



CARE Act

Community Assistance, Recovery, and Empowerment Act

Family Resource Guide

The CARE Act is a collaborative civil court process. This process is for individuals living with schizophrenia spectrum or other psychotic disorders. It connects eligible individuals with treatment, services/supports, and housing.

This guide can help you learn more about supporting your family member during the CARE process. Trainings and resources from the CARE Act Resource Center are highlighted in this guide. Additional resources to support families are also included.

For an overview, please see the [Role of the Family in the CARE Process](#) and [Introduction to Family Psychoeducation](#) trainings on the CARE Act Resource Center. In this guide, we have shared related trainings hosted on the CARE Act Resource Center.

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THE IMPORTANCE OF FAMILY IN SUPPORTING INDIVIDUALS LIVING WITH SCHIZOPHRENIA SPECTRUM OR OTHER PSYCHOTIC DISORDERS

Family members and natural supports (e.g., friends, members of social networks) are important. They can help improve the outcomes of people living with schizophrenia spectrum or other psychotic disorders.

Family members can help by:

- Helping the person meet basic needs.
- Encouraging participation in recommended services and treatments.
- Assisting in coordination with care providers.
- Maintaining connections with family and community supports.
- Providing support, encouragement, and hope.
- Promoting understanding of the person's identity considering their mental health condition.
- Highlighting the person's strengths to support their recovery.
- Ensuring appropriate care is provided at the best time and place.

Family support is important to recovery, but family members can face challenges. A person's needs, engagement, and symptoms may change quickly. The behavioral health care system can be complex. Some people living with schizophrenia spectrum or other psychotic disorders welcome help from their family, but others don't. This can be for many reasons.

The goal is for people living with schizophrenia spectrum or other psychotic disorders, their support systems, providers, and community supporters to work together. This will help with recovery.

Behavioral health and primary care providers can give crucial treatment. Community-based supports can help too. These can include churches, schools, peer-based organizations, and jobs. Recovery will look different for everyone. Hopefully, people can return to tasks they couldn't do because of their unstabilized condition.

To better understand the CARE process, please see the [**Overview of CARE Process for Supporters.**](#) For more information on the role of the family, please see the training materials for [**Role of the Family in the CARE Process.**](#)

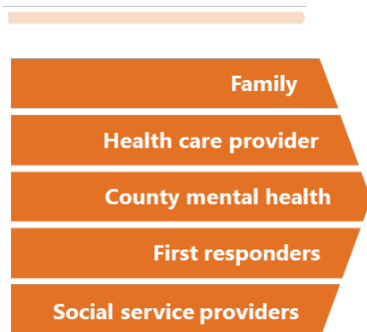
Natural Supports

"Natural supports" are informal, non-professional help. This can come from family, friends, peers, and community members. They may give emotional encouragement and help with daily tasks. They may also offer companionship and the chance to socialize or participate in activities.

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PATHS IN

Paths **in** for eligible people with psychotic disorders who meet health and safety criteria. A range of people can refer someone to get help.



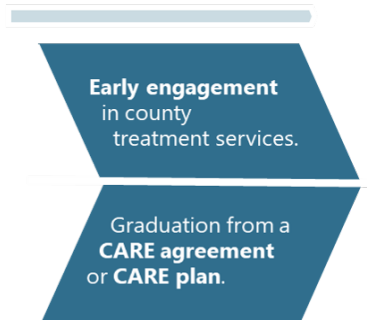
CARE PROCESS

New civil court process to **connect and prioritize** treatment, support services, and housing.



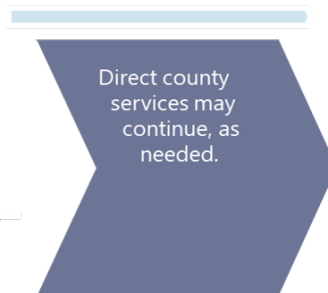
PATHS OUT

There are many paths **out** of the CARE process.



HELP CONTINUES

At the end of the process, help can continue.



The CARE Act allows specific people (known as “petitioners”) to request that someone enter the CARE process. The CARE process involves assessments and hearings. These determine whether the person (known as a “respondent”) is eligible. If the respondent is eligible, a voluntary CARE agreement or court-ordered CARE plan may be created. These can last for up to 12 months, with the possibility to extend for 12 more months. This CARE agreement or plan includes services the person can receive. These might be behavioral health services, substance use disorder treatment, housing, and community supports. For more information about the court process, see the [CARE Process Flow](#).

