



CEDAR Clinical Brief

Center for Early Detection Assessment and Response to Risk

Discussing Diagnosis of Early Psychosis with Youth and Families

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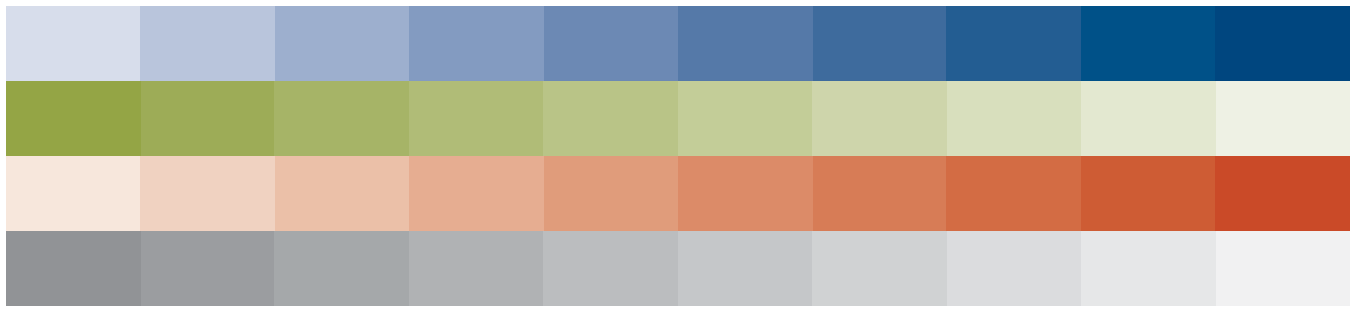


Why Discuss Diagnosis?

Clinicians may feel unsure about how to talk with youth who are experiencing early psychosis or clinical signs of risk for psychosis (termed “Y-EP” here for brevity) and their families about diagnosis, treatment, and prognosis. There are several reasons why this can be challenging for clinicians:

- Clinicians may be uncomfortable sharing information that Y-EP and families may find difficult or upsetting
- Clinicians may worry that the Y-EP and family will disagree with the diagnosis.
- Uncertainty about diagnosis of early psychosis and signs of risk is common because the presenting concerns are usually newly developing, unclear, and confounded by developmental factors, co-occurring diagnoses, or substance use.

Despite the understandable challenges, providing diagnostic feedback and psychoeducation to Y-EP and families is important and can be beneficial to both young people and their families. When provided thoughtfully, with attention to the youth and family’s culture and experience, feedback can help youth and families to better understand their experiences, and to reduce misconceptions, worry, and shame about symptoms. Feedback can help the youth to begin learning and practicing effective coping skills and strategies. (Note- for more information on what is meant by CHR and early psychosis, see our previous clinical brief, titled, [“Screening for Psychosis”](#)).



Clinician Self-Assessment

Providing clear and effective diagnostic feedback and psychoeducation to Y-EP and families requires some preparation, and it can be helpful to start with a self-assessment:

- What is your rapport like with the Y-EP and their family?
- What do you know about the youth and family's background, culture, and past experiences that might influence how they respond to diagnostic feedback and recommendations?
- What have they previously learned about psychosis and CHR?

Who Should be Present for the Diagnosis Discussion?

One consideration for discussing diagnosis is who will receive what information, and in what order. Depending on the circumstances, clinicians may provide feedback to the youth and family at the same time, to the young person first and then to the family, or to only the youth or only the family. Some factors that can influence which approach to use include:

- What is the age of the Y-EP?
 - » Are they over or under 18? (Or the age for consenting for treatment in your state?)
 - » Are there considerations regarding the Y-EP's maturity level and cognitive functioning (attention span, organization) that might impact whether or not it would be preferable to include the family in the initial feedback session? Or to provide feedback first to the family?
- What is the Y-EP's relationship with their family members like?
 - » Are you concerned that meeting with the youth and family together will be impacted by arguments between family members or high levels of expressed emotion that may reduce the likelihood that the feedback session will be effective?

