There's no Place Like Home

Home Based Care 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–-31–2

Suggested citation

Crlenjak C, Coulson L, Stavely H and Simpson R. *There's no place like home: home-based care in early psychosis*. Orygen Youth Health Research Centre 2014.

Acknowledgments

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Contents

Introduction

The onset of a first episode of psychosis generally occurs during adolescence or early adulthood and can be traumatic for both the young person and their family. A psychotic disorder can disrupt the young person's developmental trajectory with a negative impact on self-esteem and social and vocational dysfunction. 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. The way in which a psychotic disorder is first managed helps to reduce the immediate harm associated with an episode of psychosis. Home based and outreach care can help promote recovery, reduce stigma, provide an alternative to inpatient care and assist young people back to their usual lifestyle.

Context of this manual

This manual is aimed at mental health professionals directly working with young people with early psychosis and individuals responsible for early psychosis service development. The content of this manual has been derived from international evidence and more than 20 years' experience of implementing and delivering services to young people and their families.

How to use this manual

This manual has been developed as part of an overall training program that includes face-to-face training and online learning modules delivered by the EPPIC National Support Program (ENSP) and should be read in conjunction with other manuals in this series.

The ENSP is assisting with the implementation of the Early Psychosis Prevention and Intervention Centre (EPPIC) Model in early psychosis services. The EPPIC Model has been developed from many years' experience within the clinical program at Orygen Youth Health and has been further informed by the Early Psychosis Feasibility Study Report written and published by the National Advisory Council on Mental Health in 2011 which sought international consensus from early psychosis experts from around the world.[1] 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:[2]

- easily accessible expert care
- a holistic, biopsychosocial approach to clinical interventions
- a comprehensive, seamless and integrated service provision approach
- evidence-based clinical practice
- the presence of youth-friendly culture throughout the service (reflected in staff behaviour and attitudes and decor)
- a culture and 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 patients and families
- a high level of partnerships with local service providers.

The purpose of this manual is to increase awareness about the role home-based care within an early psychosis service and provide practical, 'real-world' guidance on how to do this. Home-based care should be viewed as is an integral component of the EPPIC model and is fundamental to engagement, assessment, treatment and support. Therefore this manual should be used by all clinicians and not just for the 'outreach' team clinicians. This manual consists of four sections. 'Home based care in early psychosis' describes home-based care and its delivery as part of an early psychosis service. While 'Supporting home based care in an early psychosis service' outlines the infrastructure, staffing and safety requirements for the successful delivery of home-based care as part of an early psychosis service.

The section 'Levels of home based care' is a comprehensive description of how to do home-based care across the phases of early psychosis and 'Home based care in practice' provides a practical summary for clinicians to consider when providing home-based care to young people and their families.

Home-based care refers to seeing young people with early psychosis in their home or in an environment that they feel comfortable in. It also includes the concept of outreach care where clinicians are actively mobile and go out to see young people in a variety of different locations.

Home based care in early psychosis

Home based care in early psychosis

What is early psychosis?

Early psychosis is defined as the early course of a psychotic disorder. It the period from the emergence of an ’at-risk mental state’ through to the first episode of full threshold psychosis and the ’critical period’ of up to five years from entry into treatment for the first psychotic episode.[3]

The at-risk mental state (ARMS) is often a heterogeneous clinical state thought to indicate an increased risk of imminent onset of psychotic disorder. This is prominently characterised by attenuated positive psychotic symptoms that are frequently accompanied by functional decline. Criteria to define ARMS were developed following analysis of retrospective accounts of the psychosis prodrome.[4] These criteria became known as the ‘ultra high risk’ (UHR) criteria and accurately identify young people who are at incipient risk of psychosis. The Comprehensive Assessment of At Risk Mental States (CAARMS) is an instrument used to assess psychopathology and apply these operational criteria and achieve an acceptable level of validity and reliability in their assessment.

The development of psychotic symptoms can be caused by a variety of factors that can be grouped into three main domains: biological, psychological and social. Biological factors are an individual’s genetics, biochemistry, physiology and general constitution. Psychological factors include the emotional experiences and the upbringing of the young person, and social factors are the young person’s cultural and social background. The stress-vulnerability model of psychosis forms the basis of the treatment approach to young people with early psychosis.

It incorporates biological, psychological and social factors in understanding the development of psychotic disorders. A central assumption is that environmental stressors such as relationship issues, substance use or lifestyle factors can precipitate illness in vulnerable individuals. The more vulnerable an individual, the less stress is required to trigger the onset of symptoms. Consideration of biological, social and psychological stressors, protective factors and underlying biological vulnerability can guide the development of individualised treatment plans. This model implies that implementing appropriate coping strategies may reduce the person’s vulnerability to psychotic disorder.

The course of an episode of psychosis may be described using two models: the staging and phases model. These two models are similar but differ in terms of foci.

The staging model of psychosis

The staging model outlines the stages of development of a disorder and proposes that early intervention may be both safer than those used during the later stages of disorder (due to less invasive treatment) and more effective due to shorter duration of active illness. The clinical staging model of psychosis differs from conventional practice by defining psychosis as a continuum, where treatment interventions are used at specific stages to prevent progression to the next stage of the disorder in addition to promoting recovery. The differentiation of early and milder clinical phenomena, from those that accompany illness progression lies at the heart of the concept, which makes it especially useful in adolescence and early adulthood, when most adult-type psychiatric disorders emerge for the first time. The different stages of disorder are determined by symptom severity, level of distress and disability. For example, the identification of young people with sub-threshold psychotic symptoms (stage 1b) means identifying young people at an earlier stage of disorder and tailoring treatment to this stage (see Table 1). If the young person progresses to a first episode of psychosis, their treatment needs will change and differ (Table 1).

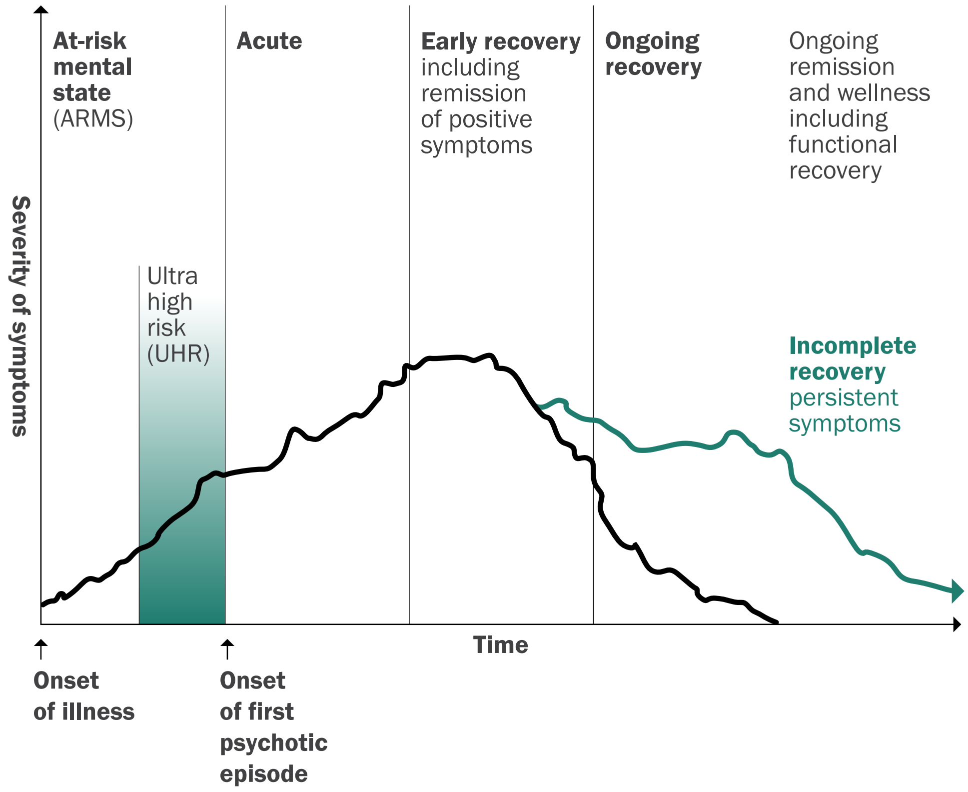
TABLE 1. **THE STAGING MODEL OF PSYCHOSIS**

STAGE	PSYCHOSIS	TREATMENT
0	Increased risk/no symptoms	Indicated prevention of FEP such as: improved mental health literacy, family education, drug education
1a	Mild or non-specific symptoms and functional decline	Indicated secondary prevention such as: formal mental health literacy, family psychoeducation, cognitive-behavioural therapy, active reduction in substance use
1b	UHR – sub-threshold	Indicated secondary prevention such as: psychoeducation, cognitive-behavioural therapy, substance use work, omega-3 fatty acids, antidepressants
2	FEP – full-threshold	Early intervention for FEP such as: psychoeducation, cognitive-behavioural therapy, substance use work, atypical antipsychotic meds, vocational rehabilitation
3a	Incomplete remission from first episode of care	Early intervention for FEP such as: for stage 2 plus additional emphasis on medical and psychosocial strategies to achieve remission
3b	Recurrence or relapse stabilised with treatment but still residual symptoms	Early intervention for FEP such as: for stage 3a plus additional emphasis on relapse prevention
3c	Multiple relapses with clinical deterioration	Early intervention in FEP such as: for stage 3b but with emphasis on long-term stabilisation
4	Severe, persistent or unremitting illness	As for stage 3c but with emphasis on clozapine, other tertiary treatments and social participation despite ongoing disability

The phases model of psychosis

The phases model of psychosis describes the course of illness and recovery using a phase-based approach. For an individual the phase model description of their illness may be completely included in a single stage of the stages model. However, the phase model is a more qualitative and clinically informative way of describing where an individual is in the course of their illness and treatment. It includes the at-risk mental state, acute, early recovery and late recovery phases. Not everyone who is at the at-risk mental state will transit to a first episode of psychosis and for those who do, it is with a view that some people may go onto make a complete or incomplete recovery. The primary intention of this early identification and treatment approach is that young people will make a complete recovery and return to their normal developmental trajectory. The presentation of young people at the different phases has different characteristics and warrants a treatment approach that is mindful of the phase of illness and tailored to meet individual needs.

