) identifies a number of barriers to family work that may present at the individual clinician level. These include lack of confidence or reluctance to take on family work, lack of commitment to family work by management, scepticism that family work is effective and resistance to the inclusive, collaborative nature of family work.[24] For example, clinicians new to youth mental health (e.g. new graduates, those coming from an adult mental health background, private practitioners) may be used to a treatment approach that focuses on the individual, where the family is a secondary concern. Others may not feel that family work falls in their domain, or if they do, feel constrained by lack of training in working with families, or by competing caseloads.[25]

Services can address these barriers in a number of ways. It should be promoted to clinical staff that all case managers need to regularly see families and provide essential elements of family work. It should be emphasised that to fully aid the recovery process, a collaborative relationship is required not only with the young person but also with their family. Again, the specialist family worker will play a central role in developing this culture and maintaining positive attitudes among clinicians within the service. Regular meetings of the multidisciplinary team, along with clinical reviews to discuss what is happening within the family, will help clinicians prioritise family work and clarify the needs of families and the nature of family work required.

Training in family work can remove some of the reluctance clinicians may feel about ‘doing’ family work, as will regular clinical supervision that allows clinicians to reflect on their work with families. Clinicians should also be able to have regular case consultations with the specialist family worker, so that they feel more comfortable in the family work they do carry out. They also need to know that they can work jointly with the specialist family worker on more specific interventions if required, and that they are able to refer families to the specialist family worker if necessary.

Instances when it is appropriate to refer to a specialist family worker tend to involve a family’s requiring more help to deal with complex issues, problematic recovery of the young person, or cases where it is not in the interests of the case worker’s relationship with the young person for them to be intensively supporting the family as well. (See page 49 for more detail on referring families to specialist treatment.)

> ‘It was about a month into seeing my case manager that he said, “Oh, we should book a family appointment”. But I felt like he needed to know about my family sooner, to understand the dynamic, because it’s a crazy, hectic family, and he had no idea of it – he just thought, “Two parents, one kid”.’
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

> ‘When you are a new clinician, family work can be daunting … but putting in the hard yards early means that the family will be more open to contacting you if concerned.’
>
> – Clinician,
> EPPIC, Orygen Youth Health Clinical Program

Service-user level: support for young people and families

The third level at which engagement with family work needs to take place is that of young people and their families themselves. For various reasons, the young person might be unwilling to have their family involved in or to receive information about their treatment. If this happens, there are issues of confidentiality and information-sharing that must be considered; however, it is important for clinicians to periodically review with the young person their decision not to involve their family and encourage them to allow it. See '"I don't want them involved" – information-sharing and confidentiality' on page 35 for further discussion.

There are also many reasons a family might be reluctant to engage with family work. On initial contact with an early psychosis service, the family may be feeling powerless and at the mercy of the healthcare system; they may have previous negative experiences of the mental healthcare system in particular. Families may also be worried that they will be blamed for the young person's illness, or criticised for how they have handled it to this point.[26]

Early psychosis services therefore need to ensure that they provide a welcoming environment, which again will be assisted by building a culture of family work into the service. Strategies to help clinicians engage families with an early psychosis service are presented on page 34. Family engagement with a service might also be helped by a family peer support program, further discussed in the next section.

Implementing a family peer support program for early psychosis

Family peer support workers are paid, trained non-clinicians with a lived experience of having a family member with early psychosis. They play a valuable role in engaging and supporting families within an early psychosis service.[20] However, it is important to note that family peer support workers are not clinicians, and should not be expected to undertake clinical duties.

The family peer support program in the EPPIC program at Orygen Youth Health evolved following a focus group of young peoples' families, in which they expressed needs for information about what is happening to their family member and to be emotionally supported. In the program, family peer support workers are trained to work alongside clinicians to support families through the initial bewildering stages of involvement with a service and issues regarding a mental illness diagnosis.

The family peer support program currently consists of two major components:

- A family resource room, staffed by a family peer support worker, where families and friends can find a range of resources on mental illness.
- Telephone and face-to-face information and support, which has become the most useful and most utilised aspect of the program.

Successful implementation of a family peer support program requires a designated program coordinator, training for peer support workers and ongoing supervision for peer support workers.[1]

In the EPPIC program at Orygen Youth Health, the role of family peer support coordinator is undertaken by a highly experienced senior clinician, whose main responsibilities include providing supervision to family peer support workers and supporting and promoting the family peer support program in the service culture. Supervision is provided to family peer support workers as an opportunity to discuss issues that arise from their interactions with families. It may be provided as individual supervision, group supervision, or a mixture of both. A family peer support worker team meeting is also held weekly as a formal supervision session. Doctors and case managers are invited to attend to present family contact requests or discuss relevant issues. All clinicians new to the service are orientated to the family peer support program.

Training of family peer support workers is carried out by clinicians or previously trained family peer support workers. More information on training for family peer support workers can be found in *Training Family Peer Support Workers in an Early Intervention Mental Health Service*, a resource developed by Orygen Youth Health.[27]

The EPPIC approach to family work

Overview

The experience of a first episode of psychosis in a young person understandably has an impact on the people close to the young person: their family and friends. Family work has therefore been an essential part of the EPPIC program at Orygen Youth Health since its inception.

The EPPIC clinical practice model is one framework for working with FEP families. In this model:

- because 65 to 75% of young people are living with families at first contact, all clinical staff work closely and cooperatively with families
- the mobile youth assessment, crisis response and community treatment team plays an important role in psychoeducation, orientation, practical and emotional support, debriefing and engaging the family in the service
  - inpatient clinicians play similar roles for young people admitted to the inpatient unit
  - family contact should occur within at most 48 hours after the initial assessment of the young person, unless there are exceptional clinical reasons why this should not be done
- case managers and treating doctors take up the work with the family and aim to make contact with families as soon as possible within the first week of allocation.

The treating team members, particularly case managers, then become the key contact for families for the length of time that a young person remains registered with the EPPIC program. They continue to build collaborative relationships with families and involve them, where possible and appropriate, in the young person's treatment and recovery process.

Broadly, the EPPIC approach to family work incorporates introductory psychoeducation for families of young people, including a group-based education option, specialised family work and a family peer support program. It involves a flexible, phase-specific approach that draws on an eclectic range of theoretical models, including crisis theory, coping strategy enhancement, supportive therapy, and systemic, narrative, solution-focused and cognitive-behavioural approaches. The therapeutic approach is one of collaboration rather than the therapist acting as an 'expert'.

Family work at EPPIC aims to: empower families to cope with and adjust to the crisis of having a family member develop a serious mental illness; minimise disruption to the life of families and maximise their adaptive functioning after an acute psychotic episode; acknowledge the specific needs of a family, to both ameliorate the possible impact of the family environment on a young person's experience and to support the family itself; and approach pre-existing problems within families with general crisis intervention principles.[28] It is acknowledged that the crisis experienced by a family may mean a recovery period is required not just for the young person, but also for the family unit and its members, which should be supported accordingly. The overriding principle is that no blame is attached to families: they are viewed as doing their best given the resources they have to cope with the challenges faced.

EPPIC family work conceptual frameworks

There are three conceptual frameworks that principally inform the EPPIC approach to family work. They are: the three key foci, which concern areas of family relationships that are affected by psychosis; the phases model of how a family's experience and needs relate to phase of illness; and the family work 'pyramid', which is a framework for what interventions might be used and when they are appropriate. These concepts are explained in more detail below. Following this, in the next section, 'Family work in clinical practice', we describe how family work interventions are delivered at EPPIC using the pyramid framework.

The three key foci of the EPPIC family work approach

There are three key foci regarding the relationship between a young person and their family that need to be considered when assessing a family's needs, and which may present opportunities for family work or interventions:

- Focus 1: the impact of the psychosis on the family 'system' (roles, relationships, routines) and upon key sub-systems (e.g. the marital relationship)
- Focus 2: the impact of the psychosis upon individual members of the family, including the young person
- Focus 3: the interaction between the family and the phases of psychosis.

A number of key family work goals and strategies related to each of these foci have been identified based on direct clinical experience from the EPPIC program at Orygen Youth Health in assessing the needs of early psychosis families. These goals are presented in Table 1.

TABLE 1. **FAMILY WORK GOALS IN RELATION TO EACH OF THE THREE KEY FOCI OF FAMILY WORK**

FOCUS	GOALS FOR FAMILY WORK
Impact of psychosis on family 'system'	Minimise disruption to the life of the family throughout the phases of psychosis. Maximise adaptive functioning of the family in the aftermath of acute psychosis.
Impact of psychosis upon individual family members	Minimise the risk of long-term grief, acute stress, reactive depression and high level of burden in individual family members in response to psychosis. Minimise the risk of the young person becoming dependent upon their family as a result of a psychotic episode. Minimise the risk of the young person becoming alienated from their family as a result of a psychotic episode. Facilitate an understanding of what is meant by the term 'psychosis' and of treatment among all members of the family.
Interaction between family and phases of psychosis	Maximise communication skills, problem-solving skills. Minimise high EE responses. Maximise the family's responsiveness to early warning signs to facilitate relapse prevention. Maximise the family's preparedness for dealing with crises associated with psychosis. Maximise the family's preparedness for prolonged recovery, if this occurs.

The phase model of family needs during early psychosis

The needs of the family and young person will differ from family to family. Needs will also change depending on which phase of psychosis the young person is experiencing: for example, whether a young person is at high risk of experiencing a psychotic episode, or has already experienced a first episode of psychosis. While there are some common experiences shared by families of young people who are UHR and those with FEP, the following mainly focuses on experiences of FEP families.

The phase-based model of the needs of families in early psychosis has been developed by clinicians working across the EPPIC program. It describes four phases of needs and experiences families may have – 'recognition that "something's not right"', 'initial contact', 'towards recovery' and 'first relapse and ongoing recovery'. These needs, and how they relate to the three key foci of family work, are summarised in Table 2 on page 25. Although this model provides a useful generalisation, it is, however, important that clinicians understand the individual experience of each family with early psychosis.

Phase 1: recognition that 'something's not right'

During this phase, families are faced with upheaval and trauma, often with little or no real understanding of the changes occurring. For some young people, the rate of change may be almost imperceptible (especially if the psychotic episode is predominated by disorganisation and negative symptoms), while for others, the onset of a psychotic episode can be sudden, unexpected and acutely traumatic.[29]

There are three stages, outlined below, that a family may have been through during this phase, before detection of symptoms in a young person and arrival in an early psychosis service. Families of young people who have been identified as UHR for psychosis may require intervention targeted at the issues that can occur within these stages.

Explanations, denial and problem minimisation

An important theme that connects the experience of families during this phase is the search for an explanation. Explanatory models will differ between and even within families, as different family members come up with different ways of explaining the early changes that often precede frank psychotic symptoms. Many families struggle to cope with conflicting explanations for the young person's behaviour, symptoms and reduced functioning, which can make it difficult for the family to agree on a plan of action.

Families during this phase may:

- minimise early problems
- attempt to explain early changes as normal adolescent behaviour
- argue with other family members regarding the best way to address the problem
- label the young person's behaviour as 'bad'
- see the young person as lazy, stubborn, hostile or selfish
- experience feelings of anger, guilt and frustration.[30]

Acknowledging there is a problem

As the situation deteriorates, and the young person's symptoms become more apparent, the family develops a clearer perception that the young person may be experiencing mental health issues and some kind of help is needed. Family members may begin to become highly fearful for the young person's safety and for the safety of the family. Previous feelings of anger and frustration may be replaced by guilt, blame and fear, including feelings of shame about earlier responses to the young person's behaviour. Alternatively, family members may experience a generalised sense of anger or injustice associated with the question, Why is this happening? Families may feel frustrated and exhausted by their continued attempts to ameliorate the situation, embarrassed by their inability to manage the problem and distressed by a growing perception that their relative may be unable to lead a happy, productive life.

Because of concerns about possible harmful consequences of mental health services or police involvement, there is often a delay in taking action, even after parents have reached a consensus that outside help is required. Finally, the task of seeking out the most appropriate assistance can seem enormous (especially for families for whom English is a second language) because the family's capacity for problem-solving may have already been stretched to its limit.

Seeking help

After family members begin to agree that mental health assistance is required, they may have their first experience of being 'let down' by the health system. Families may have to make several attempts at accessing help, often including their general practitioner, before specialised mental health assistance is received. The level of distress and confusion may be exacerbated if the young person does not recognise that they are experiencing psychotic symptoms and need help or treatment.

Even at this point, different family members may hold opposing views about the potential harm of treatments, such as medication and inpatient care; however, the overriding desire of most families is to understand the problem and to have it treated swiftly and effectively.

Phase 2: initial contact and getting support

Following detection of symptoms and help-seeking for a family member, there are a number of common points at which families may experience significant distress. These include first contact with the service, receiving a diagnosis and commencement of treatment.

At first contact with a mental health service, such as an early psychosis service, family members are often in shock, overwhelmed and frightened about the current situation and the future.[31] This can be a time of acute stress for the whole family. Acute stress may involve symptoms such as a sense of detachment or absence of emotional responses, 'being in a daze', anxiety or increased arousal (for example difficulty sleeping, irritability, poor concentration and restlessness) and depression.[20]

After diagnosis, the reaction to receiving the news of a severe illness in a loved one is often shock and denial. It may be unbelievable for the family that the young person, who recently seemed healthy and happy, has received a diagnosis of mental illness, and it may be some time before family members can fully believe or understand what has occurred. It can be especially painful for parents to watch their child, who may have been on the verge of full independence, to be given such a diagnosis. At times families even express a sense of having 'lost' their child. In the face of psychotic symptoms, expectations for the young person's future can seem unattainable.

The commencement of treatment can cause further trauma to families, possibly introducing further family distress or conflict, especially if the young person refuses or does not adhere to treatment. It often means that families have to meet with a range of unfamiliar people and familiarise themselves with medications and treatment regimens. Clinicians should be aware that this new knowledge must be integrated by families at a time when their capacity for processing information may be compromised by acute stress.