It can be helpful to talk with the Y-EP about how they prefer to structure the feedback session. Would they like to meet with their parents, or separately? In many cases, our team tends to meet first with the Y-EP to provide feedback and then invites family to join the session.



How to Begin:

It is helpful to begin feedback meeting by asking and highlighting the following points, to guide your approach:

- In our last meeting, it sounded like you wanted to know (use Y-EP/ family's own words). Anything else?
- What questions do you have for me that you want to make sure we discuss?
- What have you been told about your mental health symptoms/diagnosis by other people?
- What do you think about these changes?
- Have you spent time researching these experiences on the internet?

If you're providing feedback to someone other than the Y-EP (family, partner, another provider), ask what they're comfortable sharing. For example, some young people are okay with loved ones knowing the kinds of symptoms they experience (e.g., visual hallucinations) but prefer not to share specific examples.

Deciding Information to Share

Prior to starting feedback, you will also want to carefully consider what information you want to share. You may choose to give information about mental health diagnoses in general (e.g., they're a cluster of symptoms that can provide one way of understanding a person's experiences). It can be helpful for Y-EP and families to understand that there are no definitive tests or brain scans to make a diagnosis of a mental health problem. Instead, clinicians do our best to make a diagnosis based on information gathered (e.g., from the Y-EP, family, previous providers, records) to identify which experiences the person has had and how these match up with our diagnostic categories in the Diagnostic and Statistical Manual of Mental Disorders.



Psychosis Specific Feedback

During the discussion of psychosis, some useful statements and key points to highlight may include:

- “Have you heard the word “psychosis” before? What have you heard?”
- Psychosis is a medical term used to describe changes in the way the brain processes information, causing difficulty telling the difference between what is real and not real.
- Psychosis spectrum experiences can occur in the context of many conditions and diagnoses – so having these experiences does not mean you have any specific diagnosis in itself.
- Like any mental health symptoms, psychosis symptoms are on a spectrum ranging from mild, common experiences (e.g., seeing a shadow out of the corner of your eye they looks like a person) to high levels that interfere significantly with daily life.
- Give examples of main psychosis symptoms (using the Y-EP’s examples as appropriate).
- These experiences are more common than generally thought: about 3 in 100 people experience high level psychosis symptoms at some point in their lifetime, and about 7% will experience clinical high risk for psychosis, which involves milder, but still significant psychosis-like symptoms.
- Psychosis is not accurately described in the media (can check for assumptions about psychosis based on what they have heard).
- *If the person meets criteria for clinical high risk for psychosis, note the difference between demonstrating signs of risk for psychosis versus meeting criteria for a psychosis diagnosis. Over time, these symptoms can stay the same, go away, or get worse, and it is not possible to predict which will happen. The majority of people who exhibit some risk for psychosis do not develop fully psychotic symptoms (about 10-30% of those at risk will develop full psychosis).*
- Psychosis and psychosis risk are treatable! Research suggests that outcomes are best for people who connect with treatment as soon as possible after psychosis symptoms (or signs of risk) begin.

INSPIRES Model

Keshavan, M., Davis, B., Friedman-Yakoobian, M., & Mesholam-Gately, R. (2022). What is my diagnosis, Doc?: Discussing psychosis diagnosis with patients and families. *Schizophrenia Research*. 239. 92-94. 10.1016/j.schres.2021.10.009.

The acronym, INSPIRES can help to remember the key elements to consider when planning to share clinical diagnosis feedback with Y-EP and their families.