FAMILY MEMBERS & CARE

Role of Family Members in the CARE Process

The CARE process offers a family member **both** formal and informal ways to offer support. Remember, the CARE participant gets to decide who can be involved. Participants, families, and treatment teams should talk about expectations for family involvement.

A family member can be formally involved as a petitioner or a volunteer supporter. They can also help informally. They can do this by providing support, guidance, and encouragement. These roles are outlined below.

Respondent

After the petition is filed, the potential CARE participant is called the *respondent*. This word is often used for people going through a court process. In this guide, we call this person a *participant*, but you may see or hear the word *respondent*.

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For more information on the petitioning process, please see [CARE Act Resources for Petitioners](#).

Family as Petitioners

At the beginning of the CARE process, a family member may be involved as a petitioner. This means they file a petition to ask the court to consider whether their relative is eligible for CARE Act services.

The California Courts' Self-Help Centers can guide family members who want to file a petition. Keep in mind that neither the Self-Help Centers nor the courts provide legal advice. They can provide information and help fill out the forms. The State of California publishes a directory of Self-Help Centers based on city, county, or zip code. To connect with a Self-Help Center for completing a petition, please see the Judicial Council of California's [Self-Help Center locator](#).

Before filing a petition, consider some alternatives. These may include helping your relative voluntarily engage in services. This could include services available through county behavioral health (including full-service partnership or assertive community treatment). It could include other behavioral health services available through commercial insurance. You may also explore local social services and community-based organizations.

If you choose to file the petition, the court will then determine initial eligibility for CARE. The petition will be dismissed if the court does not find evidence that your family member meets initial eligibility. If the court finds that your family member may meet eligibility, they will order a county behavioral health agency to investigate. The county behavioral health agency will then submit a report to the court.

The court will then set an initial appearance if the report finds the individual to be eligible. You must attend this initial appearance, or the case may be dismissed. The

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county behavioral health agency will then take over the role of petitioner. You may make a statement to the court. This statement could include:

- Why you think your family member would benefit from CARE.
- Evidence to support their eligibility.
- Examples of how other forms of treatment have not been successful.

The family member may also continue to participate in the CARE process; this is only possible if the participant consents.

Local NAMI CA Affiliates and county behavioral health teams are also developing resources and other support services for family petitioners who wish to stay involved. Please check with your local NAMI chapter/affiliate and your county's behavioral health team assigned to CARE for more information. To find a local NAMI CA affiliate, see [Find Your Local NAMI](#).

Tips for Appearing in Court

Speaking publicly in a court room may be stressful. It can also be emotional. Consider ways to help you stay calm and confident. You do not need to have a lawyer with you, but you can choose to have one there at your own expense. Representatives at [Self-Help Centers](#) can help you know what to expect and how to prepare. Consider discussing the following with them:

Before the Court Date

- **Understand CARE eligibility and process:** Read about CARE [eligibility](#) and the [court process](#).
- **Organize documents:** Gather and neatly file documents you might want.
- **Practice what you want to say:** Be clear and concise.
- **Understand court protocol:** Research court rules and procedures.
- **Plan your travel:** Know the courthouse location and arrive early, if you can.
- **Consider what you will wear:** Consider professional attire, if possible.

On the Court Date

- **Arrive early:** Try to be 30 minutes early.
- **Bring necessary items:** Have your documents and notes ready.
- **Be respectful:** Address the judge as "Your Honor" and be polite.
- **Stay calm:** Keep emotions in check, speak clearly, and don't interrupt.
- **Listen carefully:** Pay attention and take notes if needed.
- **Speak clearly:** Be concise and honest in your responses.
- **Follow etiquette:** Stand for the judge, avoid disruptions.

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Family as a Volunteer Supporter

A CARE participant may choose a family member to be their volunteer supporter.