The needs of families during the acute phase may be dominated by a need for information, about both the disorder and their own reactions to stress, and a need for practical and emotional support (see Table 2 on page 25). It is extremely unlikely that family members will be efficiently processing new information about any diagnosis or treatment approaches during their initial contact with early psychosis services. It is therefore important that information is repeated throughout their contact with the service to help them process and consolidate it. Another effective tool to help with processing information is to write down information for the family (e.g. regarding treatment, the service processes, medication regimens) and to provide information sheets. This will mean that families have resources they can take away with them to read in their own time or to refer to as needed to clarify their understanding of what is happening. Information sheets should used as aids to discussion, rather than simply handed over to the family without further comment.

Clinicians should be mindful that families presenting to an early psychosis service during an acute episode may be doing so following a relapse, not only at initial presentation for a first episode of psychosis. There may be similarities between a family's experience when the young person first becomes unwell and their experience following a relapse. In some respects, they may have greater ability to cope due to previous experience and increased knowledge; in others, however, they may need increased support as they face the disappointment of their young person relapsing. It is important for the family to understand that any reoccurrence of psychotic symptoms in a young person does not mean all is lost, and that it can still be part of the recovery process (see 'Phase 4: first relapse and prolonged recovery' for more information).

It is also worth noting that the needs of a family during an acute episode, and therefore approaches to family work, may vary depending on setting and stage, for example:

- acute in the community (at home)
- in the in-patient setting
- immediately following discharge from inpatient unit.

Phase 3: towards recovery

By the time the young person has begun to respond to treatment, families may have faced multiple disruptions to daily family life and, possibly, setbacks in the process of recovery. At this point a family may begin to recognise the limits of professional intervention and their own efforts to impact directly upon the psychotic episode. As they begin to adapt to the reality of psychosis, they often become increasingly focused on identifying realistic strategies to cope with acute psychotic symptoms, to prevent relapse and to improve the recovery of their family member.

It is during this phase that the long-term consequences of the disruptions and trauma may begin to emerge, with some family members exhibiting signs that they are, understandably, developing more chronic depressive and stress-related problems. In terms of the impact of the family upon the process of recovery, the young person may begin to experience the family's level of concern as intrusiveness, particularly if they are indeed beginning to recover, which may lead to a re-emergence of conflict and increased risk of relapse. Careful work with the family at this time can help family members understand the changing level of care that might be required as the young person recovers. For instance, where the family may have been initially wary of the young person going out on their own, it may now be appropriate for him or her attend a social gathering with friends.

It is important for clinicians to strike a balance between optimism and realism about the possible outcomes for the young person as they recover from a psychotic episode. They should be careful not to over-sensitise the family to the risk of relapse, as this may lead to excessive vigilance or anxiety, and hope should be fostered. However, the family's resources for coping with future challenges, such as relapse and ongoing recovery, need to be built up and strengthened. Family informational needs during this phase may include information on appropriate levels of care for the young person during recovery, further information on treatment during this phase and how to recognise early on the signs and symptoms of a psychotic episode in case of relapse (see also 'Recognising early warning signs', on page 47).

Phase 4: first relapse and ongoing recovery

A relapse or deterioration in the young person's mental state after recovery often represents a pivotal event in the lives of families. They may need to reconstruct yet again their explanatory model of the psychosis, perhaps shifting from 'temporary' to more 'permanent' explanations if it seems that the long-term prognosis is not as optimistic as first thought. The risk of depression may increase for parents as concerns emerge regarding long-term burden and loss of long-term expectations for their child, while siblings may develop fears about their own vulnerability to psychosis.[32]

In relation to the family system, siblings at this point may be at risk of feeling stuck between supporting their parents and shifting toward independence. Marital conflict may be exacerbated as a perception of long-term stress and burden becomes consolidated.[33]

Family needs may include more targeted family work interventions (see page 49-54) and access to ongoing community support.

TABLE 2. **THE FOUR PHASES OF FAMILY NEEDS IN EARLY PSYCHOSIS IN RELATION TO THE THREE KEY FOCI OF FAMILY WORK.**

	FAMILY NEEDS			
KEY FAMILY WORK FOCUS	**Phase 1 – recognition**	**Phase 2 – initial contact**	**Phase 3 – towards recovery**	**Phase 4 – relapse and ongoing recovery**
Focus 1: impact of psychosis on family system/s	Access to appropriate treatment as soon as possible Consensus regarding the explanation for the change in behaviour	Effective treatment for symptoms of psychosis Information that minimises potential for conflict regarding treatment Help to sit with diagnostic uncertainty	Early identification and more assertive treatment for treatment-resistant psychosis Identification and intervention for more complex family issues (for example, severe marital conflict, or abuse)	Effective acute-phase treatment for relapse and relapse prevention Treatment for ongoing recovery Consensus regarding long term prognosis Assistance (for example family therapy) for complex, ongoing systemic problems
Focus 2: impact of psychosis upon individual family members	To feel safe, and to feel that the young person is safe Access to appropriate and specialised assessment, treatment and care	Effective treatment for symptoms of psychosis Practical and emotional support to minimise the impact of trauma Understanding of what has happened to their relative Repeated, clear messages about psychosis and its treatment	Early identification and more assertive treatment for treatment-resistant psychosis Early identification and treatment of ‘at-risk’ family members (for example, depression, or acute stress)	Effective acute-phase treatment for relapse Access to ongoing community supports Treatment for depression and chronic stress problems
Focus 3: interaction between family and phases of psychosis	Accurate information about the early warning signs of psychosis Information about appropriate sources of help To minimise conflict regarding the young person’s behaviour	Education about the role of the family in treatment, especially for home-based acute phase management.	Ongoing information regarding treatment during recovery phase Information regarding appropriate levels of care as recovery progresses Information regarding early warning signs of relapse. Improved communication and problem-solving skills	Psychoeducation and communication training for high levels of expressed emotion or distress

Addressing family needs during the four phases

The needs of a family will be different at each of the phases described above, and will be different for each family. Any family work model or framework should be used as a guide, to inform practice, rather than a rigid checklist. It is up to individual clinicians to assess need in every case and form an understanding of the experiences the family has had.

The EPPIC family work 'pyramid'

The EPPIC family work pyramid is a basic framework for provision of family work, once a family is engaged with an early psychosis service. It has been developed from extensive clinical experience at EPPIC. It should be viewed not as a prescriptive model, but as a flexible approach to which clinicians can bring their own skills and experience with other therapeutic models or approaches. Different models of family work or therapy can be integrated into this pyramid approach depending, for example, on an early psychosis service's resources or a clinician's level of or previous experience.

A similar concept has been used in other mental health settings to conceptualise the type of services and minimum level of support to be offered to families (for example, Mottaghipour and Bickerton 2005[34]). The pyramid framework used at EPPIC (see page 30) indicates the spectrum of family support that should be made available to families, depending on need. It is loosely graded from core family work at the lower and middle levels to more specialised family work at the apex. Each component of the pyramid is discussed in more detail in the next section.

It should be highlighted that the pyramid does not represent a linear progression through interventions. Rather, there is fluidity between levels of the pyramid, and all aspects or none may be provided as needed to families as they progress through an episode of care with the service. Most importantly, clinicians need to maintain a flexible and collaborative approach.

PART 2

Family work in clinical practice

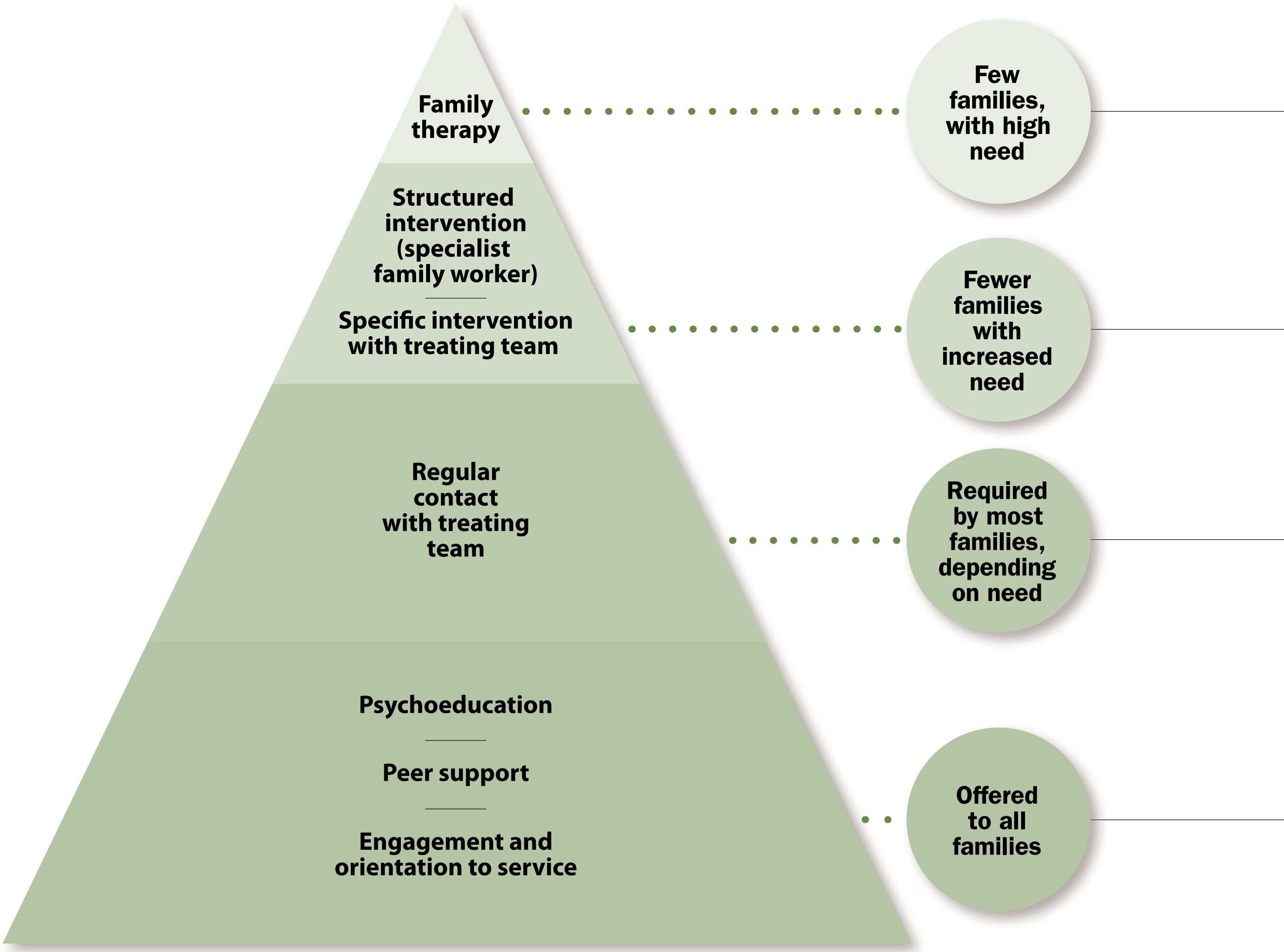
A stepped approach: the family work pyramid

Overview

This section aims to help clinicians put theory into practice by detailing practical information and strategies for family work, based on the family work pyramid. The basic premise of the pyramid framework is that the strategies presented can be used flexibly to accommodate the needs of individual families, depending on specific needs or phase of psychotic episode. A family's needs will be influenced by factors such as pre-existing coping skills, urgency of problems and pace of the young person's recovery. It is not expected that all families will need intensive support, and the number of families requiring interventions towards the top of the pyramid will be small. A list of routine elements of family work that all clinicians should feel comfortable putting into practice is shown in Box 1 on page 32.

In summary, families need to be provided with clear and accurate information about psychosis. They need reassurance about the excellent prospects for recovery from the first episode, tempered with appropriate realism about the risks of relapse. They need an opportunity to express their own feelings about their relative's illness and opportunities to ask questions. They need support to work through any anxiety, grief or despair. Finally, they need information about the kind of emotional environment which facilitates recovery, and sometimes need specific help in building skills to work towards such an environment.

The EPPIC family work pyramid



Core principles

Assumption of least pathology (assume the family is doing the best it can given its current recourses)

Flexible, phase-specific approach

Eclectic theoretical models (crisis theory, coping strategy enhancement, supportive therapy, cognitive-behavioural approaches systemic, narrative, solution focused)

Collaborative therapeutic approach – therapist is not positioned as ‘expert’

A focus on family issues in the whole team

Help family to identify any need for longer term family therapy and facilitate referral

- More specific psychoeducation
- Practical support (respite)
- Emotional support (complex grief)
- Further exploration of beliefs and attributions regarding behaviour, including help to navigate through the minefield of illness/non-illness differentiation
- Re-examine expectations
- Encourage flexible and non-blaming ways of coping
- Goal-setting (family members)
- Additional EWS and relapse plan development
- Skills development:
  - problem-solving models
  - communication skills

- Monitor support needs and enhance coping strategies
- Help develop strategies for medication adherence (if required)
- Develop EWS action plans
- Bolster strategies to address any unresolved concerns or crises
- Focus on recovery needs of family members

- Debrief family
- Ensure the family is heard
- Assist with emotional responses
- Understand explanatory models
- Discuss expectations regarding treatment
- Discuss information sharing
- Encourage contact with treating team
- Encourage self-care
- Resources and referral to other services

BOX 1. **ROUTINE ELEMENTS REQUIRED FOR FAMILY WORK**

Elements that have been shown to be generally effective in family interventions in psychosis are illness education, crisis intervention, emotional support and training in coping skills for symptoms of psychosis.[9]

The following are key routine elements of family work in early psychosis that every clinician should feel comfortable putting into practice:

- assessing and debriefing family and understanding 'the story so far'
- providing an empathetic approach: ensuring that family is – and feels – heard
- understanding the need for, and providing, a recovery approach for the family itself as well as the young person
- developing an understanding of the family's beliefs and explanatory model for psychosis
- addressing family expectations regarding treatment and outcomes
- psychoeducation
- introducing family peer support workers to family members
- ongoing assessment of the family (e.g. for stress and levels of coping)
- continuing case formulation and reformulation
- helping the family to identify early warning signs and develop strategies for relapse prevention
- assisting families to end with the service with an optimistic outlook and ability to manage in the long-term.