FIGURE 1. **THE PHASES MODEL OF PSYCHOSIS**



This manual will outline the principles of home-based and outreach care using the phase-based description of psychosis.

What is home based care?

Home-based care (HBC) is defined as providing care, treatment and support to a young person with early psychosis or FEP at home or in an environment they are comfortable with. Ideally, HBC should also be provided to the family members or supports that are involved in the young person's care and treatment; this allows families access to additional support or family work (please see *In this together: family work in early psychosis* manual developed by the ENSP). Furthermore, the term 'family' in this manual refers to the level of support the young person receives from a relative, partner, friend, flatmate or significant other.

HBC has also been described as 'treatment in the home setting, as opposed to in a hospital setting, and is distinguished from treatments offered through mainstream community mental health services'. HBC can also be called 'hospital at home'. These specialised services provide an after-hour, rapid response that prevents admission and facilitates earlier discharge from inpatient care.[5]

The fundamental principles of HBC can be adapted to fit and meet the local requirements of a particular service and young people. It is not intended to replace inpatient services in a mental health service but rather compliment, facilitate and enhance existing treatment options.

Ideally, HBC should be mobile, responsive, flexible and adaptive to the needs of the young person and their family, providing a 24/7 service with a streamlined pathway to appropriate care via a single point of contact. A multidisciplinary team approach is used in HBC to work collaboratively with young people and their families. HBC supports the principle of providing care in the least restrictive way and is should considered a first-line treatment to facilitate assessment, enhance engagement, prevent hospital admission or reduce length of stay in hospital. It should also provide a platform for early discharge from hospital and be considered for every young person that enters the service at any point in time rather than as just a crisis-driven response.

Therefore, early psychosis services need to view HBC as part of their core business, where young people and families can easily access this treatment option, within practical limits.

HBC can help facilitate and inform the initial assessment by providing a contextual understanding of the young person and their living arrangements and community environment.

The second edition of the Australian Clinical Guidelines for Early Psychosis recommends that, wherever possible, the location of initial assessment should be community-based and in a setting that is convenient to the young person and their family.' It also recommends that 'a range of treatment settings, including home-based support, supported accommodation, rooming in, outpatient services and inpatient care,' should be made available to the young person and their families. During the assessment process and initial treatment, early psychosis services can also provide links for young people and their families to additional and complimentary services by providing practical support and enhancing engagement. To determine whether care can be provided at home, risk (to self and others), available resources and the needs of the young person and family should be assessed.[3] Early psychosis clinicians should check their local service policies and procedures regarding how HBC is to be tailored and provided to young people and their families.

> ‘My first experience with the service was actually at my home, somebody must have referred me to Orygen and they sent the YAT [crisis, assessment and community treatment team, Youth Access Team] over to my house. I had no knowledge of it and I actually just had the YAT team turn up at my house unannounced to see what was wrong and to assess me. That was quite a strange experience. I was a bit scared but I eventually settled down with my new case manager and I think they did a really good job of getting me to come into this service.’
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Why do home based care?

The onset of FEP is life changing event for the young person and the family. Sometimes, FEP can result in a short hospital admission to manage worsening signs and symptoms of psychosis. Hospital admissions can be traumatic and distressing that can lead to increased anxiety and stigma for the young person and their family. HBC is provided to individuals and their families to reduce duration of untreated psychosis, and severity of the illness and symptoms and to promote rapid recovery, improving both short- and long-term outcomes for the young person. HBC is often associated with a reduction of hospitalisation. It can help promote recovery and reduce stigma by offering an alternative to inpatient care, reduce secondary morbidity and assist young people to get back to their normal social, psychological and developmental trajectory. The following section will provide an overview of the evidence for using HBC as part of treatment for young people with early psychosis; the majority of the evidence focuses on comparisons of HBC versus inpatient admissions. This section will also cover the critical factors for the successful delivery of HBC.

Assertive community treatment (ACT) is one form of HBC and can be defined as ‘a highly intensive outpatient intervention’ where community-based clinical treatment is provided by a multidisciplinary team to individuals in their homes who have difficulty in engaging in traditional treatment services.[6] ACT has similar goals to case management but its practice is different, and was shown to decrease hospital admission and decrease homelessness in individuals receiving these services.[6] ACT teams are team-operated, community-based service providers that actively engage service users and provide treatment directly in their homes. A review of ACT reported that service users receiving treatment in their homes were more likely to remain in contact with services.[6] The OPUS study was a large randomised multicentre trial that compared the effect of integrated and standard treatment in patients with FEP (n=547); the integrated treatment consisted of ACT while standard treatment involved a community health care centre.[7] Clinical outcomes and treatment adherence were improved with integrated treatment that included the ACT team.

A randomised controlled trial in Sydney conducted by Hoult and colleagues reported that home-based community treatment reduced admission rates, improved clinical outcomes, and was associated with low operational costs and high levels of service user and family satisfaction.[8] Another study conducted in Adelaide by Singh et al. (2010) investigated whether 'hospital at home' treatment was effective in people with acute mental illness who would otherwise have been admitted to hospital. The study concluded that 'hospital at home' services can provide a safe, effective alternative to inpatient care for suitable patients. The 'hospital at home' service would visit people up to three times a day, 7 days a week; this data demonstrated that HBC has the potential to reduce costs and bed pressure on inpatient services, and provide care that is satisfactory to patients and their families.[9]

A systematic review examined HBC research in the context of health care and identified six reoccurring themes of experimental services: smaller case loads, regular visits at home, high percentage of contacts at home, responsibility for health and social care, multidisciplinary teams and one psychiatrist integrated in the team.[10] Regular visits at home and responsibility for health and social care were associated with a significant reduction in hospitalisation.[11] A study in the UK that compared community-based services with hospital-based care for acute severe mental illness reported that community-based care was as effective as hospital-based care.[12] Similarly, a project on home-based treatment programs in metropolitan Toronto, Canada published in 1997 reported that attitudes towards the program were positive, symptoms were reduced, family burden was decreased, home-based treatments were preferred and the associated costs were lower than hospitalisation.[13] A qualitative interview-based study of HBC involving service users established that the helpful components are:[5]

- practical help
- being around
- being available to talk
- providing advice
- providing information about mental illness
- linking in with other helpful services.

Some of the key successful characteristics of HBC have been described in the literature. Sjolie et al. (2010) reported that the characteristics of a crisis resolution and home treatment (CRHT) are being mobile, working in the home and working with families and networks.[14] Johnson states that 'initial assessment, forming a treatment plan, managing symptoms, a practical focus, psychoeducation, assisting with social and family issues, planning around future crises, and working on early discharge planning' as the main characteristics of CRT.[15]

A randomised controlled trial by Johnson et al. (2005) investigated the efficacy of a crisis resolution team (CRT) in Islington, London for people presenting with acute mental health crisis. This study demonstrated that people receiving acute care (including a 24-hours CRT) at home reduced hospital admissions in mental health crises.[16]

A qualitative study in Finland involving children and adolescents highlighted that a major advantage of HBC is the opportunity to meet with the family in their own environment, assess their interactions as a family and evaluate their social supports. Erkolahti and colleagues reported the principles of HBC as: comprehensiveness, family-centred and safety.[17]

To date there are a limited number of studies that focus on HBC in young people with early psychosis. Kulkarni and Fitzgerald conducted a pilot study examining HBC in young people with early psychosis. They described HBC as an integrated home-based management approach for young people with FEP that aimed to effectively treat the psychotic episode, prevent secondary morbidity, return the young person to their usual lifestyle, reduce relapse and improve their quality of life.[18] The study found that 'the abilities of the families' to support the young person at home was a key success factor for implementing HBC.[18]

HBC can provide support to young people and families both before and after hospital admission to reduce the length of time a young person is admitted to an inpatient setting. Increased support at home can help prevent and delay admissions to hospital as well as enable earlier discharge home, by providing assistance, supervision, more assertive monitoring and management of risk.

> Generally, adolescence and early adulthood is a time when young people are physically healthy and often don't require intervention from healthcare professionals. It is also a time when young people are seeking increased autonomy and independence from their parents or family and are beginning to make their own decisions. For a young person who is reluctant to engage with healthcare providers or unsure how to seek help for themselves, HBC can offer a treatment pathway that is flexible, responsive and more acceptable to the young person.

Considerations for implementing home based care

There are several factors that influence HBC of young people with first episode psychosis. The general principles or considerations of HBC are: the setting, the young person and their supports. For HBC to be successful and effective it is ideal that all of the above factors are in place. Given that these factors may change over the time course of an episode of psychosis, it is important for clinicians to re-assess these factors on an ongoing basis. This evaluation will assist in determining whether HBC is viable.

The factors that impact HBC in early psychosis are illustrated in Figure 2.