There are specific roles and boundaries for the volunteer supporter. These are defined in the CARE Act. A volunteer supporter assists by helping the CARE participant:

- Understand, make, and share decisions.
- Share their preferences during CARE proceedings.
- Create their own psychiatric advance directive (PAD).
- Make their own decisions, using a supported decisionmaking (SDM) framework.
- Advocate for services that meet their cultural needs and preferences. These may be reflected in a CARE agreement, CARE plan, or PAD.

As the volunteer supporter, a family member must adopt four essential practices:

- Use a supported decisionmaking framework.
- Use a trauma-informed care.
- Remove personal bias.
- Maintain confidentiality.

The supporter is not responsible for connecting the participant to health care and social services. That is the responsibility of the county behavioral health agency and treatment team. The supporter ensures that the CARE participant's needs and preferences are heard by the team and included in treatment planning as much as possible.

The volunteer supporter role is further explained in the trainings linked in the [**Volunteer Supporter Toolkit**](#). These trainings also describe challenges of being a family member and volunteer supporter at the same time. The relationship between that family member and the CARE participant can offer familiarity, trust, and emotional safety. But the

See the [**Supporter Role in the CARE Act**](#) for more information on the role and essential practices of the volunteer supporter.

For more information and resources available for volunteer supporters, please see the [**Volunteer Supporter Toolkit**](#) on the CARE Act Resource Center.

See the training on [**Supported Decisionmaking for Volunteer Supporters**](#) and [**Maintaining Neutrality in the Supporter Role**](#)

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volunteer supporter's job is to represent what the CARE participant wants. They should not push the CARE participant to do what the family member thinks is best.

The court may remove a volunteer supporter if there is a conflict of interest with the CARE participant. The court needs to remove the volunteer supporter if the conflict can't be resolved. There are a few kinds of conflict the court might find. The volunteer supporter could have a financial or other personal interest that is different from the participant. The volunteer supporter could also disagree with the participant's decisions so strongly that they can't stay neutral.

If the CARE participant is threatening to harm themselves or others, the volunteer supporter should call emergency response (988 or 911).

Family as an Informal Support

In some cases, a family member will not serve as the CARE participant's formal volunteer supporter. Reasons could include:

- The participant may choose someone else.
- The participant may choose not to have a volunteer supporter.
- A family member may not live nearby.
- A family member may not have the time or resources to take part in this formal way.
- A family member may be uncomfortable with specific duties of the volunteer supporter role. These could include remaining neutral or using a supported decisionmaking framework.

Even if they aren't volunteer supporters, family members can still support the participant in the CARE process. They might do this by attending hearings at the request of the participant.

Information Sharing with Family Members

Several federal and state laws govern privacy and confidentiality of health-related information. This includes mental health and substance use information. These laws include the federal [**Health Information Portability and Accountability Act**](#) (HIPAA), the [**Title 42 of the Code of Federal Regulations \(CFR\) Part 2**](#), the [**California Confidentiality of Medical Information Act \(CMIA\)**](#), and the [**Lanterman-Petris-Short \(LPS\) Act**](#). These laws and regulations have requirements that practitioners must follow. Health-related information is confidential. It may not be shared without the patient's consent. Laws and regulations allow for sharing information between specific individuals

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or agencies and in specific situations, like the [Treatment, Payment and Operations clause in HIPAA](#). These laws and regulations don't allow sharing information with family members, unless the patient consents. There's an exception for medical emergencies. To help family members understand the protections around health-related information, health care practitioners must provide written information of their privacy practices. They should also be prepared to explain the laws and limits on their ability to share information.

The rules regarding information disclosures are complex. They can be frustrating for those who want to discuss information with the practitioners providing care to their family members. While the laws can stop practitioners from sharing information with families, families can share information with practitioners. This information can help treatment teams understand the person's history with mental illness and services. Families can also provide helpful background on a person. This background can include their strengths, interests, past treatment activities, and preferences. This information can help treatment teams better understand which services, supports, and treatment could best help a person recover.

When sharing information with a service provider, family members should keep in mind:

1. The information flow may only be "one way." The provider might not be able to share protected health information in return. This could include replying, confirming, or adding more detail.
2. It can be helpful to write information down when sharing it with practitioners. Written information allows it to be documented and shared with others providing care.
3. Providers often add this information to the electronic health record. This means it may be shared with the person receiving care. Family members should know that anything they share with the provider may be shared with the person.