Initial contact: assessment, engagement and orientation to the service

Engagement

Engagement is a crucial, ongoing part of a family's contact with the service and its importance cannot be underestimated. In engaging families with an early psychosis service, clinicians should aim to:

- establish a working, trusting relationship with the family
- acknowledge and establish the family's part in the treating team, with a collaborative approach
- optimise flow of information
- reach an agreement on how ongoing contact will be managed.

Clinicians need to remember that 'family' can mean a range of relationships, and they may need to engage differently with each family member. For example, grandparents of a young person may need to be approached differently to intimate partners. Friends can also play an important support role for young people.

> ‘Sometimes it’s helpful, if you’ve been in hospital or if you’ve taken time off school, to have a friend come [to an appointment] and have them talk through it with someone. It kind of gives you an ally, so when you go back to school you have one friend who knows what’s going on and can sort of help reintroduce you to school.’
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

To the age group between 12 and 16 years, ‘family’ will likely mean close family: parents or other guardians and siblings. Siblings of young people in this age group particularly need to be considered when engaging the family, as this can be an important reciprocal relationship that is often neglected in family work (see Box 2).[35] From 16 years onwards, young people may be receiving more support from partners, who may also be in contact with the service.

BOX 2. **WORKING WITH SIBLINGS IN EARLY PSYCHOSIS**

Many clinicians may find it is difficult to engage siblings in family work. Some families wish to ‘protect’ siblings or other children in the family from the impact of the young person’s psychotic episode by, for example, keeping them away from the early psychosis service or family appointments. While this may be appropriate in cases of very young children, ideally, siblings should be included in family work, and this should be discussed with the family.

Various theories highlight the importance of sibling relationships during development. Sibling support is generally associated with positive mental health outcomes in adolescence and may therefore be valuable to a young person experiencing a psychotic episode, if siblings are engaged appropriately.

Conversely, clinicians should be aware of the effect having a sibling with psychotic symptoms may have on a young person’s siblings. The onset of psychosis in one sibling may significantly disrupt an important reciprocal relationship.[35] It can also raise concerns for siblings that they will become unwell themselves.

Practical aspects of engagement

Initial contact with families often occurs within an acute care setting and may therefore be initiated by a variety of workers, such as intake workers in community mental health services, inpatient staff and crisis assessment team clinicians. Given that this may be a stressful time for the family, clinicians in this instance need to be aware that the family will need time to debrief and have any immediate concerns addressed regarding the psychotic episode, its treatment and its current or future effect on family. Other practical information needs include an explanation of the service's processes – for example, how care will be provided, how to contact the service within and after hours, what the rights and responsibilities of family members are. Some tips that may help with engagement during a clinician's initial meeting with the family are presented in Box 3.

BOX 3. **TIPS FOR ENGAGING YOUNG PEOPLE AND FAMILIES DURING INITIAL CONTACT**

- Set the scene: discuss roles, responsibilities, expectations, plans, resources and contacts.
- Write information down: often the family may feel overwhelmed by information, and it is helpful to have it written down so that the family and clinician can refer to it later.
- Be empathetic and acknowledge the family's distress and concerns.
- Check that the family has understood what has been discussed and is clear about any plans that have been made.
- Talk with the family about family work being part of 'treatment as usual', thus normalising the experience.
- Reiterate the importance of having the family involved in the young person's decision-making, treatment and recovery process.
- Make it clear that you will work collaboratively with them.
- Introduce peer support early.
- Encourage questions and contact.
- Set a shared agenda in the first session and for subsequent sessions: establish what is important for the family each time.

As a general rule, face-to-face contact with the family by a case manager should be made as soon as possible. At this first contact, it is imperative that clinicians avoid being judgemental and make it clear they are committed to understanding the family's perspective and working collaboratively. Talking to a family about their explanatory model is important to understanding what they need and what their stressors are or might be in the future. It also respects their experience of having an unwell young person in the family.

Clinicians must be flexible in accommodating the preferences of the family to engage with the service. Scheduling is important, and the ability of a family to attend appointments should be taken into consideration. It may be useful to schedule family meetings around their working hours, or to consider different settings for meetings, such as at the family's home. Clinicians should also take time to understand what the family's most immediate concerns and priorities are.

> 'It sounds obvious, but it's essential that as clinicians we are on the same page as the young person and the family about what the family's priority is. If the young person's Centrelink payment has been cut off because they didn't attend an appointment because they were becoming unwell, and the family are reliant on the young person's payment financially to maintain their rent and bills, it's really unlikely that the family are going to be interested in coming in for sessions when clearly paying their rent is their number one priority!'
>
> – Clinician,
> EPPIC, Orygen Youth Health Clinical Program

A family peer support worker can also assist with engagement (see page 41). More information on the engagement process for young people and families can be found in the ENSP manual, *Get on board: engaging young people and their families in early psychosis*.

'I don't want them involved' – information-sharing and confidentiality

When working with families, clinicians and service providers must always keep issues of confidentiality – what information about the young person can be shared with their family and with whom – in mind. A balance needs to be achieved that is right for the family, the young person and the system, and this must be a constantly revised position. Box 4 summarises the EPPIC family work approach to information sharing.

Firstly, family work should be based on the assumption and expectation that information regarding the young person and their illness will be shared with their family. Clinicians should present the issue to young person in terms of *how* or *what* information should be shared rather than *if* it should be. Clinical experience at EPPIC shows that young people are usually happy to have information shared with their family and to have their family assisted by the treating team. It can sometimes be a relief for the young person to have a family worker or family peer support worker meet separately with their family to address concerns they might have.

Clinicians should talk to the young person and their family about what information might or might not be shared with the family, giving a rationale for what information is necessary to share, such as monitoring of medication, symptoms, instances of deliberate self-harm or suicidal thoughts. They should also emphasise that providing more information to the family can help alleviate their worries or concerns about the young person and thus improve family relationships. The discussion could also cover what information the young person is happy to have shared at a future point, for example, if they begin experience an acute psychotic episode.

It is important that clinicians are aware of how they speak to the young person about what they will discuss with their family. The phrasing of these kinds of conversations should aim to help the young person feel comfortable and empowered about sharing information, and the emphasis should be on respecting the rights and wishes of the young person. For example, the issue can be framed similarly to an advance directive, with the clinician working collaboratively to understand the young person's preferences for how information is shared in the case of a future psychotic episode. The understanding should be that where possible this will occur, although it cannot be guaranteed if, for example, the clinician's duty of care is compromised (see page 38).

> 'Looking back now, I don't think there was enough support from family work – even though I didn't want that support, didn't want my family involved. But it's sort of a catch-22.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

> 'My case manager always asked me beforehand whether she could share stuff with my parents. She always asked what was appropriate to say and what wasn't, so I always felt really comfortable. Cos my parents are really quite conservative so there are some things I don't want them to talk about.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Myth

I can't support a family if the young person doesn't want them to be involved.

Not true. there are numerous ways to provide support to families without violating confidentiality or the young person's privacy. These might involve another clinician providing general support and information to the family, or asking family peer support workers to assist with emotional support of the family. You should always consider the stage of illness, level of risk and the direct impact of this on members of the family when deciding what level and depth of information to share with the family.

As well as considering confidentiality from the young person's point of view, there will be times when the family requests confidentiality. Often this will occur when a family member shares information about the young person – for example, that they are taking drugs again – with the case manager, but asks that they don't tell the young person that they have been informed about the behaviour. Ideally this kind of situation should be pre-empted by discussions (as described above) with the family and young person about what information could be shared. When it does happen, it is best to explain to the family member that the information needs to be raised directly with the young person to be the most useful. If the family member still refuses, confidentiality must be maintained; however, the information may still prompt the case manager to explore the issue in subsequent meetings with the young person without giving away the specific concern of the family member.

If a young person declines to have their information shared with their family, clinicians may need to further explore this reluctance. For example, the young person might not want to share information with their family because they feel the clinician is implying they aren't mature enough to 'sort out' the problem themselves. It may be that they don't want to worry their family, or they aren't clear about what information the clinician wants to share. Clinicians may need to negotiate to share certain information with a young person's family and not other information. Importantly, given the benefits that family work can have, they should not give up if a young person refuses to have their family involved. Their refusal should be revisited regularly and clinicians should continue to negotiate terms of information sharing. Ultimately, if there is a conflict between a young person's wishes and their best interests, particularly in a situation of high risk to the young person, the duty of care remains with the clinician and the confidence will need to be broken.

> 'I was afraid of my parents not getting me and not understanding how my mental illness was affecting me and going, "You know what? This is too much. We're going to leave and we don't want any more contact with you"'.
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

> 'I remember the service calling my mum and my dad and telling them I was seeing the service and why I there. And I got really shitty about it, because I didn't want at that point anyone to know, because I was super independent. And, I guess, still in denial about what was going on. But it would have been good if someone had said, "Look, we're thinking about contacting your parents. Do you consent for us to do that?"'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Legislation and duty of care

Legislation regarding disclosure of information and duty of care differs from state to state. It will also apply differently depending on whether a young person is a minor or not. Clinicians should familiarise themselves with relevant legislation in their state, and it is up to managers to keep staff informed and also promote discussion of issues of confidentiality and consent in their teams.

BOX 4. **AGENDA: GUIDELINES FOR MAXIMISING INFORMATION SHARING**

Assume

Begin with the assumption and expectation that information will be shared.

Grounds for sharing information

Always give a rationale for why information needs to be shared.

Explore reluctance

Discuss young person's concerns about sharing information with family (e.g. if they are worried about parent response or don't want to burden them).

Negotiate

Discuss what information the young person might be willing to share, and whether this might change at a later date.

Don't give up

Always revisit the issue of sharing information.

Abide by the Act

Confidentiality ultimately is predicated on relevant legislation (e.g. MHA).

Assessing the needs of families

When a family first comes into contact with an early psychosis service, time should be taken to assess the needs of the family: this should take place separately from the family's involvement in the young person's assessment see the ENSP manual *'Let me understand...' assessment in early psychosis*. With reference to the three family work foci (page 19), this assessment process should aim to identify needs arising from the impact of a first episode of psychosis and how they might be addressed. Ideally, it will provide insight into the family's resources for coping and problem-solving, their communication patterns and their strengths. See page 70 for examples of questions that explore the impact of FEP on the family.

However, clinicians should be aware that not all families will be ready or willing to have an assessment straight away, if at all. Even after families have agreed to an assessment, clinicians should keep in mind that family members may harbour fears about the clinicians themselves and the outcome of the assessment process. Common fears can include:

- the clinician will overtly or covertly blame the family for the psychotic episode
- the clinician will automatically admit the young person to hospital without consultation
- the clinician will fail to provide adequate follow-up after the assessment process is under way

- the young person will be turned into a ‘zombie’ by medication or experience serious side-effects
- the young person will never forgive the family for their having contacted the service.

The process of assessing family needs should be distinguished from that of taking a psychosocial history of the young person’s presenting problems. Rather than a chronological history of problems, a family assessment should focus on:

- the family’s immediate concerns about early psychosis
- their knowledge and beliefs regarding early psychosis and its treatment, including explanatory models
- the family’s composition and history (including psychiatric history, relationships, major events, history of coping with stress)
- family involvement in care, both currently and in the pathway to care
- the impact of the young person’s psychotic symptoms on both individual family members and the family system
- the family’s coping resources, and the family’s own appraisal of these
- patterns of communication and problem-solving
- the family’s preferred options for support and intervention.

See page 72 for a family assessment template.

> ‘My mum was ok – she understood that I had a problem. Whereas my dad was like, “I don’t understand why you’re doing this to our family”. It took him a lot longer to understand everything.’
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

It is essential at the first meeting with a family to allocate sufficient time (often 90 to 120 minutes) and to give the family the opportunity to relax and speak freely. If a family perceives that the clinician is rushed or that the meeting has low priority, the family may reciprocate the attitude and the opportunity to engage with the family may be lost. Qualified interpreters must be available for families who are not able to speak English, although family members should have the opportunity to decide if they wish to work with interpreters. Clinicians should also consider that they will need more time for family meetings when working with interpreters (see ‘Common challenges for family work, Language and culture’ on page 64 for more information).

Peer support from peer support workers and other families

The role and rationale for family peer support workers in an early psychosis service is presented in the chapter ‘Implementing a family peer support program for early psychosis’ (page 17). Briefly, they are non-clinicians who provide a valuable lived-experience of having a family member develop FEP to families who have previously had none. They also play a role in helping orientate and engage families to the service.

> ‘You feel so alienated from your peers and work colleagues. When our daughter first became unwell, I didn’t know what to do, or who to talk to about it. I felt like no one understood. Being able to speak with Sue [a family peer support worker] was fantastic. She was able to relate to my experience and give me a sense of hope and an idea about what may happen in treatment for my daughter. She was also great at reassuring me about the case manager. I wanted someone to tell me things are going to be ok, from someone who has gone through this before.’
>
> – Family member,
> EPPIC, Orygen Youth Health Clinical Program

All new families should automatically receive contact from the family peer support program when they enter an early psychosis service. How this is done will depend on service process; however, in cases where it is inappropriate for a family to be involved in the young person’s care (for example, families in which there is a history of abuse or neglect), clinicians must be aware of how to opt families out of an automatic system of referral to peer support.

Family peer support workers should have regular contact with a young person’s case manager, checking in with them to discuss how the family is coping or to touch base about any milestones of treatment (e.g. hospitalisation, discharge). The case manager will only share general information about the young person.

There are a number of challenges and dilemmas that may arise from family peer support that clinicians should be aware of:

- **Changing roles** Clinicians and family peer support workers may find it uncomfortable initially when the family peer support worker makes the shift from being a user of the service to being a member of staff. Both parties should make the effort to respect the importance of both ‘experiential’ and ‘professional’ knowledge.
- **Self-care and supervision** Family peer support workers must remember to take care of their own needs while they are supporting another family. It may be stressful if, for example, a family’s situation reminds a family peer support worker of their own past (or current) experiences, and they must be given opportunities to debrief. Supervision for family peer support workers is vital, as is ensuring that they feel comfortable in taking time out if they feel they require it.

