



FAMILY TIP SHEET

# Helping Families Understand Services for Persons with Early Serious Mental Illness

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A major change is underway in mental health care. Based on new research findings, we are addressing the most severe mental disorders in a new way. This is good news! Today we know that providing treatment early makes a huge, positive difference in people's lives. This new type of care is called Coordinated Specialty Care, or CSC for short. CSC programs are now in more than 200 communities across the United States. Dozens more are being planned. Family involvement and supports are key parts of CSC programs. You are working with a CSC program that uses a team to help your loved one overcome challenges and move forward with life. You will be a partner in building a successful outcome. This tip sheet gives you some information about the program and how you can participate.

### WHAT TO EXPECT FROM THE CSC TEAM

- **Respect and understanding** for your reactions to this change in your family's life. Getting a diagnosis of a serious mental illness is often frightening. The CSC team will understand your fears and worries. They will help you adjust by explaining how the CSC program works and your family's important role. This will make you more comfortable and assist you in supporting a recovery plan.
  - The team will **understand your role as a family caregiver** and the obligations that come with it, such as taking care of other family members, earning a living, and being an active member of your community. When developing the recovery plan for your loved one, all of these aspects of your life should be considered.
  - **Services should be provided in the settings that work best for you.** The team should work around your busy schedule. Expect them to meet with you at places and times that are convenient for you.
  - You will receive **detailed information on the symptoms and treatment of serious mental illnesses.** This may include classes, reading material, and discussions with staff or other family members. The more you know, the more effective you can be.
- The team will help you **understand the different parts of the program.** The staff members work as a team to support your family member and you. There are definitions at the end of this tip sheet to help you understand some of the terms used in CSC programs.
- **Shared decision-making** is a key part of the program. It is a tool to help you, your family member, and the CSC team make important treatment decisions so you can work together for the best results. Your family member will make the final decisions about what is included in the treatment plan, with input from you and the team.





*Psychosis is serious, but it is not the end of hope. Early intervention is the key to recovery.*

- You will receive **clear and accurate descriptions of the rules for sharing information** with you about your family member. You are always free to share your own observations and wishes with the CSC team. If your family member agrees, the team can share information about your loved one's treatment plan with you. The CSC team will explain options about information sharing and encourage open dialogue. It is best when everyone is working with the same information.
- The CSC team will **offer problem-solving tips**. These tips can help you and your family member reduce conflict, increase cooperation, and maintain an open, positive relationship. The team will help you understand the best ways to show your concern and support, while respecting your loved one's independence and wishes.
  - The team will provide **practical help and guidance** as your family member moves through the CSC program. The mental health system can be complicated and frustrating. Your CSC team members are experts on how best to use the services that your family may need. This can include support from social services, help with education, assistance on the job, and housing and income supports. Involvement with the police or courts also can be addressed.
  - **Crisis and safety planning** are part of the core CSC program. The CSC team will work with you and your family member to plan for managing a possible crisis. Worsening symptoms, extreme mood swings, and thoughts or behaviors about harm to self or others can be signs that a crisis is coming. The crisis plan will involve tips to help identify early warning signs and describe suggestions for how to respond. Coping skills and seeking help from the team or others will be part of the plan.
- Crisis planning may involve information about **Psychiatric Advance Directives**, often called a PAD. A PAD can be developed when your family member is doing well, then used to make decisions in a crisis when he or she has impaired judgment. A PAD includes your family member's wishes and preferences for treatment in these difficult circumstances. It can be helpful for responding to challenging situations and respecting the person's wishes.

## HOW CAN I HELP?

- Become **informed about your family member's illness and treatment plan**. You are vital to your family member's success! Consider attending a family education or support group to meet others who have mental illness in their families. Additional resources that provide information about serious mental illnesses and CSC programs are listed at the end of this tip sheet.
- **Speak up, ask questions, and voice your concerns**. Your partnership with the CSC team is built on openness and trust. If you are not happy with how the relationship is working, or you're not satisfied with the plans and progress, you need to firmly speak up. What are you seeing that helps your family member or that causes problems? What have you tried to do to help? Has it worked? How might it work better? Be specific about your concerns and concrete about actions the CSC team can take to address your issues.