Information that families can consider sharing:

- Medications and interventions that have been the most and least effective in the past.
- Mental and physical care providers the person has received treatment from.
- The person's strengths, interests, hobbies, and goals.
- How to know the person is doing well and not doing well.
- Support networks.
- Past and current living situations.
- Medical history, including diagnosis history and co-occurring diseases.

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- Situations that might stress or trigger the person.
- Existence of an advance health care directive or psychiatric advance directive (PAD).

For more guidance, it may be helpful to consult with a family advocacy service. This could include NAMI. There are NAMI affiliates across California. [Click to find a NAMI affiliate near you.](#)

For more information on California's health information privacy laws, see the State Health Information Guide at [State Health Information Guidance 1.2.](#)

USING A TRAUMA-INFORMED APPROACH

Overview of Trauma

Trauma refers to the way an event (or series of events) and experiences affect someone. Trauma can make people feel threatened, fearful, and unable to process information. They might feel this way even after the trauma has ended.¹

Traumatic events trigger a physical and protective response. People can experience a fight, flight, or freeze response. When your body is stressed it releases a hormone called cortisol. It functions as the body's built-in alarm system.² After the traumatic event goes away and the person gets support, the body can go back to normal.

But if the person does not get support or the trauma continues, it stays unresolved. The person may stay on hyper alert and the body releases too much cortisol stress hormones. These hormones can harm the body over time. They can cause physical and

What is trauma?

"Trauma results from an **event**, series of events, or a set of circumstances that an individual **experiences** as physically or emotionally harmful or threatening, which may have lasting adverse **effects** on the individual's functioning and mental, physical, social, emotional, or spiritual well-being."

—[SAMHSA's Practical Guide for Implementing a Trauma-Informed Approach](#)

¹ For more information on trauma and trauma-informed care, see [SAMHSA's Practical Guide for Implementing a Trauma-Informed Approach](#) and the [Trauma-Informed Care Implementation Resource Center](#).

² For more information about how trauma impacts the brain, see [The Science Behind PTSD Symptoms: How Trauma Changes the Brain](#).

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mental problems. This is known as “toxic stress.” It can hurt the person’s ability to experience pleasure. It can also impact their memory and emotional processing.³

This type of stress can come from many places:

- Experiencing traumatic events in childhood, known as “adverse childhood experiences” or ACEs.⁴
- Having trouble meeting basic needs for food, shelter, or safety.
- Having unaddressed physical or mental health needs.
- Repeatedly being misunderstood, judged, ignored, and stigmatized by others.⁵
- Having negative interactions with people or systems, such as emergency responders, health care providers, or carceral settings.

For family members and other natural supports, there may be different or similar sources of trauma:

- Repeatedly feeling helpless.
- Having multiple heated arguments or experiences of feeling threatened by a person experiencing severe psychosis.
- Seeing the suffering of the person living with schizophrenia spectrum or other psychotic disorders who can’t control the frightening thoughts they are having or the terrifying voices they are hearing.
- Repeatedly watching someone make choices that put them at risk for negative physical and mental health outcomes.
- Supporting someone with serious mental illness in carceral or court settings.

As an after-effect of these kinds of events, family members may feel afraid. They may also experience “compassion fatigue” or “secondary trauma.” They might feel worn down and burnt out.

See the training series on trauma-informed care for more information:

Part 1: [Foundations for Trauma-informed Care](#)

Part 2: [Goals and Principles for Trauma-informed Care](#)

Part 3: [Applying Trauma-Informed Care as a Volunteer Supporter](#)

³ For more information on how stress impacts healthy development, watch [Toxic Stress Derails Healthy Development](#) video.

⁴ For information on ACEs, see the [joint research between CDC and Kaiser Permanente](#).

⁵ For information on how feelings of stigma, especially racial stigma, can impact people, see [Trauma-Informed Care and Cultural Humility in the Mental Health Care of People From Minoritized Communities](#) or [Implicit Bias Is Behavior: A Functional-Cognitive Perspective on Implicit Bias](#).