- **Managing boundaries** Family peer support workers need to understand the boundaries that must be applied when working with families. Family peer support work should not have any adverse effects on the family peer support worker's own circumstances. They should therefore avoid making phone calls to families from their own homes, meeting with family members in the support worker's home or socialising with families they are supporting. Conversely, family peer support workers need to be mindful of the boundaries to their role in supporting a family. They should not be directive in what they tell families, and any questions regarding treatment or medication should be referred to the treating team. This will help encourage a positive relationship between the family and case manager, and is an essential way that family peer support workers help families.

Psychoeducation, information sharing and debriefing

As already mentioned, one of the main needs of early psychosis families is information that is relevant and easy to understand. It is important to remember that most families exposed to a first episode of psychosis have little prior knowledge of mental illness or its treatment. The situation is complicated by diagnostic ambiguity and instability, as well as great variability in the degree and rate of recovery. Information therefore needs to be provided to families at all stages of contact with the service, relevant to the family's needs at the time, and should be repeated to assist families in processing and consolidating the information.

> 'Right in the beginning, when Evan was admitted to hospital, I felt like even though the nurses and doctors met with us regularly, I couldn't for the life of me remember what they had told me. I would walk away feeling just as confused! Once Evan's case manager got appointed, it meant we had a regular person I could call when I had a question, or was worried about Evan's medication and the dose or about what to do if he was struggling to get to sleep. Having his case manager meet with us regularly and talk through about what psychosis was and what the medication did and how it was working or not working was really helpful. I was so scared and stressed that I needed to feel ok to ask questions and to have someone check in regularly about my understanding of what was happening.'
>
> – Family member,
> EPPIC, Orygen Youth Health Clinical Program

Psychoeducation can be delivered to families individually by a case manager – with or without the treating doctor or family peer support workers – and through multi-family group education sessions. At Orygen Youth Health, a ‘family and friends’ group is available to families that provides initial psychoeducation covering the nature of psychosis, the role and efficacy of medication and other biopsychosocial interventions, prospects for recovery and what services and support are available for both the young person and family members. Family, significant others and friends may wish to attend the family and friends group more than once, to help with understanding psychosis and its treatment, and also to gain support from the other members of the group. This may be the first time they have met other families that have an unwell young person, which can provide the important benefit of not feeling alone in their experience.

The goal of psychoeducation should be to increase a family’s understanding of their relative’s condition, including treatment and recovery for FEP, and to help them to relate to the young person appropriately – for example, how best to respond to the young person to avoid blaming them for behaviour related to symptoms, or how to talk openly to the young person about what symptoms they might be experiencing. It should cover three general areas: symptoms and diagnosis, prognosis and recovery, and treatment. The appendices provide a number of information sheets for families that will be useful when discussing these topics. Again, the value of appropriate, written information cannot be underestimated.

Explaining symptoms and diagnosis

Explaining a diagnosis – even a provisional diagnosis – to families is an important clinical task, which requires careful timing and collective consideration by all clinicians involved in the early phases of a psychotic illness.

One of the difficulties faced by clinicians is that diagnosis at first presentation can be unstable, since additional features of the illness may emerge after treatment has commenced. It is important to explain to young people and their families the need for a thorough, considered, and ongoing assessment of the clinical facts before an illness can be named. Terms such as ‘first episode of psychosis’ can be used to help families sit with diagnostic uncertainty; families should also be reassured that further information regarding the unique features of particular psychotic illnesses will be provided promptly if a more specific diagnosis is made.

Clinicians may find it useful to begin explaining a diagnosis with a conversation about ‘What is your understanding of psychosis or psychotic symptoms?’ This can explore what psychosis means to the family, including previous or current family experiences of mental illness or mental health services and the family’s explanatory model(s). When exploring the latter, clinicians should remember that family members may have differing explanations for the psychotic episode. They should ensure that each family member’s thoughts are validated and that each member’s beliefs and explanatory models are encompassed.

Naming the illness and explaining the diagnosis will give the family a framework to use to understand the young person's behaviour and what the focus for recovery will be. This in turn will help with their relationship to the young person. The following points may help when talking about a young person's diagnosis to their family.

- 'Psychosis' or 'psychotic episode' may be less stigmatising than 'schizophrenia', which at the early stage of psychosis may not be an appropriate diagnosis. Some families, however, might find 'psychosis' too vague, and it may be helpful to explain to them about why it is used as a term rather than the names of specific conditions.
- Families should receive detail about the symptoms of psychosis, and be shown how these may have manifested in the young person's behaviour.
- Clinicians should introduce the concept of the stress–vulnerability model, and how it relates to phases of illness, treatment and recovery.

Discussing the future: prognosis and recovery

Prognosis

It is likely that once family members have begun to emerge from the immediate crisis of the first acute symptoms of a psychotic episode, the focus may begin to shift to long-term issues such as the young person's future and prognosis. Often the question of cure is raised, with the implicit hope that the young person will remain symptom-free and return to their former self. Whatever a young person's prognosis might be, it should be made clear that prognosis is a changing state, and it will be revisited throughout the young person's contact with the service.

Important points to make when delivering the message regarding prognosis include:

- The focus in FEP is on recovery (rather than a 'cure').
- There is a high probability that a young person with a first episode of psychosis will recover and return to their normal life and developmental and career trajectories.
- Relapse may occur, even during recovery, and can vary greatly between individuals. It is therefore difficult to provide an accurate prediction of the long-term course of the illness for a particular young person.

Recovery

Families and young people should be informed that recovery includes not just remission of symptoms, but also social, vocational and psychological recovery. It is usually not a straightforward process, and often the social, vocational and psychological recovery will take longer than symptomatic recovery.

See the appendices for information for families that will help discuss

- positive outcomes of recovery
- other aspects of recovery
- how to help with recovery.

Discussions about long-term recovery will consider the following factors:

- premorbid history and age of onset

- response to medication
- level of insight and acceptance
- availability of supports
- complicating factors, such as ongoing substance misuse, co-morbid depression or anxiety, or high levels of interpersonal stress.

This discussion may raise fears for families when symptoms are resistant to initial treatments or where insight is poorly developed. These families can be informed that ‘treatment resistant’ psychosis can sometimes be treated more effectively with second- and third-line medications such as clozapine, in conjunction with more intensive psychosocial interventions. A young person’s denial of illness can be reframed as a self-protective measure. Families can be reminded that while some young people develop insight rapidly, for others the process is gradual, while others may never develop beyond denial and rationalisation.

It is not imperative that the young person, or even their family, acknowledges that they are unwell; what is more important is whether or not they are adherent to treatment. Some young people will continue to take medication and meet with their case manager or doctor despite never openly acknowledging they have FEP or have had a psychotic episode.

Treatment

As many families will have little knowledge of treatment approaches for early psychosis, explaining the approach to be taken to a family will help them to better support the young person in their treatment. Topics to cover include the biopsychosocial framework of psychosis and the phases model of early psychosis, and how these inform the treatment approach, including medication and psychosocial interventions.

Psychoeducation regarding medication should explore the family’s understanding of medications, address any misconceptions they might have, and provide information about early psychosis and medication as required. Note that it is important that the prescribing doctor and the case manager consider the young person’s feelings or concerns about medication. There are a number of sources of medical information for young people and families. NPS MedicineWise has a range of tools and information sheets on antipsychotic agents at www.nps.org.au/medicines/brain-and-nervous-system/medicines-for-psychotic-conditions. See also the ENSP manuals *Medical management in early psychosis: a guide for medical practitioners* and *Medical interventions in early psychosis: a practical guide for early psychosis clinicians*.

Some useful information to provide includes:

- Medication helps to balance chemicals in the brain to improve symptoms.
  - Use the neurotransmitter model, if appropriate, to explain in more detail how medications work.
- Positive psychotic symptoms, such as hallucinations, delusions and confused thinking, usually improve most rapidly following medication, while negative symptoms, such as lack of motivation, usually take longer.

- Continuing to take medication, even after symptoms have been controlled, is usually advised, to protect against relapse and maintain recovery. It may also help the young person to cope better with the stress of returning to usual activities.
- The desire to stop taking medication is common and quite normal. This may be for valid reasons, such as unpleasant side-effects, or because every time a young person takes their medication it reminds them that they have an illness. Everyone who is prescribed continuing medication has to balance these feelings with the possibility of becoming unwell again, and what that would mean to them.
- Treatment may also focus on other comorbid conditions.

Psychoeducation regarding psychosocial interventions should discuss the important role of these interventions in treatment, and cover the options available, including individual and group interventions.

Regular contact with treating team

Contact with the family needs to be regular, with frequency dependent on the phase of illness. During the acute phase, for example, case managers might contact families as often daily or every second day. But even when the young person is well, it is important to maintain contact. Clinicians should be proactive in this, contacting the young person and family monthly and encouraging them to come in regularly to touch base.

> ‘Every time I caught up with Eddie’s case manager, she would ask how we were going as a family and how Eddie was going, and we would chat about what psychosis was, how we thought it was impacting on Eddie. She really cared, and wanted to keep checking about what she could, or the doctor could be doing, to support us in order to support Eddie. It meant a lot that she cared about asking.’
>
> – Family member,
> EPPIC, Orygen Youth Health Clinical Program

The support given to families during their ongoing contact with an early psychosis service will also change focus depending on the phase of psychosis. For example, in the acute phase, families may need support ‘getting through it’, or reminders about the importance of taking medication. Towards recovery, clinicians may focus on relapse prevention and recognition and management of early warning signs over page. During recovery, they may talk about options for the young person to return to work or school.

It is crucial that throughout this contact clinicians highlight the role of the family in recovery – instilling in family that they are active participants in and essential to the recovery process for the young person. They should also maintain a sense of hope in the family and emphasise the family’s own recovery process and need for self-care.

Recognising early warning signs

A period of early warning signs (EWS) commonly precedes a relapse by one to four weeks.[36] This period of EWS offers a window of opportunity to reduce further deterioration in the young person's mental state or functioning. Because family members are often the first to notice EWS, they need to be helped to recognise them and to know what to do if they occur. However, a balance needs to be struck between increasing a family's awareness of EWS (and preparing them to act) and the risk of over-sensitising them to fluctuations in the young person's behaviour, which could lead to increased anxiety and unhelpful hypervigilance. In discussions with the family about EWS, clinicians should remain optimistic, and emphasise that managing EWS is a preventative measure and part of maintaining recovery.

Clinicians should help the family to identify what the EWS for their young person might be (a list of common EWS is provided in page 79) and work collaboratively with the young person and their family to develop a relapse action plan based on these EWS. Suggested questions to help with this process include:

Detecting the problem:

- What first made you realise that something was 'not quite right'?
- When did you notice something was definitely wrong?
- What do you think were the early, subtle behavioural or personality changes?
- Which signs were noticed first?
- Did these changes get better or worse over time?

Contextual information:

- What was going on at the time of these changes?
- Were there any stressful events in the person's life at that time?
- Did the changes seem to come 'out of the blue'?

Family members' reactions:

- Who first noticed these changes?
- How did the family and the young person explain these changes?
- Was anything done or suggested to address the concerns? By whom?
- What were people thinking about the changes?
- Was there agreement/disagreement about what was happening and what to do?
- Thinking back, what do you think were the most important changes you noticed in the young person or the family?

Seeking help:

- Who first sought help? From where?
- How was the decision to seek help made, and was there agreement on the course of action?
- What was the experience of seeking help like?
- If you were to notice these changes again, what help would you look for?
- How do you think you would seek help again? Would it be the same way or differently?

A sample EWS action plan is presented in Table 3 over the page.

TABLE 3. **AN EWS ACTION PLAN DEVELOPED WITH INPUT FROM A YOUNG PERSON AND HER FAMILY**

STAGE OF EWS	EARLY WARNING SIGNS	YOUNG PERSON'S STRATEGIES	FAMILY'S STRATEGIES
EARLY	Withdrawal Distance Low energy Lack of interest Depressed mood	Use some relaxation/distraction exercises: e.g. have a bath, do something I enjoy (like going to the beach), do some exercise, listen to music Try to have quiet time around others (in lounge room) rather than in my room If I can't solve a problem, try taking a break from it and distracting myself for a while Talk to friends or people I feel comfortable with Spend 10–20 minutes trying to solve the problem/issue	Encourage young person to use her own relapse action plan Assist in maintaining young person's usual routines and attempt to reduce stress and demands where practical Support each other and spend time together Discuss observations together and then check out what's been happening for the young person Try to adhere to normal family routines
MIDDLE	Eating less Trouble sleeping Preoccupied Vague	Even though it might be the last thing I feel like doing, turn up to my appointments Try to talk to Mum and Dad about what is going on	Encourage adherence to medications Encourage young person to contact case manager to arrange review Gently enquire if we can offer support (e.g. help waking up) Acknowledge that young person may not share concerns due to not wanting to worry us (let her know we are likely to worry less if we know what is going on) Mum to seek support from good friend

Table continues over page

STAGE OF EWS	EARLY WARNING SIGNS	YOUNG PERSON’S STRATEGIES	FAMILY’S STRATEGIES
LATE	Not going out of the house Getting angry at small things Poor appetite (stopped eating) Suspiciousness about people Concerns about house being monitored	Contact case manager or doctor for extra support	Offer to accompany her to next appointment If no success, inform young person that family members will be contacting team to get advice Sit down together and plan what to say Be aware of own limits, ensure family members get some ‘time out’ Discuss plan with young person but don’t confront her with a list of concerns

Adapted from *Family work for relapse prevention in early psychosis: a cognitive-behavioural approach* (2012).[37]

Specific interventions with treating team (may include specialist family worker)

While all families should receive psychoeducation and will find this a useful and adequate intervention, others may require more specific family work interventions. Often this is because the impact of the psychotic episode on the family and the family system is substantial, and they need practical strategies for coping with the young person’s changed behaviours and their own changed expectations of the young person. If the family is not coping, it may be that this is affecting the young person’s recovery. There may also be issues of confidentiality or difficulties with engagement.