FIGURE 2. **GENERAL CONSIDERATIONS OF HOME BASED CARE**

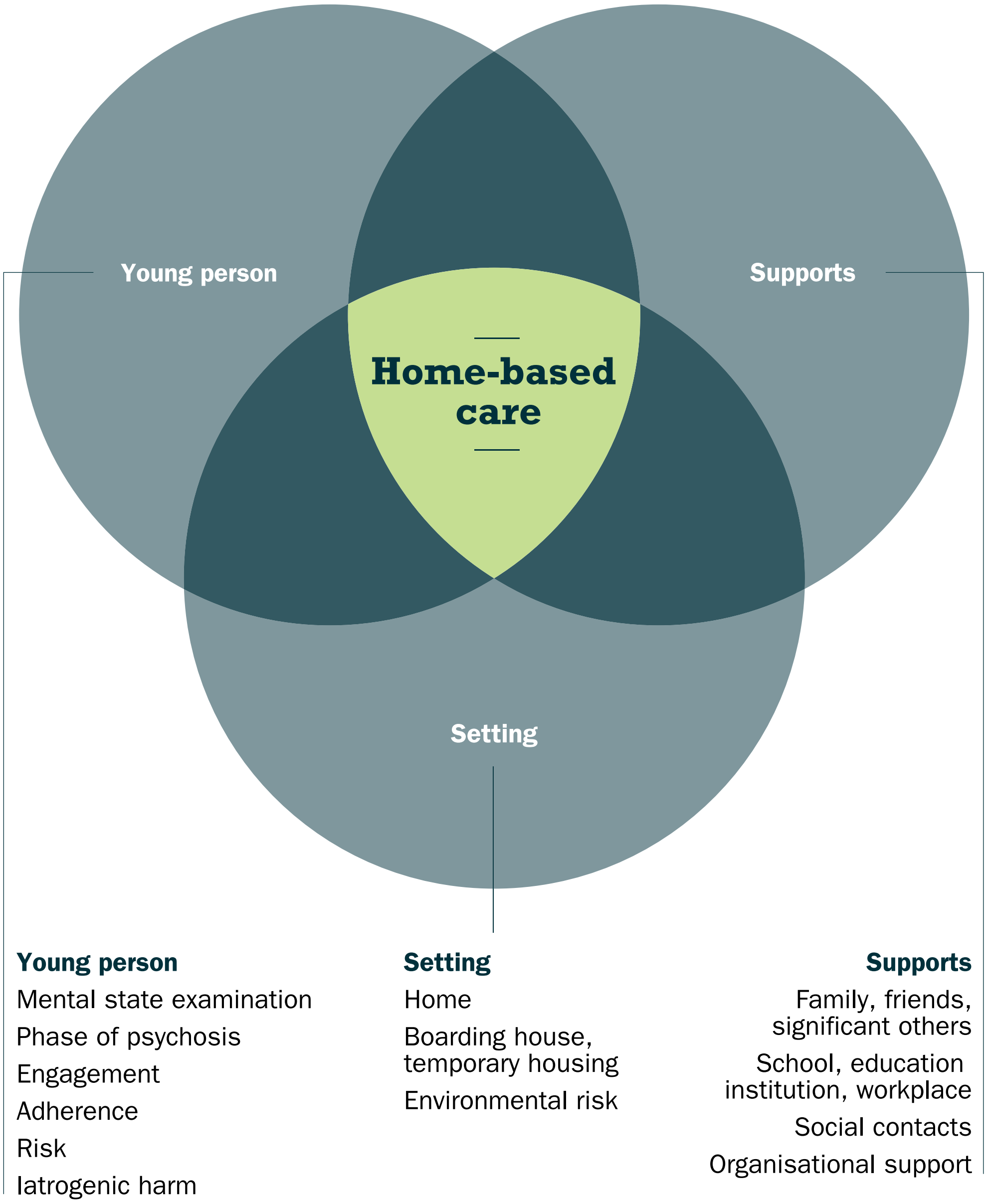


Figure 2. Illustrates the interaction between the factors such as the young person, the supports and the setting when deciding whether HBC is appropriate.

For example, a young person living in a shared house (setting) may change the people they are sharing their house with (supports) that may have an impact on how comfortable they feel discussing confidential information in the shared house (young person) and, therefore, may not be happy for HBC to continue in the same way. Clinicians need to be aware of this interaction and should be flexible in negotiating with the young person how their support is delivered by the treating team. In this case, the clinician might offer to pick the young person up and go to a different location such as a local cafe or park if the young person would feel more comfortable in that setting.

The following sections further describe the factors of HBC and how these interact with each other in more detail.

CASE SCENARIO **JAMES**

James was a young person being seen within an early psychosis service and he was living independently in a student shared house when he started noticing early warning signs of psychosis. He was becoming paranoid, had an increase in auditory hallucinations and was having trouble thinking clearly. He contacted his clinician and treating doctor to let them know what was going on. When the doctor and clinician came to see James at home later that day, it became apparent that he was not coping well – his room was very disorganised and he didn't have any clean clothes to wear (a change from the usual presentation). When asked about his medication, James said that he had lost his prescription and wasn't sure where his existing supply had gone. The clinician and doctor arranged another prescription for medication and went with James to the pharmacy to pick it up. On the way, James reported that he was having trouble remembering things, and would often find himself loosing track of time. Although James housemates were very supportive and helpful, he was finding it difficult to remember to take his medication and he recognised that he wasn't eating, showering or sleeping well. In discussion with James, the treating team contacted his mother and James agreed to spend a week at home with his parents. They discussed that for a short period, James' parents would take responsibility for reminding him to take his medication, and support him with meals, personal hygiene and other daily tasks. The doctor and clinician also discussed increasing their support and monitoring in the short term, seeing James daily for the next week. James was agreeable to these plans. The increased support and the rapid provision of HBC meant that James was able to get back on track quickly and gain short-term additional clinical and family support that prevented further deterioration in his functioning and possible acute relapse of psychosis. Due to deterioration in James mental state and poor adherence, an increase in support along with a change in setting was required to facilitate quick recovery.

The setting

Treatment setting is an important aspect of providing care to young people with early psychosis. The choice of treatment setting may be influenced by the severity of presentation or other psychosocial circumstances, for example, if a young person is homeless or is in out-of-home care.[3]

It is imperative that clinicians make an effort to see the young person in different settings such as the home, school, workplace, employment agency or housing office, park or a cafe.

> When working in a young person's environment it is important to remember that the usual environmental cues for an 'appointment' are not present. There is no reception area and other people in professional context are absent. It is important that clinicians know how to set their behaviour outside of 'office environment'. Clinicians should carefully communicate the rationale for choosing to home visit to the young person and their family. For example, 'I've noticed that it has been difficult for you to come into appointments, we thought we'd come out and see you at home instead'.

Also, it is important that clinicians are able to make changes to HBC quickly if the setting they have originally chosen has not worked such as a busy household that is not conducive to private conversations or has too many interruptions.

Treating teams that have the capacity to respond quickly and see young people in a variety of settings are likely to gain their trust and facilitate the necessary contact to build rapport, and commence and monitor treatment. Clinicians involved in HBC need to be able to work in a different framework compared with a hospital or clinic-based setting. The usual supports offered to clinicians in hospital or clinic settings are not as easily available, such as quick access to resources, phone numbers, internet, other clinicians and doctors unless these are taken to the young person's environment. Therefore, generally HBC clinicians need to be more prepared than a clinician in a hospital-based or clinic-based setting. HBC clinicians need to be comfortable with and prepared to operate from their 'clinical bag' and work car, 'on the road' by carrying necessary paperwork, using mobile phones, technology and up-to-date contact lists for relevant agencies and other parts of their early psychosis service.

In addition, HBC clinicians need to function with a high degree of flexibility and confidence that is often garnered from experience as they will be constantly required to 'think on their feet', make vital and autonomous decisions about the young person's safety.[18] The treating team are professional 'guests' in the young person's home/environment and need to understand that the relationship is different to that in a clinic or hospital setting. Clinicians are invited in and may be expected to follow the social norms of the household such as removing shoes, sitting in a particular room (e.g. the lounge) and accepting offers of tea or coffee. The dynamic of the relationship is shifted when visiting a young person in their home. Clinicians are not in their own environment (the service) and so need to be mindful about how this will impact on the young person's behaviour, or on the behaviour of others who are present such as family members.

> Cultural and family norms are important considerations in HBC. Clinicians need to be aware of different family and cultural norms prior to home visiting. Additionally, the potential risks in the home environment such as other family members, animals, weapons and neighbourhood should be carefully considered prior to HBC. Careful communication with the young person as well as the clinical team about when you are planning on visiting the young person is important. It is equally important to communicate that you have been there if the young person isn't home when you visit by leaving a calling card or letter with your contact details and being careful about maintaining confidentiality.

It is important for clinicians to assess how the environment or setting might impact on ability to carry out HBC. For instance, it may not be safe for the clinicians to enter the home due to environmental hazards or risk (e.g. a pet that is particularly protective of its owner or housemates who are not welcoming of services). In this case, although the young person and their supports may be willing to engage in HBC, it may not be safe for the clinicians to do so. A thorough environmental risk assessment should be carried out during the initial biopsychosocial assessment and re-evaluated prior to every home visit. Confidentiality is also important to consider, especially if the young person is living with people who are not directly involved in their care. Clinicians need to be mindful of how their presence might affect existing relationships within the young person's household or if the space is private enough for the young person to feel comfortable discussing sensitive topics. For more information on issues of working collaboratively with young people, confidentiality and risk please see the ENSP manual *'Let me understand…' assessment in early psychosis.*

CASE SCENARIO **DUNCAN**

Duncan was living in a boarding house when he was referred to the early psychosis service. He had been living there for a couple of years after moving from a rural town and did not have any friends or family that he was in regular contact with. Duncan was quite reclusive and rarely left the house except late at night because he felt more comfortable in the dark. The treating doctor and clinician spoke to Duncan on the payphone before visiting for the first time to gather some information about the other residents in the boarding house. Duncan couldn't provide much information because he didn't interact with the other residents. He agreed that the clinician and doctor could visit at a particular time (so he knew to expect them) and told them to knock on the front window of the boarding house (which was his bedroom window) when they got there. The clinician and doctor went to Duncan's house and when they arrived saw two men walking in the front door which was wide open. Both the clinician and doctor did not feel that they could make an accurate assessment of safety and decided to try to talk to Duncan in the car instead. The clinician and doctor followed Duncan's instructions and knocked on the window, calling out to him. Duncan initially replied and told them to come in. The clinician suggested to Duncan that the house may not be private enough and that they could meet in the car out the front instead. Duncan was hesitant and required some convincing but eventually agreed and the initial assessment took place in the car. Due to Duncan's level of anxiety, the appointment only lasted 20 minutes before he felt he had to go back inside; however, he agreed to a basic safety plan and felt okay for the clinician and doctor to come back again the next day.