*You know your family member best. Share your concerns and observations with the clinical team.*

- **Encourage your family member to be honest and direct** about how they feel and what they need. Sharing their concerns and suggestions may feel awkward at first, but with regular feedback, the CSC team can plan services that will lead to success.
- Finally, **pay attention to safety issues**, as this is something your loved one may not talk about. The clinical team may not be aware if a depression is deepening or self-harm is a growing concern. Share your observations and instincts and any relevant history.
  - Provide your family member with **structure and support for the treatment plan**. Acknowledge his or her progress and hard work. Confront setbacks with optimism and a “can do” attitude. Prompt and remind your family member about his or her plan and what he or she wanted you to do to help. Give helpful and wanted feedback about how your family member is doing, including noting any important changes that you see.
  - Take notes and **keep track of changes** in mood, behavior, or daily routines. Are there times of the day when things are worse or better? Are there things you do that reduce tension or that help your family work together? Note actions that help or those that cause problems. Changes in sleep and activity patterns can be signs of problems developing.
- Share background on your **family’s culture and strengths**. This helps the team be aware and sensitive about your family. What is important to your family? How do members of your community think about mental health problems? Some individuals are ashamed to admit to having this health problem because it is often misunderstood by their community. How do your community’s attitudes affect you and other family members?
- Maintain a **patient and hopeful attitude**. Recovery is real, but it takes time and may involve setbacks along the way. Your calm and positive attitude will inspire your entire family.
- **Take care of yourself**. These can be difficult times for everyone. You may feel a special obligation to support everyone in your family, but do not neglect self-care. Without it, you may have burnout, exhaustion, and your own health problems. Pay attention to how you are feeling. Try to take some time each day to do something you enjoy or that relaxes you. Exercise can be helpful. Participating in a family support group can be a great resource for encouragement, hope, and connecting with others. Talk to the CSC team about options that are available to you. Your faith community can provide spiritual solace and strength. Churches may offer practical help in tough times through volunteers who can provide transportation, babysitting, meals, and moral support.
- **Attend to other important relationships** with family and friends. Sometimes when confronting a challenging and lasting problem, we tend to ignore other important people in our lives. Maintaining and nurturing these relationships is important for keeping your own life in balance. You and your family members can help each other get through tough days by understanding and supporting each other.



## RESOURCES

### Government Agencies

#### Substance Abuse and Mental Health Services Administration (SAMHSA)

[Understanding a First Episode of Psychosis](#)

#### National Institute of Mental Health (NIMH)

[Fact Sheet: First Episode Psychosis](#)

#### HHS HIPAA Decision Tree

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## ADDITIONAL RESOURCES

[National Association of State Mental Health Program Directors \(NASMHPD\)](#) has a wide variety of technical assistance products, developed with support from SAMHSA, that address many aspects of CSC programming. A [web-based primer](#) for families on first episode psychosis may be particularly helpful.

[National Alliance on Mental Illness \(NAMI\)](#) and [Mental Health America](#) are two national advocacy groups that have developed information on early intervention programs and have local affiliates that often provide support and information groups for families who have a family member with a mental illness. They also provide web-based materials that can be helpful.

## GLOSSARY

**Community Mental Health Centers (CMHC):** These often house CSC programs. These are multiservice agencies that provide mental health and often substance use services to individuals regardless of their ability to pay.

**Coordinated Specialty Care (CSC):** This program model has been shown to be effective in helping people with Early Serious Mental Illnesses, including psychosis. It has been described in some detail in this tip sheet.

**First Episode Psychosis (FEP):** This refers to the first time someone develops psychosis, which is a serious disturbance of one's thought processes that can involve odd beliefs, fear, and seeing or hearing things that others do not see or hear.

**Health Insurance Portability and Accountability Act (HIPAA):** This U.S. law provides privacy and security safeguards for medical information. It requires that if your family member is over 18, he or she must give permission to have information shared with you and that he or she must specify the kind of information that can be shared. HIPAA is sometimes misunderstood to prevent information sharing. It does not prevent sharing and only requires consent to share information, which can be handled informally.

**Medicaid:** Medicaid is a health insurance program for people with low incomes or who have a disability. Many young people may qualify for Medicaid services, which often are more comprehensive than services offered through commercial insurance.

**Shared Decision Making (SDM):** This is a method for fully informing you of your options and the likely outcomes of different choices in developing a treatment plan. It is through this dialogue that your family member will choose how to proceed with treatment and recovery.

**Supported Employment or Education (SEE):** These services should be part of the CSC program to help your family member get or keep a job and/or stay in school. Services can involve working with the school or employer to help them understand your family member's needs so they can stay on track with their life. "SEES" often refers to the Supported Employment and Education Specialist on the treatment team.

**State Mental Health Authority (SMHA):** This agency in your state government is responsible for overseeing all public mental health services. They can be contacted for information about CSC programming in your state.

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