The bulk of the ongoing contact with the treating team to this point will have been carried out by case managers; however, more specific interventions may require the involvement of a specialist family worker, either indirectly, via consultation, or directly, in a joint intervention with the case manager or doctor.

Common scenarios where a family may benefit from specific family work interventions, and which may require the help of a specialist family worker, include:

- the young person has expressed concerns about or refused to have their family involved (see 'I don't want them involved' – information-sharing and confidentiality on page 35)
- there are high levels of tension and distress in the family, which may be distracting from engagement of the young person (e.g. during assessment)
- there are high levels of familial conflict
- young person displays verbal or physical violence
- family members or young person are exhibiting difficult behaviours (drug use, non-adherence)
- there is a history of long-term, difficult family problems
- the young person is showing persistent symptoms/multiple relapse
- a family is recently arrived from non-English speaking countries
- engagement and 'boundary' issues.

The role of the family in recovery

In the case of high stress or conflict in the family, the role of the family in recovery may have to be reviewed. At this point, families may need more specific information and psychoeducation about what they can do to improve the emotional environment of the family, along with 'hands-on' support to do this. For example, it may help to increase family contact or home visits for a period.

Interventions may include discussion of examples of potential stressors from the individual, environmental and interpersonal domains, and review potential protective factors such as the coping skills of the young person and family. Those factors the family can influence should be emphasised and distinguished from those they cannot.[37]

Ways the family can help recovery and reduce the likelihood of relapse include:

- managing stress and conflict
- providing and communicating love, warmth and support
- having and expressing hope for the future
- maintaining a strong social support network.

Interpersonal stressors that have been linked to higher rates of relapse in psychosis include:[2,7]

- being critical about the person and what they do
- focusing on negatives
- being intrusive or over-controlling

- exerting excessive pressure to perform
- having frequent conflicts and arguments
- self-sacrificing behaviour (e.g. sacrificing all your resources for an ill relative).

An information sheet that can be used to help families create a positive emotional environment is provided on page 80.

Structured intervention with a specialist family worker

Some young people will experience prolonged recovery from a first episode of psychosis, and/or will go on to have multiple relapses. The possibility that they may not fully recover needs to be considered at this stage, along with interventions to further try to assist the recovery process by helping the family adjust to the situation or improve coping skills. This may include asking families to participate in more structured, behavioural interventions.

The process for involving a family in structured intervention may be as follows:

- Case manager (in consultation with specialist family worker) reassesses the family's needs.
  - This may involve addressing any persistent problems that the family is experiencing and setting goals.
- If needed, the family should be provided with more specific psychoeducation about the role of the family in recovery.
- If the family needs help with developing skills to help them manage the emotional environment, they should be encouraged to participate in a structured intervention to improve skills for communication and problem-solving (see Box 5).

Myth

When a family is referred for specialist family work intervention, the key clinician does not continue with family work.

Not true. The clinician and family worker should collaborate to provide ongoing 'regular' family work as well as targeted interventions.

Structured family interventions can be carried out either with a single family or within groups. McFarlane (2004)[38] describes a multi-family group treatment method, a version of which has been used at Orygen Youth Health. This type of intervention is emerging as an effective, evidence-based treatment in FEP.

Whether delivered in groups or singly, the key elements of a structured intervention are: encouraging a genuine working relationship with the family and maintaining a positive approach; information that provides an illness model; enhancing coping strategies for difficult behaviours by promoting stability and structure within the family; a behavioural approach that focuses on current issues, problem-solving and goal-setting; cognitive strategies to help family members attend to their own needs; and improving communication to reduce levels of expressed emotion or heightened states of emotional distress (see page 11).[39]

BOX 5. **STRUCTURED INTERVENTIONS FOR SKILLS DEVELOPMENT**

In a randomised controlled trial of a structured intervention to prevent relapse in early psychosis, Gleeson et al. (2009, 2010) found that the intervention was associated with a reduction in relapse rates at 7 months, longer time to relapse and a reduction in perceived stress in families.[11,21] The following describes some of the components of the intervention used in this trial. For more information, read *Family Work for Relapse Prevention in Early Psychosis: a Cognitive-Behavioural Approach*.[37]

Communication skills training for families

Clinicians should explain that clear communication skills will help families create and maintain a positive emotional environment. Learning effective communication will help families:

- reduce negative emotion in the family
- better manage interpersonal conflict
- improve interpersonal skills in the young person, through modelling
- better discuss EWS and the relapse action plan
- improve quality of relationships generally.

A discussion of the core skills of effective communication may cover:

- active listening
- expressing positive feelings
- making requests
- expressing negative feelings.

Page 82 contains and information sheet for families on core communication skills.

BOX 5. STRUCTURED INTERVENTIONS FOR SKILLS DEVELOPMENT CONTINUED

Problem-solving

The following points can be used to explain the rationale for learning problem-solving skills:

- Families are likely to face a wide variety of problems, from the relatively simple such as organising an outing, to the more difficult, such as addressing drug use or aggressive behaviour.
- It would probably be helpful for all of us to 'sharpen up' on our problem-solving skills.
- When stress levels are high, it is good to have an agreed method to tackle problems. It can help to get others involved and to promote teamwork.
- Problem-solving techniques can be effective for a range of problems and can be used by the family in the future.

Therapists can review a family's current problem-solving approaches by asking questions such as:

- When you have a problem, how do you usually try to solve it?
- Can you give an example of how you dealt with a recent problem?
- Who was involved in the discussion?
- Did you agree on what the problem was?
- Did you and others in the family generate and evaluate solutions?
- Did you agree on a solution and implement it?

They can then practise new problem-solving skills with the family by taking them through the following steps:

- Step 1: Define the problem.
- Step 2: Generate possible solutions.
- Step 3: Evaluate suggested solutions.
- Step 4: Decide on a solution.
- Step 5: Plan how to carry out the solution.

The problem-solving model provided on page 84 can be given to families to help with this process.

Family therapy

Most families will find the level of intensive support they need decreases as their young person recovers. However, there are a small number of families that may not only require targeted interventions for specific challenges or structured interventions for potentially established disorders, but also further therapy to address underlying family issues. These issues may be related to long-standing difficulties that are outside of new ones that might have been caused by the advent of the young person's psychosis. They include pre-existing relationship or marital difficulties between the parents, problems such as a family member's gambling addiction, or where there has been a disclosure by one of the family members of a history of abuse.

In the case where a clinician has identified issues that might require long-term family therapy, it may be appropriate to refer the family to an external family therapy provider (for example, Relationships Australia, or the Bouverie Centre in Melbourne). This is for both time-related reasons (longer-term therapy may be beyond the scope of the period of care at an early psychosis service) and also because it can be useful to have problems related to long-standing difficulties treated separately from those presented by the psychosis. However, it will be up to each early psychosis centre to determine the level of family therapy they are able to provide.

The role of the treating team and the specialist family worker in this case is to introduce the idea of specific family therapy to the family and prepare them for it. External therapy should be framed as a part of the family's self-care, as an important way to reduce some of the burden they are under.

> 'Sometimes I thought it became about my family's dynamic and problems – my parents' own relationship problems – and I was like "Oh hey, what about me?" So I think the case manager has to be good at managing those family dynamics if they can and steering it back to what you've agreed to talk about.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Common challenges in family work

There are a number of common challenges that a young person and their family might face that can make it difficult for them to engage with a service or treatment, and therefore can affect the young person's recovery. In some, but not all, of these cases, extra interventions from a specialist family worker may be required, possibly with family therapy – the 'top' end of the family work pyramid. The following section aims to address these challenges, providing practical examples of when a family might require specific interventions and what these might involve.

Aggression

Acts of aggression by a young person can be particularly difficult for families to cope with, as they pose a risk to other family members and provoke fear and anger. Although physical aggression is obviously the greater problem, sustained verbal aggression can also be very threatening.

Therapeutic intervention for aggression is based on the premise that no family member should be required to tolerate another's aggressive behaviour. This should be stated clearly and directly to family members. Behavioural strategies of limit-setting and problem-solving can then be applied. Clinicians (either case managers or the specialist family worker) should also inquire into family members' attitudes to aggressive behaviour, as an individual is unlikely to change a behavioural pattern that others reinforce.

It is important to distinguish between aggression that is clearly related to episodes of acute psychosis and that which is part of a more general behavioural pattern. In the former case, psychoeducation may help avoid particular triggers of aggressive behaviour. If aggression is part of a more general behaviour pattern, it may help to obtain from the family a sense of the stable personality traits of the young person. If it becomes apparent that aggression is part of a longstanding problem that clearly predates the onset of the psychosis, this may help the young person and the family understand the causes of aggressive behaviour and implement strategies to deal with it.

Aggression that is unexpected and out of character for the young person can be particularly shocking and traumatic for early psychosis families, compared with families whose relative has been ill for some time and who may be more used to (though not necessarily accepting of) aggressive behaviour. The young person often will also be distressed about their behaviour and will need time for individual debriefing.

CASE SCENARIO **LUKE**

Luke, 20 years old, experienced his first episode of psychosis 6 months ago. During his acute episode he became verbally and physically aggressive towards his mother, Jen, pushing her against a wall. This resulted in his traumatic admission to hospital, in which police and paramedics were involved. Prior to this, Luke had no history of violent or aggressive behaviour.

During the onset phase of Luke's psychotic episode, Jen noticed irritable and aggressive behaviour emerging and worsening, which she attributed to Luke's relationship breakup, some financial issues that he was experiencing and a subsequent increase in his cannabis use. Luke reported to the treating team when he was unwell that he thought his mother was an imposter who was going to harm him and he felt that he needed to protect himself.

Luke's beliefs about his mother have subsided with treatment; however, the treating team considers it important to address them with Luke's family due to the risks posed by the beliefs if they should reoccur.

The case manager arranges an appointment to meet with Luke's mother alone. They discuss the nature of Luke's first admission to hospital and acknowledge how traumatic and distressing this must have been for Jen and Luke. Jen is provided with an opportunity to debrief about the experience.

At the next appointment with Jen, the case manager inquires into Jen's beliefs about Luke's behaviour to gain a better understanding of her explanatory model. Jen does not believe that Luke's aggression was linked to his psychotic episode and says that Luke would never do anything to harm her. She states that the stress that Luke was experiencing at the time (the relationship breakup and financial situation), coupled with substance use, caused the aggressive behaviour. She believes that now that he has stopped using cannabis, the aggression is unlikely to occur again. In addition, Jen strongly states that she never wants Luke to go back to hospital again because of the trauma he experienced the first time around.

The case manager uses the stress–vulnerability model to explore how stressors could have an impact on mental health and the emergence of symptoms. She agrees with Jen that the stressors Luke was experiencing contributed to his aggression. The case manager provides some particular psychoeducation about the symptoms (Capgras delusions) that Luke experienced, and acknowledges that this was very frightening and disturbing for Luke and for Jen. The case manager agrees with Jen that Luke would never hurt her intentionally, but says that Luke's symptoms mean that at times he might not be able to recognise his mother, which could increase the risk of aggressive behaviour. Jen agrees to work on a more formal safety plan because of the unpredictable influence of psychotic symptoms. The case manager also agrees that the hospital admission was very traumatic for all involved, and suggests to Jen that the best way to prevent this from happening in the future is to work with Luke to develop an early warning signs plan. That way Luke, Jen and the case manager can intervene early to prevent future episodes of aggressive behaviour.

Non-adherence to treatment

Non-adherence to medical treatment is a particular issue for people with psychosis. Rates of non-adherence soon after initiating antipsychotics have been shown to range from 48–74% in people with schizophrenia.[15] Reasons for this include adverse effects of the medication, lack of insight into illness, lack of efficacy of treatment and lack of belief in the benefits of pharmacological treatment. Importantly, patients with the support of family or significant others show improved adherence compared with those who don't.[15,40] Therefore, it is not just the young person, but the family too who need to be accepting and supportive of medical treatment.

Basic behavioural strategies for monitoring medication and managing adherence problems will enable families to help their young person adhere to treatment. These include incentives for regular tablet-taking, such as crossing off days on a calendar, or aids such as dosette boxes. However, other issues require a more subtle approach. People with early psychosis frequently have no previous experience of long-term treatment regimens, and simply presenting a rational case for the use of medication can be insufficient. It is often necessary to accept a degree of experimentation with dose, while avoiding a judgemental or critical position.

A young person refusing or forgetting to take their medicine can be a source of frustration and conflict for families. They can feel helpless, or that the treating team blames them for the young person not adhering to treatment. Clinicians should avoid placing responsibility for the young person's adherence on the family, and instead try to provide them with the skills to encourage the young person to take their medicine. It may be important to review with families and the young person why adherence is a problem, and the family should be involved in developing strategies to help with adherence. Some young people may have cognitive or memory deficits that mean they simply forget to take medication, while others may be reluctant to take medication because of current or anticipated negative consequences of using medication, such as side-effects. Families will need an understanding of the causes of non-adherence to support the young person in the most appropriate way.

For further information and strategies to help with non-adherence, see the ENSP manual *Medical interventions in early psychosis: a practical guide for early psychosis clinicians*.

CASE SCENARIO **KELLY**

Kelly is 16 and has been taking the antipsychotic risperidone for 2 months. The medication worked effectively and rapidly, with a reduction in the frequency of her auditory hallucinations and diminished paranoid ideation and associated distress. However, now that Kelly's symptoms have receded, she has stopped taking her medication every day because of side-effects – she is complaining of headaches, starting to gain weight and feeling 'stressed out'. Her mum, Tracey, has been encouraging her to reduce her medication, as she is also not happy with the side-effects her child is experiencing, and believes that now Kelly is better, she doesn't need as much medication. Tracey has also been reading on the internet that antipsychotic medication can make people gain lots of weight and cause heart-attacks.