The young person

The phase of illness and severity of clinical symptoms will have an impact on the young person and ultimately on how (or whether) HBC is delivered and effectively managed. An individual's mental state can fluctuate greatly especially for young people who are exposed to stress, use substances and do not have adequate supports in place. Clinicians need to consider how mental state will impact on HBC, for example, whether the young person's behaviour is likely to be influenced by their mental state and if so how? A thorough assessment of mental state (especially during the acute phase) is required to determine whether a young person is suitable for HBC. This is often an ongoing process where engagement, assessment and risk assessment are all occurring simultaneously.

Symptoms displayed by the young person will determine whether they will require hospitalisation. Kulkarni states 'the dangerousness of the symptoms expressed by the patient rather than intensity of these same symptoms that determine whether or not an individual will require hospitalisation'.[18] Clinicians must remember that HBC needs to be a safe option for the young person, the family or other supports and the clinicians who are providing HBC. Acute psychosis can be successfully managed and treated without hospital admission, although this is jeopardised by symptoms that increase risk such as believable command hallucinations to harm.

Detailed biopsychosocial assessment, comprehensive risk assessment and substantial collateral history can help inform and support decisions pertaining to risk management and the feasibility of HBC. However, there will be some circumstances in which hospital admission is the best and safest option, even if for a short period of time until HBC can be resumed. Circumstances can include the young person being new to the service, having no collateral history, no community supports, experiencing florid psychotic symptoms, having nil or low insight, having a history of impulsivity and risk-taking behaviour. A young person's situation and circumstances will need to be assessed on an individual basis and a course of action determined. Information is the key to comprehensive risk assessment and engagement is the key to accessing information; clinicians need to obtain both to clarify whether HBC is appropriate for that particular young person.

A young person's hostility or aggressive behaviour combined with delusions targeted towards family members may also determine whether HBC is the appropriate treatment approach in this situation.[18] Suicidal thoughts and actions will need to be thoroughly investigated to determine whether this will have an impact on HBC or rule out HBC all together. Equally, phase of illness will impact on how, and for what reasons, HBC might be carried out. During the acute phase, HBC might be used with the aim of preventing hospital admission or assisting the early discharge of the young person from hospital via early discharge management or building engagement through ongoing assessment. In this case, HBC provides additional structure and support to the young person and their family. On the other hand, during the recovery phase, HBC might be used to promote functional recovery, maintain engagement, address practical issues (such as employment or housing issues) or to provide therapeutic interventions in the most appropriate setting. HBC also has a crucial role in relapse prevention. Factors associated with incomplete recovery in psychosis such as comorbidity (substance use or depression), impaired adherence to treatments (psychosocial and biological) and inadequate access to services or resources, can be identified and more assertively addressed using a HBC model.[19]

The needs and preferences of young people and their families/supports should be discussed when considering whether to offer HBC as they may or may not feel that HBC is the best option. This can be for a variety of reasons including family stress levels, capacity of the young person and family to manage HBC, level of acuity of the young person, the needs of other family members. Or a young person, for instance, may feel more comfortable meeting with a clinician in a neutral environment (such as a cafe) rather than the lounge room of their house. Clinicians can easily offer these options to young people (and explain to families) when discussing HBC.

> 'Meeting my case manager outside of Orygen makes it feel more like we're equals so it's not just "I'm your case manager now". It makes me feel more comfortable and relaxed. You [a young person] don't feel that your case manager is intimidating. It makes it more casual and breaks that formality.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Engaging the young person

Engagement, both at the service and clinician level, is a crucial element when thinking of providing HBC. Often HBC can be a positive tool for engagement, improving relationships with both young people and their supports by providing care in the most comfortable environment. Clinicians need to understand that engagement with some young people may take time to establish. In such circumstances it may be useful to focus on symptomatic relief, providing information and practical support such as Centrelink, doctor's certificate or financial assistance to enhance engagement. Poor engagement can also be a barrier to young people receiving HBC, and ironically HBC can often be the key to improving engagement. For more information on engagement please see the ENSP manual *Get on board: engaging young people and their families in early psychosis.*

Whether or not a young person is able to participate in a HBC plan despite being engaged with the treating team needs to be considered. A young person may be engaged with the treating team and service, and be agreeable to HBC, but may not be adherent with treatment. For example, the HBC treating team asks the young person to take medication in the morning upon waking but the young person forgets to do this. Clinicians need to consider that although the young person may be willing to take their medication, they may not be organised enough to be adherent with treatment plans. In this instance, HBC can be flexible so that a home visit can take place to help with medication administration or other practical aspects of treatment and care. In other cases, the young person may not agree to HBC because they do not have insight into the nature of their psychotic symptoms and the need for treatment. The treating team then needs to consider whether HBC is the best option.

The supports

Gaining an early understanding of the young person's family, through an assessment of their needs and willingness to be involved, is an important consideration in HBC as the family are the constant primary supports in the HBC model.[18]

The relationship a young person has with his or her family will vary with age, living arrangements, cultural expectations and the degree of autonomy the young person has in relation to their supports. The extent of family involvement in a young person's care should reflect individual circumstances.[20] Often during the first psychotic episode, a young person who is living with family (particularly the parents or a partner) will need increased support during the acute phase with the degree of support lessening as the young person recovers. Family structure plays a large part in this especially with the formation of modern families for example, divorced, remarried, stepfather/mothers, half-siblings/step-siblings.

Clinicians need to be mindful of the needs of those providing support, especially during the acute phase illness, as HBC relies heavily on the capacity and competency of the family members. Additionally, work schedules and availability of family members and extended family are important aspects of successful HBC.[18] Family members should be encouraged to take time off from work if viable as this will emphasise the importance of supporting their family member. Clinicians may be able to provide additional support to family members with medical certificates or letters for their employers if necessary.

It has been reported that young people with over-involved families remain engaged in treatment and are more likely to recover compared with families that are more distant and disengaged.[18] The family being vigilant during the acute phase can be very helpful for the young person. Increased family involvement during the acute phase is often a necessary support for the young person for a period of time. The family will also need to be supported by the clinical team to gradually reduce their level of vigilance as the young person recovers from the acute episode. This will also help address any issues that have arisen between the young person and their family during this period.

Supports that might be included to facilitate HBC may be family (parents, siblings, partners or other members of the young person's extended family), friends the young person lives with and is willing to have involved, or other supports that may not live with the young person such as teachers, workmates, friends or other support workers. Although these people may not live with the person, they may be able to provide enough support for HBC to be carried out, for instance by 'dropping in' or phoning the young person to provide additional practical support or being there to open the door when the treating team arrives. This approach requires a high degree of collaboration from everyone involved in HBC. The young person needs to agree to supports being involved with their care, and the supports being able to carry out the required tasks. The treating team needs to clearly articulate and document the tasks, responsibilities and contingency plans for everyone involved if the situation takes an unexpected turn.

> 'It would be nice if clinicians gave you warning about coming to your house to see your parents. Clinicians should say something like "We plan on coming over to you just to chat with your parents is there anything you would like us not to discuss with your parents?" that type of thing. You don't really want your parents to know that you feel suicidal. You don't want to tell them that because then they'll stress out and not know what to do. So just a general discussion about what we'll be talking about at the home session and about what you don't want to be said, what you don't want your parents to know and what you do want your parents to know, all that sort of thing.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

The treating team needs to gain an understanding of the supports' capacity and willingness to be involved in the HBC plan and how reliable they are. For instance, can the family or supports cope with 24-hour care if necessary? Do the family or supports understand why medication needs to be carefully monitored? Is the family willing to be involved? If they are willing to be involved, then the clinician would need to determine how long this would need to occur. In addition, clinicians need to be mindful of the impact of family members' involvement in care on their relationship with the young person. The young person may not be willing to accept the involvement of their parents even if their parents are able and willing to provide this support. This can cause discord in the relationship, therefore, the benefits need to be carefully weighed against with the potential costs of involving supports in HBC. For instance, having family members monitor the young person's adherence can sometimes cause conflict and may also be contraindicated if the primary supports are part of the young person's delusional system. Therefore, each family and young person's situation requires thorough assessment and consideration before HBC can occur.

> Families need to be willing and able to carry out the treatment plan in collaboration with the treating team for HBC to be a viable option.

Bearing in mind that families and other supports (such as friends or partners) may have had both positive and negative previous experiences with mental health services and this may have set expectations (or presumptions) about what the early psychosis service offers or how it operates. It is important for the treating team to be clear about these issues with supports very early on to ensure that everyone is 'on the same page'.

It must also be stressed that time, engagement and talking with the family about what is happening not only for the young person but also for themselves is very important. The family needs to be supported as much as the young person and this will often have the flow on effect of allowing them to be engaged with the clinicians and available to the young person. Young people in share-house situations can have very supportive friends who are keen to help but need guidance on how best to do this. Experienced HBC clinicians are ideally placed to provide this.