- **Individualize.** Each individual may respond differently to learning about a diagnosis; it is therefore important to get to know the person/family, develop a therapeutic alliance, and prepare for the conversation in advance. Adjust your approach depending on what you know about the person and their family's culture, values, and concerns that they want addressed in the feedback.
- **Normalizing, non-stigmatizing.** Let the Y-EP and family know that there is a spectrum of psychosis experiences and normalize them as a type of human experience. Identify possible stigmatizing beliefs that families may hold about psychiatric disorders, avoid use of stigmatizing labels (e.g., "crazy"), and note ways the media can reinforce misinformation in society. If possible, it can help to incorporate a family partner or information about family groups or advocates available in the family's region.
- **Setting.** It is important to have a safe setting and to ensure confidentiality while having a conversation. Plan ahead about who will be part of the meeting (see section above). If providing feedback via videoconference, be sure the Y-EP and family join from a private, reliable internet connection, have allotted ample time for the session, and minimize potential distractions.
- **Person-centered perspective.** As noted above, it is important to guide your discussion based on the youth and family's perspectives, including areas of agreement and disagreement. Information you share should be framed within a thorough understanding and respect for the individual's and family's values and preferences and to highlight these values. The Y-EP, with support of the family, are partners in treatment decisions, with the clinician providing information and ideas to consider.
- **Information.** It is helpful to provide accurate and comprehensive information about the diagnosis and the youth and family's concerns. The amount of information shared during a feedback session can be overwhelming for many youth and families. Sharing some written information about the symptoms, treatments, etc. can help ensure that the youth and family are able to understand as much as possible. Written information provides an opportunity for the Y-EP and family to review later, formulate follow-up questions, and refer to it when they consider next steps for treatment. (See our previous clinical brief on "[Screening for Psychosis](#)" for one resource that can be helpful to share.)
- **Reassure, repeat as needed, respond to questions, and instill hope.** Information about diagnosis is difficult to process. It is important for the clinician to be patient and take time to check in with the youth and family about their questions and worries. Validate concerns while also emphasizing hope. Let them know that you are glad they participated in the assessment with you, because this is the first step towards connecting with helpful available treatments. Note that emerging evidence suggests that early treatment can help reduce symptoms and reduce risk that they get worse.
- **Empathize, and empower.** Empathize and validate the youth and family's reactions while also highlighting ways in which they are already taking important steps towards recovery. Youth and families may have a range of reactions to learning about the diagnosis. Some will be upset by the diagnosis and worried about the future. Others may feel relieved to finally have a better understanding of what is causing the symptoms they are experiencing. It is important to empathically tune into the youth and family's responses. Many youth and families may also appreciate hearing about hope for improvement and from hearing/reading examples of recovery stories (e.g., <https://strong365.org>)
- **Strategize and consider next steps.** Share information about available treatment options and next steps that the youth and family can take to reduce the impact of symptoms on their lives. Share treatment recommendations and resources and assist the youth and family with connecting with treatment.



What if there are concerns about using the term “psychosis”?

In most cases, it is helpful to provide information about psychosis including what it is and what it means to experience psychosis symptoms or signs of risk. In some circumstances, such as if the Y-EP and family are unlikely to believe the diagnosis, may react angrily or disengage from treatment, or have previous experiences or stigma that would make using the term psychosis interfere significantly with the process of feedback, providers may opt instead to provide more general feedback about mental health symptoms first and work on developing rapport with the client and family before introducing the clinical term psychosis.

- “You did a great job talking to me about these experiences/changes that you’ve begun to notice”
- “You told me about difficulties including [say a few words about what the person told you, using their language].”
- “These are difficulties that can go away, stay the same, or get better, and getting further assessment and treatment early can minimize risk for having worse difficulties.”
- “As a next step, I recommend [include treatment or assessment recommendation].”



Do you have questions that you would like us to address in future clinical briefs?

Do you want further information about specialized assessment or treatment for early psychosis?

WEBSITES:

[MHTTC Early Psychosis Working Group](#)
[New England MHTTC Early Psychosis Learning Collaborative](#)
<https://www.mapnet.online>
<https://www.responsetorisk.org>
<https://cedarclinic.org>
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The Early Psychosis Learning Collaborative (EPLC) is part of an initiative by the Substance Abuse and Mental Health Services Administration (SAMHSA)'s New England Mental Health Technology Transfer Center Network (MHTTC), which provides training, technical assistance, and tool and resource development to enable states and mental health practitioners to provide recovery-oriented practices within the context of recovery-oriented systems of care. To learn more about us, please see: <https://mhttcnetwork.org/centers/new-england-mhttc/eplc-landing-page>