Kelly's case manager schedules an appointment with Kelly's doctor to talk about the side-effects and what they can do to support Kelly to continue taking her medicine by providing some strategies for managing side-effects. The case manager emphasises that it is Kelly's choice, and provides more psychoeducation about the need to continue on medication even after symptoms subside. Kelly says she doesn't care, she'd 'rather be sick than fat'.

The doctor and case manager acknowledge that there can be 'crap' side-effects to medication, but there are ways they can be ameliorated. The doctor assures Tracey that while some antipsychotics may cause heart problems, it is unlikely with risperidone, although weight-gain may be an issue. She says, however, that it is very important to monitor for side-effects and it is a good thing for Tracy to be so concerned for her daughter.

The doctor and case manager suggest that Kelly keep taking risperidone at her current dose, but that she come back in a month for a medication review to consider reducing the dose. Kelly and Tracey are given some tools to help with side-effects and potential weight-gain. They are provided with specific strategies for managing Kelly's diet, and information about how medications may act to increase appetite and reduce feelings of satiety. The doctor talks about the importance of exercise, asking Kelly to consider how she can fit it into her day. Kelly's case manager suggests that together they can work on a goal of increasing exercise and how to deal with obstacles that currently get in the way.

Although Kelly doesn't seem keen on taking medicine still, her mother agrees that it is in her best interests, and says she will work with Kelly to adhere to treatment until the next medical review.

Persisting symptoms

Persisting positive symptoms in the face of treatment often cause a sense that the treating team, the family or the young person have failed, particularly following the optimistic tone of the early recovery message. While allowing time for the family to express feelings of disappointment, clinicians should try to combat despair. Working with the family at this time it may be useful to:

- review the family and young person's achievements and the challenges they have overcome so far
- remind family that everyone recovers in different ways and at different rates
- reconsider psychosocial factors that may be hindering recovery, such as EE and other stressors such as work or school
- consider structured, cognitive-behavioural therapy family intervention (usually in consultation with or referral to specialist family worker).

Negative symptoms, including apathy, amotivation, anhedonia, boredom, emotional blunting and withdrawal, should be discussed in family sessions. The clinician may need to discuss realistic levels of physical and social activity for the young person, particularly during the early stages of recovery. Progressive goal-setting, combined with encouragement and continual reinforcement, is an effective behavioural strategy for families to use to help with these symptoms.

CASE SCENARIO **DAVE**

Dave, 19 years old, developed psychotic symptoms part-way through his second year of university. After the first acute episode, he moved back to the family farm in New South Wales, but decided after a few weeks that he was feeling too isolated there. He moved in with his older sister, Chloe, back in Melbourne so that he could be around friends.

Chloe has just started a new job, and is busy and stressed. Dave continues to have both positive and negative symptoms, and Chloe finds herself snapping at Dave's 'lazy' behaviour because he won't help out around the house or do grocery shopping when he's home all day and she's at work.

Chloe attends Dave's next appointment with his case manager, because she wants to know why he isn't getting better. She expresses sadness that her little brother is unwell, and says she always feels guilty about 'losing it' at him because she knows he needs support. But she also finds it frustrating that he can't look after himself, and says that he needs to 'grow up'.

Dave says that mostly he just feels tired and hopeless all the time, but also that he is still experiencing auditory hallucinations, and that he doesn't want to go up the street to the shops because he tried it once and all the people and the noise make the voices worse.

Both siblings have been minimising Dave's condition to their parents when they speak on the phone, for fear of worrying them.

The case manager says that it is obvious Chloe needs help with coping, and allows time to discuss the impact of the persistent symptoms on Dave's current functioning, particularly the need for him to 'do less' at the moment. The case manager explains the importance of a positive emotional environment at home to help with recovery. She says perhaps it might be a good idea to reduce some of the emotional burden on Chloe by telling their parents more about Dave's persisting symptoms. She reminds them that it's important to maintain realistic optimism, and that persisting symptoms or even relapse can be part of the recovery process.

The case manager works with Chloe on some basic communication strategies so that she can express herself to Dave without getting angry or making him feel like a burden. The case manager says it is important for Chloe to ask Dave about how he's feeling and to try asking him to help her with things rather than telling him to do them. Dave agrees to try harder to help out at home, and he and Chloe think of some ways he can do this without getting overwhelmed by his environment and 'wigging out' again. An appointment is made for Dave to see his doctor about whether he needs to increase or change his medication to help with his persisting symptoms. The case manager also refers Chloe to a family peer support worker so that she can talk through some of the common frustrations of living with someone with mental health problems and feel that she is not so alone in having to cope.

Substance use

Substance use is common among the 12–25 years age group, and excessive use can exacerbate and prolong psychotic symptoms. It can also increase criticism and hostility from family members who view the young person as responsible for their illness or not helping themselves to recover.

Clinicians should explore with the family the reasons behind drug-taking in a non-judgemental way. They should aim to help family members understand why the young person is continuing an apparently self-destructive behaviour. A problem-solving approach (see Box 6) may help the family discover potential solutions to the problem. Rewards are an important aid in improving low self-esteem which frequently accompanies drug-taking. For more information about substance use and psychosis, see the Orygen Youth Health Research Centre manual *Cannabis and psychosis: an early psychosis treatment manual* (2002).

BOX 6. **A GUIDE TO PROBLEM-SOLVING WITH FAMILIES IN RELATION TO SUBSTANCE USE**

- Explore family members' perceptions of current problems.
- Identify areas of consensus about the problem, being as specific as possible.
- Identify how the family would like things to change, once again being as specific as possible.
- Brainstorm a list of possible strategies for changing the problem; include ideas that might not work.
- Identify the options the family would like to try first.
- Discuss what might go wrong and prepare for this.
- Take action – decide when and how strategies might be carried out.
- Review outcomes at the next session and explore other possible strategies.

CASE SCENARIO **NEENA**

Mick and Evangeline have expressed concern regarding their 20-year-old daughter Neena's continuing cannabis use. They report that they often argue with Neena about her use and also with each other about what they should do to 'make her stop using'.

As it is obviously a source of distress to the family, and because of the increase risk of relapse from Neena's use, Neena's case manager suggests the family attend some structured problem-solving sessions with the specilaist family worker.

In the sessions, the specialist family worker first seeks to clarify Mick and Evangeline's beliefs, attributions and expectations regarding cannabis use, and what is driving their concern and distress. Although they are frustrated and hurt by what they perceive to be Neena's defiance of their parental authority, their main worry is the increased risk of relapse posed by continued cannabis use.

In Evangeline's view, smoking cannabis was the main cause of Neena's illness, and that 'if she would only stop smoking, everything would be fine'. Both she and Mick are adamant that 'we have to stop her from using', and Evangeline also thinks that the treating team should 'do more' to convince Neena to stop.

The specialist family worker acknowledges the distress of Neena's parents and the sense of urgency they have to do something to stop her cannabis use. He provides further psychoeducation using the stress–vulnerability model, in which Neena's cannabis use and some of the family's responses are identified as stressors that interact with an underlying vulnerability. He suggests that an 'all or nothing' view of Neena's substance use may not be the most helpful one, and that although ceasing cannabis use would reduce Neena's risk of relapse, it would not guarantee that it didn't occur: there is a likelihood of continuing vulnerability despite cessation of drug use.

Further information about cannabis is provided, along with the motivational stages of change regarding drug use. The specialist family worker also discusses the widespread nature of the issue, the difficulties inherent in attempting to effect behavioural change in others, and the difficulty many young people faced in reducing their drug use, particularly when it is common in their social network.

However, he reassures Neena's parents that the issue is being taken seriously by the treating team. He suggests other approaches such as harm minimisation strategies as alternative ways of tackling the issue, and works through a problem-solving model to help them come up with some strategies. As well as reducing some of Evangeline's anxiety, the process helps her and Mick develop a shared view of the situation in which they can work together on new strategies. They decide to trial a 'no cannabis in the house' rule, and to ban Neena from using the car when intoxicated.

Language and culture

While they should not necessarily be viewed as a 'challenge', language and cultural barriers may have a significant impact on clinicians' abilities to work effectively with families – particularly regarding families where English is not the first language. Clinicians should be aware that cultural constructions of mental illness may vary, as may the expectations that people from different cultures have of clinicians and the treating team. The expected roles of individuals within the family may also need to be considered by the clinician. If the young person has adopted the attitudes and values of the dominant culture, this may create issues where there are clashes between these values and the family's expectations of the young person.

Clinicians should seek information regarding language and cultural issues from the family and (where appropriate) from 'cultural interpreters', such as religious or community leaders. Sometimes the way in which the treatment program is delivered may need to be modified. Clinicians should also consider the place of traditional healing practices in the treatment plan.

Other considerations include:

- confidentiality and how to discuss this with family
- using telephone versus face-to-face interpreters
- the duration of sessions that include interpreters (longer for using face-to-face interpreter and limits on phone interpreting)
- what fact-sheets are available from multicultural organisations (see Box 7) to provide written information about psychosis and other mental health diagnoses
- different challenges encountered by asylum seeker families, for example:
  - members of a newly arrived migrant group might find that the pool of interpreters for a particular language is small, compromising confidentiality
  - young people and families who have experienced persecution in their country of origin may be wary of speaking to an interpreter from the same country but who is of a different religious or ethnic group.

Information about working with mental health in a multicultural context, including working with interpreters, can be found from the organisations listed in Box 7.

BOX 7. **RESOURCES FOR MENTAL HEALTH CLINICIANS WORKING IN A MULTICULTURAL CONTEXT**

Australia's national multicultural mental health body is the Multicultural Mental Health Association of Australia: www.mhima.org.au

For guidelines and factsheets on working with interpreters in mental health settings, see:

- Victorian Transcultural Mental Health: www.vtmh.org.au
- Transcultural Mental Health Centre (NSW): http://www.dhi.health.nsw.gov.au/tmhc/default.aspx
- Transcultural Mental Health Centre (QLD): http://www.health.qld.gov.au/metrosouthmentalhealth/qtmhc

CASE SCENARIO **NADIF**

Nadif is a 17-year-old whose family arrived from Somalia 5 years ago. He developed positive symptoms recently, during his final semester at high school, where he began talking about voices, or spirits, telling him he was going to fail everything. After the school counsellor convinced Nadif's parents to take him to a doctor, he was admitted to the EPPIC in-patient unit, where he was prescribed antipsychotic medication. The treatment regimen was explained with his family and an interpreter present.

However, when Nadif and his father later attend an outpatient appointment, his case manager observes that he doesn't appear to be improving. When pressed, Nadif says he hasn't been taking the medication. His dad insists that Nadif's condition is not medical and can't be treated by tablets. He refuses to take Nadif's prescription to the pharmacist, and says they have been trying to heal Nadif through traditional spiritual methods. They plan to return to Somalia next month so Nadif can get proper treatment from a well-known traditional spiritual healer. Nadif appears ambivalent about taking medication, looking to his dad for direction. He says he 'just wants to get better'.

The case manager is concerned that Nadif hasn't taken any medicine and asks him to come back another time with his father to talk with a doctor about options. Although Nadif speaks perfect English, his dad is not fluent, so the case manager arranges for an interpreter to be present so that his dad can fully express himself. The case manager contacts Mental Health in Multicultural Australia to find out what the Somalian spiritual healing might involve. He consults with Nadif's doctor about the process, who is satisfied that the process won't be harmful to Nadif or exacerbate his symptoms. They therefore agree to present medication not as an alternative, but as something that can be done in conjunction with traditional methods.

At the next meeting, the case manager and doctor take time with an interpreter to understand Nadif and his dad's explanatory models. They listen and spend some time working through information sheets in Somalian that discuss psychosis, explanatory models and why medicine might help Nadif get better. The doctor asks Nadif's dad if he will compromise – he may not believe the tablets will work, but many people in the service have found they do. He suggests that perhaps Nadif could take them as well as receive traditional healing, just in case they do work. The case manager adds that this way they would be providing Nadif with as many chances as possible to get well. The treating team, Nadif and his dad discuss the changes that they might observe in Nadif's thinking, emotions and behaviour if the treatment was to work.

Nadif's dad is still not convinced, but he and Nadif agree for Nadif to take the medicine for the next month at least, while they wait to go to Somalia. The case manager makes another appointment with Nadif, his father and the interpreter 3 weeks time to review how things are going, and whether the medication has made any difference.

Abuse

Sexual abuse and prolonged physical abuse create particular difficulties when dealing with families experiencing early psychosis. Abuse constitutes a fundamental breach of the relationship between adult and child, resulting in strong feelings of suspicion, mistrust and anger on the part of the person who is suffering the abuse. Such problems are always difficult to deal with, but the occurrence of a psychotic illness is likely to intensify these difficulties even further. In these situations, clinicians should contact protective services about the appropriate course of action. In the states and territories of Australia legislation exists that compels any health professional who is aware of ongoing physical or sexual abuse of a child up to the age of 18 to report knowledge of that abuse to the relevant authority. If specialist counselling for sexual assault is available, this should be discussed in sessions with the client, and unconditional support should be available to the client about having experienced or continuing to experience abuse, whether specialist counselling is sought or not.

Models of family work in FEP

A number of approaches and models of family interventions have been developed and trialled internationally. In addition to the EPPIC approach outlined in this manual, the following may also be of use to clinicians.

OPUS (Denmark)

The OPUS study was a trial of integrated treatment in early psychosis. Compared with standard care, the OPUS model of integrated care showed better outcomes at 2 years for psychopathology, adherence to treatment, comorbid diagnosis of harm and dependence, client satisfaction, social outcomes (first year only), and use of health services.[41]

The integrated treatment involved an assertive community treatment model complemented by family involvement in care and social skills training. The family work component of this model was as follows:

- an attempt was always made to contact at least one family member
- young people and their family were all encouraged to participate in psychoeducational groups
- family treatment followed the McFarlane manual for psychoeducational treatment for multiple family groups
    - this included 18 months of treatment for 1.5 hours every second week in a multiple-family group with two therapists and four to six patients and their families
- the focus was on problem-solving and development of skills to cope with the illness.