Young people and families from culturally and linguistically diverse backgrounds may respond differently to HBC. It is important to be mindful of the cultural norms of the family and to be respectful of these. Clinicians may need to consider the use of interpreters to help with communication with the young person and their family. The *Australian Clinical Guidelines for Early Psychosis 2nd Edition* outlines key good practice points on how to work with interpreters, please see the guidelines for further information. It is also important for clinicians to be aware that some people may never have experienced HBC in any other setting, so a clear explanation of the aims and expected outcomes of HBC is needed. Sometimes it is useful to identify a key spokesperson for the family or someone to communicate the treatment plan to, particularly for large or complex family situations. Families should be involved regardless of their location (country, interstate, overseas) to obtain background and collateral information to help facilitate engagement, support and treatment.

Supporting home based care in an early psychosis service

Supporting home based care in an early psychosis service

Staffing

A multidisciplinary team that includes nurses who are able conduct biological screening, medication administration and physical monitoring is crucial to support HBC in an early psychosis service.[2]

Allied health staff members (social workers, occupational therapists and psychologists) are important for providing a well-rounded and comprehensive service. These staff members can offer specialist interventions and discipline-specific input required to inform and enhance treatment plans.

For new assessments of unknown young people or home visits that have the potential for complications, it is advised that two staff members go on home visits. For example, the risk assessment indicates that two clinicians are required for safety purposes or the main treating clinician may require the skills of another team member to complement the aim of the visit (e.g. family work or occupational therapy assessment). ‘Two heads are better than one’ especially when clinicians are attempting to engage the young person and their family, provide information, and assess mental state and risks. Having two clinicians enhances the repertoire of interviewing styles available to engage the young person and helps to ensure that nothing is missed during the interview. Clinicians may also complement each other by making sure that all relevant questions are answered and treatment options discussed with the young person and their supports. Furthermore, having two clinicians present enables the team to not only use the time efficiently but engages with the family or other supports (one sees parent and one sees the young person). It is also very useful to have one clinician to be a scribe to enhance recall when writing up the assessment later. However permission should always be sought from the young person and family, or whoever is present at the interview, prior to taking any notes.

Infrastructure

Multidisciplinary teams working to deliver HBC to young people with early psychosis will require access to registered cars to be able to make home visits or visits to other community settings. The team will also require access to mobile phones and possibly IT equipment. Please see the *EPPIC model and service implementation guide* for more information.[2]

Safety

Safety is an important aspect to consider when thinking of providing HBC to a young person and their family; safety should determine whether HBC will occur.

Assessing risk in home based care

When considering HBC, clinicians and treating teams need to have an understanding of the risk factors involved in home visiting or community treatment and ways to mitigate these risks. It is advisable to collect this information prior to commencing HBC to make a decision about whether HBC is safe for the young person, the family/other supports and for clinicians. These risk factors can be considered as part of the previously described figure as pertaining to the young person themselves, the supports and the setting/environment in which HBC will be carried out.

A comprehensive risk assessment is based on the degree of rapport and engagement with the young person and the family, and the quality and quantity of information pertaining to the young person's mental state and risk that is obtained. An initial risk assessment should be carried out as part of the intake process. A more comprehensive risk assessment can then be carried out when the first face-to-face assessment occurs. It will usually involve a more thorough assessment of the young person's mental state, assessment of their social situation (who they are living with or who else might be present in the environment) and an assessment of the home. An assessment of both static (historic) and dynamic risk factors is needed, and risk should be reassessed at every home visit. Risk assessment is an ongoing and dynamic process of decision-making and the concept of risk is a changeable perception that can change at any time. Clinicians and the service need to have agreed upon protocols and responses for managing risk. Clinicians and treating teams need to be flexible but also carefully consider how to mitigate for certain risk factors. This should be a discussion that occurs as a team with experienced senior clinicians and/or medical staff members to develop an initial risk management plan. Often, clinical review meetings can be a good opportunity to discuss these issues in greater detail, and formally discuss and document a risk management plan with input from the consultant psychiatrist, especially if there are issues around high risk. Early psychosis services may need to have additional structures and processes in place to review risk in situations where there may be significant risk issues, complex presentations and chronic high risk presentations.

An assessment of risk for HBC includes a clinical risk screening at intake and risk assessment at the face-to-face assessment. In line with the more general principles of assessment, risk assessment should include information about the young person, collateral information from the family, past service providers and other healthcare, education or social welfare professionals involved with the young person (please refer to the ENSP manual '*Let me understand…' assessment in early psychosis*). Information from as many sources as possible will provide a more rounded, comprehensive assessment. All referral information should be read thoroughly to screen or pick up, any potential risks – this will help the clinician to think about potential risk factors that may not be obvious.

In general, risk assessment should include:

- Risk to the young person: risk of harm to self (accidental or intentional), risk of death (accidental or intentional), risk of deterioration in mental health, risk due to vulnerability or circumstances.
- Risk to the family/supports or others: risk of harm to family/supports.
- Risk to the clinicians: risk to clinicians from young person, family, others (housemates/neighbours/visitors), environmental risk (health hazards).
- Risk to the community: risk of harm to general community as a result of the young person's behaviour, for instance, is the young person driving their car while acutely manic/psychotic?

For all of these domains, past history of risk, current risk factors and future/potential risk factors should be identified. In addition, a risk assessment should articulate the agreed upon management strategies to mitigate risk. For example, for a young person who is new to the service and who has a past history of aggression or violence towards others but no current indicators of risk of violence, the treating team may decide that a home visit should only occur if two clinicians are available with a predetermined plan of how to manage any potential escalation. If there is an increase in risk, it is necessary to review the young person as soon as possible so that the risk assessment and management plan can be updated to reflect this change. It is advisable that clinicians discuss this with the treating doctor, a senior clinician or a consultant psychiatrist to determine the best course of action. It is important that all risks are documented and communicated clearly. Any significant risks should be easy to identify in health information systems, files, electronic patient management boards or shift plan. For a more detailed discussion about risk assessment, please refer to the ENSP manual '*Let me understand…' assessment in early psychosis*.

Levels of home based care

Levels of home based care

Home based care across the phases of early psychosis

The various phases of psychosis can be seen as a continuum with young people moving back and forth between the different phases of psychosis and recovery.

Clinicians should aim for seamless and consistent provision of care across phases of illness. HBC can be used as an intervention that supports recovery at any stage of the disorder for all young people with early psychosis. However, it is important that clinicians understand how they might use HBC at each phase as different levels of HBC may suit different phases. This will be described in more detail in the next section.

Short intensive HBC will best suit young people in the acute phase of psychosis, when they may rely heavily on family and other supports. As symptoms and functioning improves and the young person begins to recover from the psychotic episode it is normal to expect that they will begin to seek independence again and take control of making decisions about their treatment. Short intermittent HBC, and less frequently extended HBC, may be more appropriate as the young person until HBC is no longer required.

Providing HBC should be approached with some caution. The aim of HBC should be to provide a timely and appropriate treatment option for those young people who need it. HBC has the potential to be used in a way that may become detrimental to the young person in the longer term; HBC should be delivered in a way that empowers a young person to help-seek and does not promote dependency. Clinicians need to be mindful that not all healthcare services (in fact very few) operate using these principles and so caution must be exercised. A balance is needed between providing a service that is accessible and assertive and a service that discourages young people from independently help-seeking or encourages dependence. Clinicians need to be mindful that teaching young people how to access help for themselves is empowering, assists them to become informed and involved in their treatment, and will benefit them in the longer term.

Short intensive home based care

Entry to service for young people may also be an indicator for using HBC especially where they may be reluctant to seek help. It is very important for the young person to develop a good relationship with the service and clinicians upon entry to the service, and for clinicians to obtain a comprehensive assessment of the young person's mental state and psychosocial situation. HBC is an assertive approach that provides opportunities to maximise engagement by taking the care into the young person's environment, while clinicians have the opportunity to conduct an assessment of the young person and their situation. Other aims of HBC during this period include providing support to families to reduce burden and distress, maintaining treatment within the community and avoiding a potentially traumatic hospital admission, and reducing hospital bed days.

The *Australian Clinical Guidelines for Early Psychosis 2nd Edition* describes the acute period as 'the presence of psychotic features such as delusions, hallucinations and formal thought disorder' that may occur 'with comorbid conditions of depression, obsessive-compulsive disorder, post-traumatic stress disorder, anxiety disorders or substance use difficulties.'[3] In the acute phase of psychosis, it is expected that a young person will rely more heavily on the supports they have available to them and so HBC may be used more extensively in this phase. The overall aim of HBC during this period is to reduce symptoms of psychosis and improve overall quality of life. Reducing symptoms of psychosis may include interventions to target positive, negative or cognitive symptoms; improving quality of life includes promoting functional and social recovery, and addressing social and welfare issues.

Short intensive HBC is indicated when a young person requires additional support, monitoring or intervention at home or in the community for a discrete period of days or weeks. This is common during the initial stages of entry to service, when young people and their families may be experiencing distress due to the onset of a first episode of psychosis and treatment may need to be initiated quickly. This is also common when a young person is experiencing an increase in acute psychotic symptoms or a short exacerbation of risk issues.

HBC in this phase it is important to initiate treatment in the home and prevent or shorten admission to hospital where possible. Typically, the first episode of psychosis is unclear and the clinical picture is still emerging. Short intensive HBC during this phase provides an opportunity to initiate treatment in a safe and effective way while providing support and practical assistance to the young person and their family.

HBC needs to be guided by the principle of continuity of care and to minimise the number of transfers of care that the young person experiences (e.g. one clinician may provide assessment, case management and HBC). In reality, short intensive HBC is often provided by shift workers and continuity can be second to demand and roster requirements, so in some instances having one consistent clinician is difficult to achieve. HBC may not be appropriate when there are risks to clinicians' and family members' safety, when a young person requires containment due to the nature of their symptoms or exposure to ongoing destabilising factors (conflict, relationships, stress) or other risk factors (e.g. continued drug use) that are likely to cause further deterioration in their mental state. Other instances include when the young person or family lack motivation or are unwilling to engage in treatment, when the young person does not have insight into the nature of their difficulties, or there are limited supports or supervision available.