First Episode Psychosis Program (Canada)

The First Episode Psychosis Program (FEPP) in Toronto, Canada, uses a family recovery framework that was designed to meet the needs of a large, multi-level integrated early psychosis program that serves approximately 3 million people.

Services for families in this model are based around four stages: managing the crisis, initial stabilisation and facilitating recovery, consolidating the gains and prolonged recovery. The interventions carried out at each of these stages is presented in Table 4.

TABLE 4. **THE FEPP FAMILY RECOVERY FRAMEWORK INTERVENTIONS BY STAGE**

STAGE	INTERVENTIONS WITH FAMILY
1. Managing the crisis	Frequent contact High support Practical and emotional support to minimise impact of trauma Repeated, clear messages about psychosis and treatment Education about role of family in treatment
2. Initial stabilisation and facilitating recovery	Further support and education Focus on family coping and staying well Problem-solving and coping strategies for dealing with psychosis Intensive work for high-risk families Short-term group-based intervention: may involve psychoeducation group and family coping group
3. Consolidating gains	Psychoeducation booster sessions to incorporate knowledge into everyday practice Focus on early warning signs, treatment compliance and targeted problem-solving Promote increased independence from system More intensive family work from specialist family worker for high-risk and high-need families Ending
4. Prolonged recovery	Individual work to help with changing expectations, adapting to less-than-full recovery and transition to long-term services

Adapted from Addington et al. 2005.[16]

Meriden (UK)

The Meriden West Midlands Family Programme is a training and organisational development program that promotes the development of family-sensitive mental health services.

It uses a behavioural family therapy model of family work, a practical, skills-based intervention usually delivered over 10 to 14 sessions. The program focuses on psychoeducation about psychosis and treatment, recognising early signs of relapse and developing a relapse plan, and promoting positive communication, problem solving skills and stress management within the family. The needs of all family members are addressed, and individual family members are encouraged to identify and work towards clear goals.

Interventions are tailored to each family, generally given in the family home, and may include:[42]

- meeting with the family to discuss the benefits of the approach
- agreeing with the family that they are willing to try the approach
- assessment of individual family members
- assessment of family's communication and problem-solving skills
- reviewing family's resources, problems and goals
- meeting with the family to plan how to proceed and establishment of family meetings
- information-sharing about psychosis and reaching a shared understanding
- early warning signs and relapse prevention work – development of 'staying well' plans
- helping the family to develop effective communication skills
- supporting the development of the family's problem-solving skills
- information booster sessions
- review and ongoing support or closure.

The Lambeth Early Onset and Outreach and Support in South London service

The Lambeth Early Onset (LEO) and Outreach and Support in South London (OASIS) service was one of the first early intervention services rolled out in England. Its structure and programs are modelled closely on those of the EPPIC program at Orygen Youth Health, with the LEO FEP service operating in conjunction with the OASIS UHR service.

The LEO Community Team provides assertive community-based follow up for 2 years for LEO patients who continue to reside in Lambeth, UK. Specific interventions include cognitive behavioural therapy for psychosis, on-site vocational service, group interventions, and family support and psychoeducation groups.[43]

Appendices

Questions to help with assessing family need

Questions to assess knowledge about psychosis

Previous experience	Have you had any previous experience of other people with psychosis? How did that situation compare with the current one? What did you know about psychosis before your relative became unwell?
Previous information provided	What opportunities have you had to find out about psychosis? Have you been given any written information? Do you have any questions about any of it?
Symptom/behaviour knowledge	What do you think are the major symptoms of psychosis that your relative is experiencing? Is there anything about your relative's behaviour that doesn't make sense?
Explanatory model	What does each of you think caused the psychosis? Why do you think your relative is experiencing a psychotic episode? You've been given the doctor's view; do you have a different idea about how the psychosis developed?
Prognosis	How does the future look for your relative? (short- and long-term)
Treatments	What medication is your relative taking? What have you been told about how these medicines work? What do you know about the additional treatments your relative has been receiving? Are there any other forms of treatment that you wish your relative was receiving?
Perception of risk	Do you have any concerns that your relative could be in any danger, or of danger to him/herself? Do you ever worry that s/he could be a threat to anyone? Have there been any instances of this? How were they managed?
Other	Families sometimes have their own opinions even after talking to the doctors here: is there anything you disagree with – for example, the diagnosis, or the treatments selected? It would be helpful to hear your thoughts.

Information
sheet for families

Questions to explore impact of psychosis on families

Practical impact	What changes to the family routine have occurred?
	Has anybody had to stay home from work recently?
	Is it more difficult to do essential daily tasks, such as cooking and cleaning?
	Has anybody considered moving out when things have become difficult?
	Has it been difficult to get to sleep these days because of his/her behaviour?
	When was the last time you had some time to relax and enjoy yourselves?
General health	Has anybody been getting sick since your relative became unwell?
	Are there any physical health problems in the family?
	Has anybody been tempted to use alcohol or drugs to cope with the psychosis?
Cognitive impact	Has anybody found they are preoccupied with particular concerns about psychosis?
	Are there any bad memories of recent events that stand out?
	Does the future ever look hopeless to anybody because of what's happening?
Emotional impact	Does anybody have any regrets about anything that has happened?
	Is anyone bothered by feeling scared recently? (or edgy, angry, upset, etc.)
	Does anybody have nightmares because of what has been happening?
	Has anybody been feeling down or depressed after what has happened?
	How much energy does everyone have for doing everyday things?
Impact on family system	How do you think the family as a whole is coping?
	What is the family doing to support each other?
	Who would you say is shouldering most of the burden at the moment?
	Who would you say is taking the most responsibility for making decisions?
	Do you have the chance to discuss together the best way to deal with things?
	Does anybody find they just prefer to stay away from the house these days?

Family work assessment formulation

FAMILY COMPOSITION (INCLUDING GENOGRAM)

Who lives in the home/demographic details/recent changes/contact time with the relative

FAMILY HISTORY

Psychiatric history/relationships/major events

FAMILY INVOLVEMENT

Pathway to care/current (identification/help seeking/monitoring/support)
Services (‘Family and Friends’/ Support group/Family worker
Collaborative relationship?

IMPACT OF ILLNESS

Individuals/system/family on illness/stigma

UNDERSTANDING OF ILLNESS

Psychosis/recovery/relapse/explanatory model/illness- personality/treatment/expectations

PROBLEMS (CURRENT)

Frequency/triggers/behaviours/results note differing perspectives on problem definition/cause/importance/effect/solutions)

COPING AND SUPPORT

Strengths/needs

RECOMMENDATIONS

Education/support needs/interventions

Information
sheet for families

Positive and negative symptoms

A positive symptom indicates that there is too much of certain types of thinking or behaviour. 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’

A negative symptom indicates that there are not enough of certain aspects of a person’s usual functioning. These 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.

Positive symptoms are most marked during the acute phase of psychosis. Negative symptoms can be present during the prodrome (early), acute, and recovery phases.

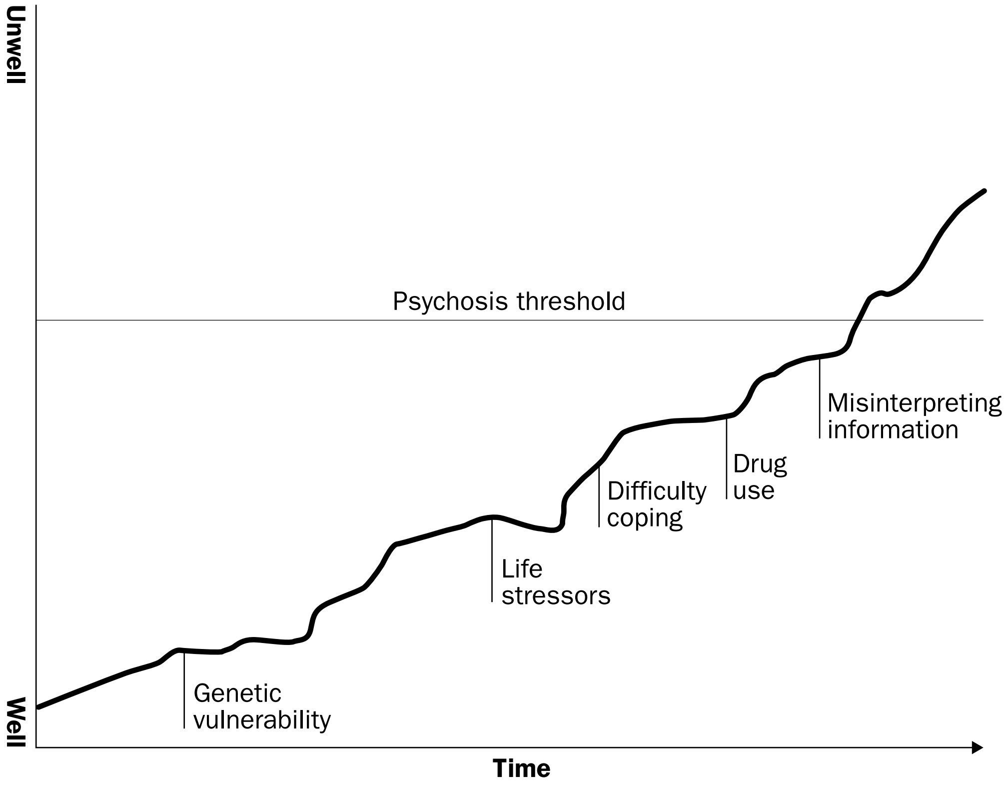
Most people affected by psychosis will experience both positive and negative symptoms to some extent.

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

Information sheet for families

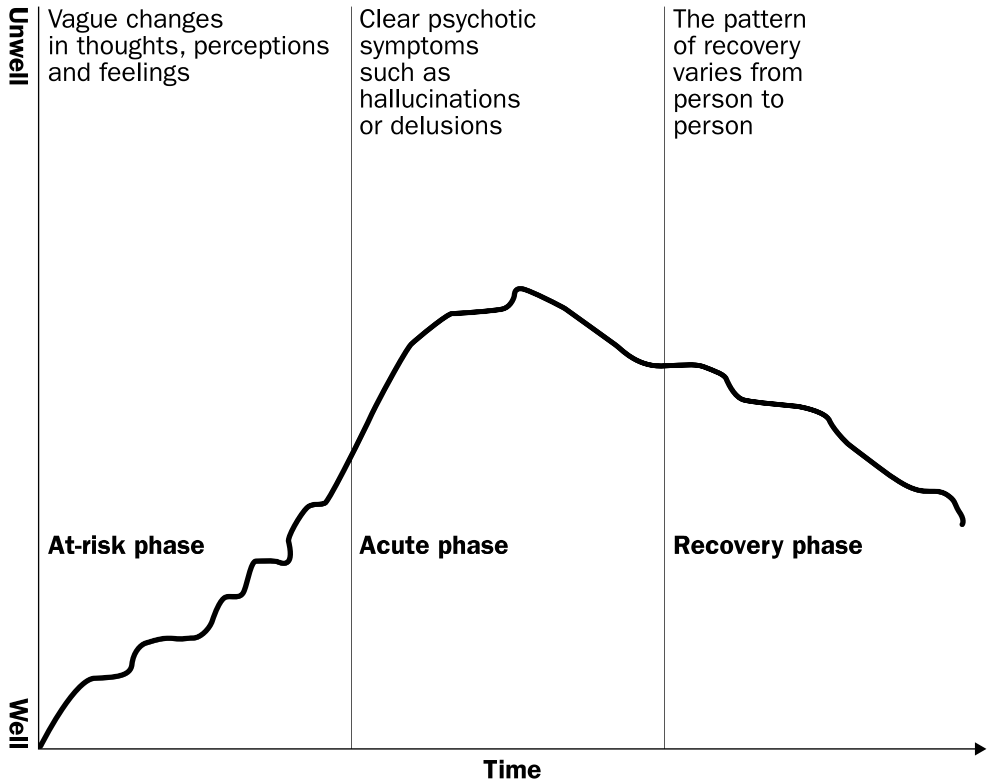
What causes psychosis? An example

There is no one cause of psychosis, and no one currently can say exactly what causes it. It is similar to the question, Why do some people develop diabetes and others do not? There can be a range of factors involved; it may be that a young person has a genetic vulnerability that can be impacted by factors such as drug use, stress and so forth. A possible pathway to a psychotic episode is shown here.



Information sheet for families

Phases of psychosis



(The length of each phase varies from person to person)

Information
sheet for families

Factors affecting recovery from a psychotic episode

Recovery is not always a smooth process and is likely to have its ups and downs.

Positive things we expect in recovery include:

- reduced psychotic symptoms
- increased social activities
- improved confidence and concentration
- slowly being able to take responsibility
- feeling more in control
- a gradual return to the former level of functioning.

However, we sometimes see the following things:

- depression and/or anxiety
- reduced confidence and self-esteem
- difficulties with memory and concentration
- a slow return to normal activities, like work or study
- low motivation, loss of interest, feeling tired
- changes in sleeping and eating
- wanting to be alone
- frustration, and wanting to get back to a normal life as quickly as possible.

Things that can help recovery include:

- taking medication as prescribed
- a good understanding of what has happened
- someone to talk to about the experience of psychosis
- realistic expectations and hope for the future
- a sense of purpose or direction
- a supportive family and friendship network
- a stable living situation, and a calm, structured environment
- physical health
- opportunities to pursue interests and fun activities
- help in managing stress
- financial security
- some interest in work or study.