HBC may be carried out by a separate team in conjunction with support from usual treating team/clinicians. For example, some services operate with business-hours clinicians and after-hours clinicians. Business-hours clinicians usually have responsibility for a caseload of young people who are also assigned to a treating doctor; they provide the majority of care, co-ordination, intervention, psychological therapies and support to the young person and the family during the normal 9–5 day. After-hours clinicians may become involved if the young person experiences a crisis or exacerbation of symptoms that requires additional support. This might include crisis assessments, home visits in the evenings or on weekends to supervise medication, phone support, family work or facilitation of admission outside usual business hours. In this case, the after-hours clinicians provide a supportive complementary function to the usual treating team's tasks and the usual treating team remain the primary clinicians involved in providing treatment. Often this will occur over a short time period until the crisis or exacerbation in symptoms has settled.

KEY ASPECTS FOR SHORT INTENSIVE HOME BASED CARE

- 24/7 availability
- Rapid response
- Flexibility and ability to provide increased HBC visits
- Address practical/social issues for both the young person and family
- Medical/nursing staff available
- Administer/supervise medication
- Provide practical help/symptomatic relief
- Provide education and support
- Provide therapy/counselling (single session/time limited, such as family work, psychoeducation or medical/medication information for substance use)
- Facilitate and advocate for short inpatient care
- Continue engagement with the young person and liaise with the treating team during inpatient care

The team who provides the short intensive HBC will need to make decisions about who is appropriate to see and would remain involved until the crisis is resolved, ensuring that the young person is linked with ongoing supports. Communication between teams such as the mobile assessment and treatment team (MATT) and continuing care team is paramount. Collaborative treatment plans that are accessible to the teams and clear documentation of goals and progress in the clinical record are important.

CASE SCENARIO **DJ**

DJ was receiving care from an early psychosis service and had made a good symptomatic recovery from his initial presentation and was being followed-up by an early psychosis continuing care team. His mother contacted the after-hours mobile assessment and treatment team (MATT) during the middle of the night because she was concerned with her son's mental state and behaviour. She said he was having difficulty sleeping, appeared agitated, hypervigilant and he was paranoid that his neighbours were conspiring against him and talking about him. His mother had also noticed that he had become increasingly isolative, appeared preoccupied and irritable the previous 2 weeks; she assumed that this was because he had recently failed to be successful in a job application.

After obtaining some collateral history from his mother, the after-hours team clinician accessed the available electronic information regarding DJ's initial presentation, treatment and background history. The after-hours team clinician and his mother were then able to engage DJ in a telephone conversation to assess his current mental state and risks. The after-hours team clinician reassured both DJ and his mother, formulated a basic safety plan and planned to liaise with his existing treatment team to provide follow-up.

DJ was encouraged to take his night-time medication to aid sleep while the after-hours team clinician continued to speak with him until he gradually settled. DJ subsequently reported a reduction in distress, was thankful for the contact and agreeable to follow-up the next day.

The following morning, the MATT clinician contacted the case manager to discuss what happened with DJ overnight and the short-term management plan that was put in place. Clinical information pertaining to DJ's mental state, risks, supports and plan were documented electronically and faxed to his treating team and made available on the local mental health information systems for future access.

DJ's case manager briefly discussed his recent clinical presentation with the treating doctor. He subsequently rearranged his schedule so that he and another clinician could undertake a home visit later that day to further assess DJ's mental state, risk and the need for additional biological interventions and support in the community setting.

DJ was initially seen at home alone. The clinicians then spoke with his mother separately to get additional collateral information before seeing them both together to clarify a plan. DJ had a good rapport with his case manager and was forthcoming with information. He disclosed that he had recently been non-compliant with his oral medication in the context of sexual dysfunction and had also used methamphetamines again, in part to deal with perceived failure at gaining employment and to enhance his libido.

CASE SCENARIO **DJ** CONTINUED

DJ had previously been reluctant to disclose his side effects in regards to sexual dysfunction as he was embarrassed. He had decided to stop his medication due to sexual dysfunction side effects and his relatively stable mental state.

When he began to experience paranoia again he was reluctant to tell his mother or treating team in case he was hospitalised. His case manager provided psychoeducation about the common side effects associated with antipsychotic medication, normalising his experience and acknowledging his concerns regarding his dysfunction. Additional information was provided in a non-judgemental way about the risks associated with methamphetamine use and how it impacts on mental state. DJ's treating team reassured him that they will be supporting him to stay in the community and that they will review his medication due to the unpleasant side effects.

DJ was still ambivalent about his paranoia and experiencing distress. His case manager offered a medical review with his regular medical registrar in the subsequent days and introduced the possibility that other biological interventions may help reduce his paranoia and provide some symptomatic relief. His mother agreed to take time off work to help monitor and support her son and the treating team offered her a Medical Certificate for her place of employment. Both DJ and his mother were reminded of contact numbers if DJ's mental state further deteriorated and they required immediate contact.

Upon return from the home visit, his case manager spoke with his regular treating doctor and they decided to make a referral to the HBC team to continue to monitor his mental state, provide additional support to DJ and his mother and to supervise administration of benzodiazepines and hypnotic medication to provide short-term symptomatic relief.

A referral for home treatment was discussed with a clinician from the HBC team specifically requesting daily home visits in the evening to support to DJ and his mother. Relevant clinical information and documentation with a detailed plan was forwarded to the HBC team prior to the home visit that evening. DJ and his mother were informed of the approximate time that the HBC team would visit the home and contact numbers for the HBC team.

The HBC team visited DJ and his mother to review his mental state and risk. They provided additional psychoeducation regarding the role of HBC team, information about as required prescribed medication and reassurance about the treatment plan with an emphasis on community treatment. Clinicians who attended the home allowed both DJ and his mother time to discuss their frustrations and they conversed casually with them to enhance engagement. Nursing staff administered and supervised his prescribed medications.

CASE SCENARIO **DJ** CONTINUED

DJ and his mother were informed that if possible they would be sent familiar clinicians for consistency and reduce burden on the young person and family.

DJ attended a medical review with his mother, treating doctor and case manager the following day. His case manager had already spoken with the HBC team in regards to DJ's mental state during the home visit the previous evening.

His doctor and case manager discussed the importance of recommencing medication to treat psychotic signs and symptoms.

Following a detailed discussion between DJ, his doctor, mother and case manager, they agreed to commence DJ on a new antipsychotic agent (considered to have less sexual side effects) and to continue with benzodiazepines and regular hypnotic medications to help reduce his distress. The HBC team continued to be involved daily to monitor his mental state, supervise and administer medications, and to support DJ and his mother. His case manager would also continue to liaise with the HBC team about DJ's presentation and the plan throughout the period of HBC.

The HBC team continued to home visit daily for the next 2 weeks. Each day they monitored his mental state and risk, administered medication, provided additional psychoeducation when deemed necessary (i.e. medication, common side effects, time expected for medication to be effective, coping strategies, and alcohol and drug use). DJ continued to meet weekly with his case manager and treating doctor during the period of HBC. He experienced some symptomatic relief and gradually his preoccupation with paranoid themes reduced. DJ's motivation to comply with current medication regime increased as he became less symptomatic. He was also keen to learn more about the psychosocial recovery program offered at the clinic, with a longer-term plan to recommence the work force when fully recovered.

His care was eventually transferred back to his case manager after a joint home visit with HBC team and the case manager. His mother returned back to work and they both reflected on the period of HBC as a positive intervention.

Short intermittent home based care

Short intermittent HBC is indicated for most young people who are receiving treatment from an early psychosis service at some time during their recovery. The young person may still be experiencing symptoms or issues that have an impact on their overall functioning; HBC may enable the clinician to target these symptoms or issues more effectively.

The non-acute/early recovery stage is defined as a period of 2 years where there is a remission of symptoms, the young person has returned to work or school and is able to manage their own day-to-day needs and/or is participating in recreational activities and peer relationships.[21] The overall aims of HBC during this period is reducing symptoms (positive, negative, cognitive and comorbidity), improving quality of life by supporting functional recovery, improving family support, re-engaging with the young person and maintaining engagement, facilitating physical investigations/assessments (magnetic resonance imaging, electrocardiograms, blood tests), introducing vocational recovery consultants/services and psychosocial recovery.[21]

It is also very important that clinicians monitor for treatment resistance and signs and symptoms of prolonged recovery throughout the early recovery phase. If symptoms persist longer than 3 months following initial acute recovery, then attempts should be made to treat/address persistent symptoms via various biological, psychological and social interventions.

The clinician initiating short intermittent HBC should set clear aims for HBC.
Some examples of aims can include:

- Providing specific interventions for skill development within the environments in which they might be used for example, social, psychological or occupational therapies in the home or school.
- Providing assistance with housing or other community based agencies where the young person may have difficulty doing this independently.
- Re-engaging with a young person who has decided they no longer wish to come into appointments or are at risk of disengaging from the service.
- Providing family work to a family who find it difficult to attend service appointments due to other commitments.
- Increasing resources for the young person in home/context.

Please note that this list is not exhaustive and clinicians should always keep in mind the potential benefits of taking the care and treatment into the home or other community settings.