Information
sheet for families

Common early warning signs

Checklist

☐ Difficulty concentrating

☐ Being preoccupied with one or two things

☐ Racing thoughts (rapid speech)

☐ Feeling depressed or low

☐ Having difficulty following what they are saying

☐ Believing their thoughts may not be their own

☐ Concerns about being watched

☐ Feeling useless or helpless

☐ Feeling confused or puzzled

☐ Feeling stubborn or refusing to carry out simple requests

☐ Feeling very excited

☐ Being open and explicit about sexual matters

☐ Speech becoming jumbled and full of odd words

☐ Sleep becoming restless or unsettled

☐ Behaving odd or differently

☐ Being unable to cope with everyday tasks

☐ Eating less than usual

☐ Feeling like playing tricks or pranks

☐ Being quiet or withdrawn

☐ Talking or smiling to himself or herself

☐ Not bothered about appearance or hygiene

☐ Being violent

☐ Thinking they could be someone else

☐ Feeling dissatisfied with theirselves

☐ Having aches and pains

☐ Losing their temper easily

☐ Having no interest in things

☐ Thinking they are being laughed at or talked about

☐ Feeling tired or lacking in energy

☐ Movements seem slow

☐ Believing their thoughts might be controlled

☐ Being aggressive or pushy

☐ Being irritable or quick tempered

☐ Feeling tense, afraid or anxious

☐ Hearing things that others cannot hear

☐ Spending more money than usual

☐ Laughing or crying a lot with no apparent reason

☐ Feelings of depression

☐ Feeling distant from the family

Information
sheet for families

Creating a positive emotional environment

Encourage contact with ongoing care and medication adherence

Don’t argue or force the issue. You can only encourage, it is not your responsibility.

Discourage use of illicit drugs

If it is a problem, discuss this calmly but firmly. Seek further information about drugs and their effects. Remember that you are not responsible for changing this behaviour.

Modify expectations

Have realistic expectations of what your relative can cope with. This will vary according to the phase of recovery. Meaningful, but not over-demanding, activity is the goal. A gradual increase in expectations about a return to full function is best. Suggest one change at a time, and progress one step at a time.

Beware of over-crowding

Time-out is important for all. People are recovering from psychosis may need more ‘quiet time’ alone than before the episode. Withdrawing at times and slowing down a bit can reduce stress and be helpful in the early stages of recovery.

Set limits

Have normal household rules that are clear and realistic. Agree on rules together.

Let the ‘small stuff’ slide

Focus on positive changes, rather that difficulties or things that you can’t change.

Creating a positive emotional environment (continued)

Seek help

Don’t ignore concerns about early warning signs or thoughts of suicide. Do not put up with violence or aggression: even if related to the illness, it is not acceptable.

Maintain a sense of hope

Recovery takes time, and a plateau period is common. Focus on any small gains and victories, even if they seem small.

Carry on business as usual

Try to keep family life as normal as possible: it’s important that the family recovers as well. Stay in touch with friends and other family members.

Look after yourself

The recovery of the family is important. Stay in touch with friends and other supportive people. Don’t neglect your own health and needs: you will need to be in good shape to support your relative.

Keep it calm and clear

Keep communication simple, to the point and calm.

Solve problems

Use a step-by-step method of dealing with problems.

Adapted from McFarlane, 2004.

**Information
sheet for families**

Core skills for effective communication

Active listening

Listening is a skill many people take for granted. It means more than waiting for the other person to finish so you can have your say. Here are some useful listening skills:

- Make eye contact with the other person
- Look interested and pay attention
- Don’t be distracted by other things such as the TV or radio
- Ask clarifying questions
- Check that you have understood what the person is saying when you are unclear

Expressing positive feelings

Everyone likes to be appreciated and told that they are doing well. Praising people for things such as their pleasant attitude, willingness to help, or nice appearance will increase the chance that they will continue with these behaviours. It will also help them feel good about themselves. You can praise someone for small things, as well as bigger things. Here are some suggestions on how to praise someone:

- Look at the person
- Describe exactly what he or she did that you liked
- Express how you feel to the person
- Avoid ‘back-hand’ compliments (such as, ‘That was great what you did, but you should have done...’)

Core skills for effective communication (continued)

Making a request

Asking someone to do something can be tricky: it’s easy to sound like you are being demanding, nagging or making the other person feel guilty if they refuse your request. Some suggestions for how to make a request are:

- Be clear about exactly what you would like the person to do
- Tell the person how much you would appreciate their help
- Use positive ‘I’ statements (‘I would really appreciate it if you would...’, ‘It would help me feel a lot less worried if you could…’)
- Keep your voice pleasant, not angry or demanding, and keep your body language open and positive

Expressing negative feelings

Sometimes you need to let people know when you are feeling upset, angry, scared, disappointed or sad. Expressing these feelings prevents you from becoming resentful about the issue, and lets the other person know they are doing something that is upsetting you. These hints might help:

- Look at the person and speak firmly
- Say exactly what the person did that upset you
- Tell the person how you felt about what happened
- Take responsibility for suggesting how the issue can be resolved (for example, ‘This isn’t working - we need to find some other solution’).

Adapted from Mueser and Glynn, 1999.

Information sheet for families

Sample problem-solving model for families

Step	Hints
Step 1 **What is the problem or goal?** Talk about the problem/goal, listen carefully, ask questions and get everyone's opinion. Then write down exactly what the problem is.	Agreeing on the problem can be the hardest step. The problem should be: specific (not general) described in terms of 'action', not 'attitude' regarded as a challenge to be solved broken down into a series of smaller problems, if needed.
Step 2 **List possible solutions** Write down all ideas, even bad ones. Ask everyone to try to provide at least one solution. List the possible solutions without any discussion at this stage.	Aim to get at least 5 suggestions. Don't throw out any ideas at this stage. Just list the ideas, don't start discussing them yet.
Step 3 **Discuss each possible solution** Quickly go down the list and discuss the main advantages and disadvantages of each one.	Don't automatically dismiss any ideas Some evaluations may only need to be brief.
Step 4 **Choose the 'best' solution** Choose the solution, or a combination of solutions, that can be carried out most easily to solve the problem.	Use combinations of solutions. If you can't agree, compromise by trying one solution and then another.
Step 5 **Plan how to carry out the best solution** Do you have the resources needed? Are there any major pitfalls to overcome? Are there any difficult steps that need to be practised?	Make sure someone is responsible for writing plans down. Anticipate and plan for possible obstacles. Rehearse situations that may be difficult.
Step 6 **Review the plan** Focus on what has been achieved and what people did right. Revise as necessary. What was the outcome? How was it evaluated? By whom? Was it reviewed?	More than one attempt may be needed. Don't worry if the plan didn't work this time, we can learn from each attempt and get closer to succeeding.

References

1. Stavely H, Hughes F, Pennel K et al. *EPPIC Model and Service Implementation Guide*. Melbourne: Orygen Youth Health Research Centre, 2014.
2. McNab C and Linszen D. Family intervention in early psychosis. In Jackson H and McGorry P (ed). *The Recognition and Management of Early Psychosis*. 2009.
3. Mueser K and Glynn S. *Behavioral Family Therapy for Psychiatric Disorders*. Oakland: New Harbinger Publications, 1999.
4. Early Psychosis Guidelines Writing Group. *Australian clinical guidelines for early psychosis*, 2nd edition. Melbourne: Orygen Youth Health, 2010.
5. Linszen D, Dingemans P, van der Does J et al. Treatment, expressed emotion and relapse in recent onset schizophrenic disorders. *Psychol Med* 1996; 26: 333–42.
6. Miklowitz D and Goldstein M. *Bipolar disorder: a family-focused treatment approach*. New York: Guilford Press, 1997.
7. Barrowclough C, Johnston M and Tarrier N. Attributions, expressed emotion and patient relapse: an attributional model of relatives' response to schizophrenic illness. *Behavior Therapy* 1994; 25: 67–88.
8. Pharoah F, Mari J, Rathbone J et al. Family intervention for schizophrenia. *Cochrane Database of Systematic Reviews* 2010;
9. Kreyenbuhl J, Buchanan R, Dickerson F et al. The Schizophrenia Patient Outcomes Research Team (PORT): updated treatment recommendations 2009. *Schizophrenia Bull* 2010; 36: 94–103.
10. McGorry P. Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of schizophrenia and related disorders. *Aust N Z J Psychiatry* 2005; 39: 1–30.
11. Gleeson J, Cotton S, Alvarez-Jimenez M et al. A randomized controlled trial of relapse prevention therapy for first-episode psychosis patients. *J Clin Psychiatry* 2009; 70: 477–86.
12. Gleeson J, Cotton S, Alvarez-Jimenez M et al. A randomized controlled trial of relapse prevention therapy for first-episode psychosis patients: outcome at 30-month follow-up. *Schizophrenia Bull* 2011; DOI: 10.1093/schbul/sbr165:
13. Grawe R, Falloon I, Widen J et al. Two years of continued early treatment for recent-onset schizophreniz: a randomised controlled study. *Acta Psyhiatr Scand* 2006; 114: 328–36.
14. Schlosser DA, Miklowitz DJ, O'Brien MP et al. A randomized trial of family focused treatment for adolescents and young adults at risk for psychosis: study rationale, design and methods. *Early Interv Psychiatry* 2012; 6: 283-91.
15. Mitchell A and Selmes T. Why don't patients take their medicine? Reasons and solutions in psychiatry. *Adv Psychiatr Treat* 2007; 13: 336–46.
16. Addington J, Collins A, McCleery A et al. The role of family work in early psychosis. *Schizophrenia Res* 2005; 79: 77–83.
17. Tennakoon L, Fannon D, Doku V et al. Experience of caregiving: relatives of people experiencing a first episode of psychosis. *Brit J Psychiatr* 2000; 177: 529–33.
18. Barrowclough C, Tarrier N and Johnston M. Distress, expressed emotion, and attributions in relatives of schizophrenia patients. *Schizophrenia Bull* 1996; 22: 691–701.
19. Addington J, Coldham E, Jones B et al. The first episode of psychosis: the experience of relatives. *Acta Psyhiatr Scand* 2003; 108: 285–89.
20. Leggatt M. Minimising collateral damage: family peer support and other strategies. *Med J Aust* 2007; 187: S61–S63.
21. Gleeson J, Cotton S, Alvarez-Jimenez M et al. Family outcomes from a randomized control trial of relapse prevention therapy in first-episode psychosis. *J Clin Psychiatry* 2010; 71: 475–83.
22. Addington J, McCleery A and Addington D. Three-year outcome of family work in an early psychosis program. *Schizophrenia Res* 2005; 79: 107–16.
23. McCann T, Lubman D, Cotton S et al. A randomized controlled trial of bibliotherapy for carers of young people with first-episode psychosis. *Schizophrenia Bull* 2013; 39: 1307-17.
24. Fadden G. Overcoming barriers to staff offering family interventions in the NHS. In Lobban F and Barrowclough C (ed). *A Casebook of Family Interventions for Psychosis*. Chichester, 2009.
25. Slade M, Holloway F and Kuipers E. Skills development and family interventions in an early psychosis service. *J Mental Health* 2003; 12: 405–15.
26. Fadden G and Smith J. Family work in early psychosis. In Lobban F and Barrowclough C (ed). *A Casebook of Family Interventions for Psychosis.* West Sussex, 2009.

27. Orygen Youth Health. *Training Family Peer Support Workers in an Early Intervention Mental Health Service.* Parkville: Orygen Youth Health, 2012.
28. Crisp K and Gleeson J. Working with families to prevent relapse in first-episode psychosis. In Lobban F and Barrowclough C (ed). *A Casebook of Family Interventions for Psychosis*. Chichester, 2009.
29. Lincoln C and McGorry P. Pathways to care in early psychosis: clinical and consumer and perspectives. In McGorry P and Jackson H (ed). *The recognition and management of early psychosis: a preventative approach*. Cambridge, 1999.
30. Etheridge K, Yarrow L and Peet M. Pathways to care in first episode psychosis. *J Psychiatr Ment Hlt* 2004; 11: 125–28.
31. Power P and McGorry P. Initial assessment of first-episode psychosis. In McGorry P and Jackson H (ed). T*he recognition and management of early psychosis: a preventative approach*. Cambridge, 1999.
32. Lively S, Friedrich R and Rubenstein L. The effect of disturbing illness behaviours on siblings of persons with schizophrenia. *JAPNA* 2004; 10: 222–35.
33. Early Psychosis Prevention and Intervention Centre (EPPIC). *Prolonged recovery in early psychosis: a treatment manual*. Melbourne: EPPIC, 2002.
34. Mottaghipour Y and Bickerton A. The pyramid of family care: a framework for family involvement with adult mental health services. Ae*JAMH* 2005; 4:
35. Bowman S, Alvarez-Jimenez M, Wade D et al. Forgotten family members: the importance of siblings in early psychosis. *Early Interv Psychiatry* 2013; doi:10.1111/eip.12068.
36. Birchwood M, Spencer E and McGovern D. Schizophrenia: early warning signs. *Adv Psychiatr Treat* 2000; 6: 93–101.
37. Family Work for Relapse Prevention in Early Psychosis Writing Group. *Family Work for Relapse Prevention in Early Psychosis: a Cognitive-Behavioural Approach*. Melbourne: Orygen Youth Health, 2012.
38. McFarlane W. Family interventionin first-episode psychosis. In Emann T, MacEwan G and Honer W (ed). *Best Care in Early Psychosis Intervention*. London, 2004.
39. Goldstein M. Psychoeducational and family therapy in relapse prevention. *Acta Psyhiatr Scand* 1994; 89: 54–57.
40. Glick I, Stekoll A and Hays S. The role of the family and improvement in treatment maintenance, adherence and outcome for schizophrenia. *J Clin Psychopharmacol* 2011; 31: 82–85.
41. Petersen L, Jeppesen P, Thorup A et al. A randomised multicentre trial of integrated versus standard treatment for patients with a first episode of psychotic illness. *BMJ* 2005; 331: 602.
42. About the Meriden West Midlands Family Programme. 2014; viewed 8 April. http://www.meridenfamilyprogramme.com/about.php.
43. Power P, McGuire P, Iacoponi E et al. Lambeth Early Onset (LEO) and Outreach & Support in South London (OASIS) service. *Early Interv Psychiatry* 2007; 1: 97-103.
44. Mueser K and Glynn S. *Behavioral Family Therapy for Psychatric Disorders*. Oakland: New Harbinger Publications, 1999.

NOTES

NOTES

NOTES

Printed on 100% recycled paper, made carbon neutral.

This manual has been funded by the Australian Government