KEY ASPECTS OF SHORT INTERMITTENT HOME BASED CARE

- HBC is a planned approach to a specific issue with clear aims to support the young person's goals.
- HBC may be carried out by 'usual' clinician or case manager who is the main coordinator of care.
- HBC is used as an additional resource or to 'scale up' the existing support or resources that the young person has available to them.
- HBC should be provided by the young person's usual treating team (clinician and doctor) to minimise the number of transfers of care. HBC may also be provided by additional clinicians, working together with the young person and their treating team for a distinct period or on a particular goal.
- HBC should be implemented easily and when required by the young person or their family; this type of HBC at any stage of the young person's involvement with the early psychosis service.

CASE SCENARIO **JESS**

Jess has been coming in for appointments at the early psychosis service for 6 months after an initial psychotic episode. She made a good symptomatic recovery and is well engaged with her case manager. Together they have been working on goals that focus mainly on anxiety management and return to tertiary education. Specifically, Jess was interested in pursuing a floristry career but had been unsure about how to go about following this up independently. Jess and her case manager met with the Vocational Specialist in the early psychosis service who was able to provide some advice around suitable education pathways. The Vocational Specialist spoke with Jess and the case manager about the benefits of attending TAFE open days to find out more about potential courses that Jess may be interested in. Due to Jess's anxiety, she was reluctant to do this herself.

At the next appointment, Jess had not followed up on any of the suggestions that the Vocational Specialist had made because of her anxiety about being able to do this herself. She and her case manager discussed the benefits of attending the open days to find out more information. The case manager suggested that they do this together so that the case manager could support Jess to use some of the anxiety management techniques she had been practising in sessions.

HBC enabled Jess to access community settings that she would not have done herself, supported her goal of returning to tertiary education and a floristry career, and was an appropriate choice for her to use the anxiety management techniques in a real-life situation.

Extended intensive home based care

Extended intensive HBC may be indicated for those young people who are difficult to engage in traditional office-based treatment and who may require more assertive outreach and prolonged engagement. Often, young people who are identified as difficult-to-engage who may also have poor adherence to treatment and are more likely to experience negative social and vocational outcomes. These young people can often be at risk of treatment drop-out or being 'lost to follow up' and may have an increased risk of repeated cycles of relapse, resulting in readmissions, a greater chance of receiving coercive treatment and exposure to iatrogenic harm. These young people are often likely to have complex presentations, that is, presenting with psychosis and personality disorder traits, substance abuse issues, non-engaging psychological adjustment (sealing over), a trauma history, poor family or social supports, forensic history, chronic and current high risk of harm to self or others, poor insight, low intellectual functioning, poor premorbid functioning or a prominent negative symptom profile. Factors such as substance abuse issues, poor psychological adjustment, poor family and social supports, poor insight, low intellectual functioning and poor premorbid functioning have been associated with poor response to biological treatments and are indicators for an incomplete recovery.[19]

There is no consensus definition of incomplete recovery, this is a period that is characterised by the persistence of positive symptoms and ongoing poor function that may be influenced by the presence of positive and negative symptoms, depression, anxiety, and social and cognitive deficits. Interventions focus on the modifiable factors that contribute to the incomplete recovery of psychosis.[3] The overall aims of HBC in this phase are to reduce the impact of ongoing symptoms, maintain or improve engagement, support functional recovery, improve family support, strengthen care coordination and prevent 'revolving door admissions'. For young people who are disengaged from treatment, continuing contact by phone or text message can help to maintain links with the clinician. Furthermore, regular visits at the same time each week and leaving a calling card can help the young person realise that the clinician is responsive and will continue to be available when the young person is ready. This method reduces barriers that a young person might experience when accessing or receiving a service and works to improve or maintain engagement with the clinician and the service.

KEY ASPECTS OF EXTENDED INTENSIVE HOME BASED CARE

- Reducing barriers to accessing ‘care’, that is, taking the ‘care’ into the young person’s environment, where the majority of the clinician’s work with the young person occurs outside of the early psychosis service setting.
- Improving engagement with the service and clinician for the young person who is hesitant to see a mental health clinician.
- Reducing the stigma of receiving mental health support and treatment and assertively engaging the young person.
- Improving adherence to treatment. Adherence strategies such as picking up or taking medication (if given in the form of a long-acting injection) and close monitoring of adherence and mental state/risk.
- Reducing signs and symptoms with an important focus on addressing psychosocial recovery goals and the impact of negative influences on recovery such as working with substance abuse issues.
- Improving (or ‘bolstering’) support with regards to ongoing unresolved positive/negative symptoms, poor coping, chaotic lifestyle or for intensive support with functional goals. This type of support differs to short term support in that it is aimed to address many different goals over a longer time period. For the young person with complex issues, there may be a number of goals that are worked on with the clinician to address multiple needs.

Flexibility and consistency are essential in the approach of extended intensive HBC. Clinicians need to work with the young person’s goals and provide a consistent approach, this is especially important when working with young people who may have a chaotic lifestyle. The appointments by clinicians need to be easy to remember for the young person; therefore, it is recommended that clinicians visit on the same days at the same time each week (e.g. Mondays, Wednesdays and Fridays at 2 pm). Additional appointment times may be scheduled as required and clinicians need to be responsive and receptive of changeable workload with complex young people. The clinician can also help inform and educate other professionals and services working with the young person. A coordinated approach between the services can help reduce confusion for the young person and help the young person obtain the appropriate assistance from those services. Additionally, this approach can improve communication between the services and help support other workers to manage challenging behaviours that in turn may help reduce the frequency and severity of crisis experienced by the young person. It is recommended that a clearly documented care coordination plan that outlines a clear crisis plan is shared among the different services involved with the young person; this will help promote a consistent approach and assist the young person to achieve or work towards therapeutic goals. Also multi-agency case conferences can be offered to share concerns and coordinate services approaches and management plans.

CASE SCENARIO **KRISTOS**

Kristos is a 17-year-old male who lives at home with his parents and older brother and attends a community school for young people who have had difficulties engaging with traditional schooling. He is a young man with longstanding history of behavioural problems since childhood, a history of impulse control problems, a diagnosed learning disability, occasional deliberate self harm, extensive substance abuse problems and a history of aggressive behaviour. He has several convictions and is currently pending court for several counts of armed robberies and for stabbing his brother.

He was diagnosed with a first episode of psychosis 12 months ago after a prolonged period of cannabis and methamphetamine abuse. His engagement with the early psychosis service has been poor and he has developed limited rapport with his previous case manager. Kristos's insight into his mental health issues is limited and he continues to regularly abuse substances.

Both Kristos's parents and his older brother are substance users and are at times very hostile, critical and dismissive of the early psychosis service's involvement. Kristos has a history of aggression, he frequently threatens his parents for money and his parents find his intimidating behaviour increasingly alarming. His family members have previously disengaged with services because they felt their needs were not met (i.e. that the mental health services could lock up Kristos to stop his substance abuse).

Initial attempts to manage Kristos were difficult due to his complex needs, frequent crises, time needed to liaise with different services (Youth Justice, Disability Health Service, Child Protection Service and Alcohol and Drug Services) and his mandatory attendance with other agencies as part of a previous court order.

The youth mental health service decided to provide extended intensive home-base and outreach care to Kristos and his family for extra support.

The aims of this were to:

- Provide more intensive and responsive support to Kristos in crisis.
- Coordinate care and liaise with other agencies.
- Further develop engagement with Kristos and his family.
- Provide more frequent monitoring of mental state and risk.
- Assist Kristos to develop adaptive coping strategies.
- Assist Kristos to address anger management issues.
- Provide concurrent alcohol and drugs counselling.

The case manager arranged for regular monthly case conferences to discuss each agency's involvement with Kristos and to identify shared goals.

CASE SCENARIO **KRISTOS** CONTINUED

This provided a good opportunity for the different service agencies to communicate with each other, establish a rapport and develop a good working relationship.

This also allowed each agency to understand the crisis plans, which in turn helped ensure a coordinated and consistent approach was provided when attempting to manage Kristos's challenging behaviours. To improve communication and planning information regarding court dates and appointments and Kristos behaviour were communicated via the team.

There was an obvious and immediate need to try and streamline Kristos's appointment times to improve rapport, increase attendance and to reduce burden on Kristos and his family. Key workers attempted to coordinate meetings and appointments for the same day so that Kristos was able to attend. The different agencies were able to share their own practical and effective behavioural interventions to help manage Kristos across settings.

The case manager agreed to collect Kristos from school each Wednesday to liaise with his support worker at school, monitor his mental state and risk, and occasionally facilitate medical reviews. Previously, Kristos's mother had to collect him from school and transport him to his appointment. This was time consuming and often led to additional and unnecessary conflict and distress between Kristos and his mum. The weekly contact would occasionally involve more informal sessions over lunch at a fast food restaurant; this provided a more relaxed environment to have therapeutic discussions.

The case manager collecting Kristos achieved a number of things:

- increasing contact with the young person and family
- liaising regularly with school in their environment (insight into school environment)
- increasing time to speak with Kristos (captive audience, 30 minute car ride)
- decreasing financial and emotional toll on mother
- facilitating regular medical reviews.

This arrangement proved to be very successful and practical for the young person and the family.

Medication supervision had previously been a constant issue for conflict between Kristos and his mother. His previous negative experience with anti epileptic medication was an additional barrier to adherence. Given that cannabis and methamphetamine use was unlikely to cease in the near future, it was essential that Kristos was adherent with antipsychotic medication to reduce chance of acute paranoia and prolonged recovery.

CASE SCENARIO **KRISTOS** CONTINUED

The case manager provided psychoeducation about the advantages and disadvantages of oral versus long-acting injection medication. Kristos eventually came to the decision that monthly injections were preferable rather than frequent prompting and monitoring from his mother. The consistent administration of long-acting injections helped to reduce poor adherence.

Additional family work was provided when the case manager needed to discuss Kristos's treatment with his parents. Kristos's parents received a consistent message from all services regarding behavioural issues and were able to work with the case manager and other agencies to develop a shared safety plan. This safety plan was also communicated to other parts of the early psychosis service so that a standardised approach and response was given to Kristos when he presented in crisis.

Home based care in practice

Home based care in practice

Roles, boundaries and self-disclosure

HBC can offer more flexibility to the young person and clinician compared to traditional office-based appointments. It does, however, have the potential to confuse roles and boundaries as the environmental setting promotes non-traditional interactions.[22] Clinicians should ask for permission to enter the home and ask where to have the appointment. Clinicians should ask for example, 'Is it ok to have our appointment for the next hour or do you have other things that you need to do?' This respectfully acknowledges that the clinician is a guest in the young person's environment. If visiting the home regularly for appointments, a pattern will naturally emerge, where the clinician and young person develop their own environmental cues.

CASE SCENARIO **JOSH**

John was referred to the early psychosis service and after a short time disengaged from office-based appointments. The clinician decided to initiate extended HBC to address engagement difficulties and other functional goals. After a period of time visiting Josh at home, it became apparent that Josh was choosing the same time (11 am) for his appointments each week and choosing to sit in the same lounge chair in his living room for each appointment. At the beginning of each appointment, the clinician and Josh began by talking about what Josh had been doing over the past week since the last appointment and set an agenda for the session. These subtle cues and structure helped Josh and the clinician to prepare and be engaged in the appointment.

It is important for clinicians to keep appointments with young people and their families when providing HBC. Having an open discussion with the young person and their family about the clinician's role and availability at the beginning of HBC helps the young person understand the purpose and expectations of the appointments. Failing to arrive on time or postponing home visits can be detrimental to engagement for the young person and families. This may be avoided by clearly outlining expectations during the initial stages of HBC, by saying 'sometimes we may need to call up and reschedule our times due to other work-related tasks but we will let you know if we need to do this'. Try to not to miss or reschedule an appointment more than once in a row and aim to communicate expected delays as soon as possible.

The young person and their family may have more influence in their own environment and are more 'in charge'. Clinicians need to be aware of how this may impact on their role in this situation as they may be more susceptible to the young person and their family asking personal questions. Sometimes, clinicians may be more inclined to use self-disclosure for young people who are difficult-to-engage. Appropriate disclosure can help facilitate engagement but clinicians should be aware of what they are disclosing and why.[22] Some young people and families may enquire about marriage status, children or cultural background as it may be a form of engagement and is socially accepted within their culture.[22] Clinicians should make a conscious decision about self-disclosure based on the best interests of the clinician and the young person.[22] Sometimes clinicians would ask why it is important for the young person to know this information. Clinicians should determine the level of self-disclosure depending on theoretical orientation, professional training and personal preference. Clinical supervision times would be a useful way to determine the motivation for self-disclosure and how this will impact the outcomes of HBC.[22] Clinicians may find themselves in situations where the professional relationship has changed in HBC. Young people may ask for personal favours such as borrowing money or young people may offer gifts to the clinician; these situations should be treated with respect and caution but can also be used to address boundary issues. If clinicians live in the same area or close to the young person and their family they should avoid being involved in their HBC as this can confuse the professional relationship. For more information about this, please refer to the ENSP manual *Get on board: engaging young people and their families in early psychosis.*

> 'I haven't actually had any home visits. I did have YAT [crisis assessment community treatment team] call me quite a few times like mostly that's how they sort of checked in with me rather than coming for a visit but I think I would have found it very intrusive. Once, I had a case manager drop me at home, which was really lovely now that I think about it, but I didn't really want them to see where I lived because it's already such a one-way dynamic that they know so much about you and you know very little about them. They [clinicians] are very unwilling to share anything about themselves as there're all these rules about what they can share, so I think for me it would be even more intrusive if someone did come to my house to visit me. I would worry about them making judgements about my home.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

Confidentiality

Confidentiality needs to be discussed with the young person at the beginning of HBC, if family members are involved this needs to take place (or repeated) in their presence. A systematic review by Gulliver et al. (2010) that examined barriers and facilitators to help-seeking in young people reported that nearly half of the studies cited confidentiality and trust-related issues as a key barrier, second to stigma.[23] Limits to confidentiality should be carefully explained to the young person. Young people should also be reassured that information will only be shared with specific individuals to ensure their safety.[20] At times, it will be difficult to maintain strict confidentiality as the family are functioning as important primary supports in HBC.[18] Although this is important in any aspect of the young person's treatment and care, potential barriers to privacy and confidentiality might be more of a concern when conducting HBC. For example, if visiting a share-house and the young person is not home, is it ok with the young person to leave a calling card from the early psychosis service? The people the young person is living with may not be aware of their involvement with your service and this might impact on their privacy. Similarly, if visiting in the family home, is there sufficient privacy available if the young person does not want their family involved in certain discussions?

> 'In the case of housemates, if they [case managers] are going visit my flat then maybe they can find a time when my housemates won't be there or maybe if my housemates do happen to be there then don't say "I'm so-and-so's shrink". Maybe they should just prepare [you] in case you run into friends or housemates or stuff like that because it could lead to an awkward conversation.'
>
> – Young person,
> EPPIC, Orygen Youth Health Clinical Program

The treating team

Good communication skills are essential for every clinician working with the young person and their family when delivering HBC. Often the family and the young person would be unfamiliar with youth mental health services and would require clear instructions from the treating clinician.[18] Specifically, when undertaking HBC, clinicians skilled in assessment and crisis management with excellent interpersonal communication skills are required. As mentioned previously, a multidisciplinary team approach should be used for HBC, and where possible, having consistent clinicians providing care is important. Gender and ethnicity should be carefully considered when matching clinicians and young people and their families. Discussing HBC at clinical reviews will allow a therapeutic match with the young person's needs and the skills of the clinician. Clinicians have to create their own place in each family's environment and need to be confident doing so.

Checklist and preparation

A high degree of preparation and planning is required to successfully and efficiently undertake HBC. Clinicians should use a 'safety check' before they go out on a home visit to ensure that they communicate their location, expected time out/back, contact numbers to their team.

The following box is a guide of practical considerations for clinicians who may be less familiar with HBC.

PRACTICAL CONSIDERATIONS IN HOME BASED CARE FOR CLINICIANS

Preparation:

- Determine the goal or purpose of the visit. Why am I going? Why are you providing HBC?
- Is this an assessment or part of usual treatment? Or a new young person entering the service?
- The number of visits required will need to be considered in terms of how familiar the young person/family is with the process and expectations of HBC. If it's the first visit, young people and families will not know what to expect.

Clinicians need to ask themselves the following questions:

- Does the young person need a medical review?
- Does medication need to be administered or supervised?
- Are there risk issues that require two clinicians?
- Who else needs to come with me? This can also be determined by the purpose, for instance if the initial assessment team are involved then likely two clinicians will need to be involved.
- What is their role and how will this impact the young person?
- Will peer support workers or family peer support workers be attending?
- Have I read the notes?
- What information do I need?
- What is the current risk assessment and management plan?
- Last presentation/mental state examination?
- Current treatment?

Time and location:

- Where am I going? It is important for clinicians to inform others of their whereabouts and expected time of return.
- How long will it take to travel to the young person's house?

PRACTICAL CONSIDERATIONS IN HOME BASED CARE FOR CLINICIANS

Time and location continued:

- How long will the appointment be? This will depend on a number of factors but a rough estimate of time should be made based on the purpose of the visit.
- Is there enough time? The clinician needs to prioritise what should to happen during the appointment.
- The worst case scenario in terms of duration of appointment and how this can be managed. If there are possible delays expected, for instance where attending to a crisis that may result in facilitating admission to inpatient care, what contingencies can be put into place? Are there other clinicians available to assist or manage workload?

Practicalities:

- Is there enough petrol in the car?
- Will traffic be a problem? Do I have a phone? Do I have all the necessary numbers?
- Am I aware of the organisation's policies and protocols for home visiting?
- Does the early psychosis service know where I will be and am I contactable?
- Do I have all the up-to-date contact details including the address and mobile numbers?
- Do I have all the necessary paperwork for assessment and screens?
- Scheduling home visits to maximise travel time?
- Where multiple home visits are planned in one shift/day the clinician should try to (within reason) plan their visits so that a minimum amount of time is spent travelling between visits.

Summary

HBC is providing care, treatment and support to young people and their families at home or in an environment they are comfortable with. It can provide positive support before and after hospital admission to reduce the length of time a young person is admitted to an inpatient setting and enable earlier discharge home, by providing assistance, supervision and more assertive management of risk. HBC in early psychosis assessment and treatment can help promote recovery, reduce stigma, reduce secondary morbidity and assist young people get back to their normal developmental trajectory as well as offer assistance and support to families. It also can be care that all clinicians within an early psychosis service can provide. HBC can provide an insight into a young person and their family that can never be achieved with solely office-based appointments.

The setting, the young person and their supports are all important factors to consider in HBC as these things can ultimately determine whether HBC is appropriate in different situations. HBC can be used as an intervention that supports recovery at any stage of the episode for all young people with early psychosis and those young people identified as UHR of psychosis. Ideally, HBC should be delivered by multidisciplinary teams of nurses, social workers, occupational therapists and psychologists that can provide well-rounded, comprehensive care such as biological screening, medication distribution and monitoring, psychosocial interventions and offer any other specialised interventions as required.

For a young person who is reluctant to engage with healthcare providers or unsure how to seek help for themselves, HBC can offer a treatment pathway that is flexible, responsive and more acceptable to the young person. HBC can also be a real support to families, assist with their engagement and provide care to young people in the real - life setting.

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NOTES

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Printed on 100% recycled paper, made carbon neutral.

This manual has been funded by the Australian Government