Goals & Strategies of a Trauma-Informed Approach

A “trauma-informed approach” promotes a culture of safety, empowerment, and healing. You can support a person living with schizophrenia spectrum or other psychotic disorders using a trauma-informed approach. You can also use a trauma-informed approach toward yourself. The Substance Abuse and Mental Health Services Administration (SAMHSA) is an agency that leads efforts to advance behavioral health. They put out a [Practical Guide for Implementing a Trauma-Informed Approach](#). It shares the goals of this approach:

- Understand the impact of trauma and recognize trauma symptoms.
- Support recovery and optimal life and health outcomes.
- Honor the person and avoid re-traumatization.

What does this look like in practice? At its core, taking a trauma-informed approach means using compassion and humility to support others and yourself.

In our series on trauma-informed care, we have a training on [Applying Trauma-Informed Care as a Volunteer Supporter](#). In this training, we include strategies for taking a trauma-informed approach:

- **Anticipate and reduce triggers.** Predict what might cause stress. Then, figure out how to reduce the triggers. Do this either beforehand or in the moment.
- **Use cultural humility.** Recognize that others are the expert of their own culture, values, and beliefs. Ask the CARE participant to share their experiences, knowledge, and resources. This will help you support their well-being.⁶
- **Focus on cross-cultural communication.** Even if you consider yourself a part of a CARE participant’s culture, remember that many things shape someone’s culture. Learn about the CARE participant’s individual norms and preferences. These can include personal distance, gestures, eye contact, and posture.⁷
- **Take a strengths-based approach.** A strengths-based approach relies on drawing out strengths and abilities. This approach focuses on building someone's

⁶ For more information on cultural humility, view the [American Psychological Association article](#) or the [Cultural Humility](#) video.

⁷ For more information on cross-cultural communication, view the [Collaborative Framework article](#), the [Communication Theory blog post](#), and the [Healthforce Center at UCF blog post](#).

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confidence and hope. The focus is on what someone can do. The focus is not on what they can't do, what their symptoms are, or what difficulties they face.⁸

- **Use trauma-informed listening skills.** Show the other person that you are listening and trying to understand. Be attentive and patient. Rephrase what the CARE participant says without making any of your own comments or judgments. Ask clarifying questions. Make summary statements.
- **Hold space for others.** Holding space means to be with someone without judgment. Practice empathy and compassion. Accept someone's truth, no matter what it is.⁹

You can use these strategies in the way you interact with the CARE participant. The strategies can also help you as you manage the impact of trauma. If you are experiencing the after-effects of trauma yourself, please see the next section on self-care.

Self-Care for Family & Other Natural Supports

Supporting someone is important and rewarding. But it can also be taxing and cause fatigue. This fatigue can threaten someone's own well-being. It can also threaten their ability to provide support.¹⁰ There are several factors that cause burnout. They can include:

- Gradual exposure to commitment strain.
- Feeling unsupported by others, including systems.
- Loss of hope.
- Lack of progress.
- Accumulation of intensive contact.

Possible symptoms of burnout:

- **Being overwhelmed:** feeling like you can't do what you need to.

"One of the hardest, yet most important parts of being a caregiver, is taking time to attend to self-care. It is self-care that restores energy and builds that capacity to give care, yet it is often neglected."

—The Dance of Caring: A Caregiver's Guide to Harmony

⁸ For more information on the strength-based approach, see [Strengths-Based Approach for Mental Health Recovery](#).

⁹ For more information on holding spaces for others, view this [What it Really Means to Hold Space for Someone](#) video.

¹⁰ For more information on burnout, see this article on [Caregiver Burnout](#).

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- **Mental health affected:** emotional irritability, lack of empathy, problems with mood, and feeling helpless.
- **Physical health affected:** negative physical symptoms, including fatigue.
- **Interpersonal and communication problems:** feeling like you just want to quit, not keeping your commitments, feeling too negative or critical.
- **Self-medicating:** Relying on substances or harmful habits to relax and cope. Substances could include alcohol, cigarettes, drugs, or foods. Habits could include over-spending or gambling. These things release good hormones. This can offset depression in the short term. This can also create problems in the long run.

If you are feeling burnout symptoms, think about how you can improve your well-being. Consider what helps you reduce stress. This could include taking walks. It could also include spiritual practices, prioritizing healthy behaviors, or counseling. Consider celebrating wins and mourning the challenges you face.

You can create a **Self-care On the Spot (SOS)** list. This list should have at least five safe, effective self-care tools. These can help you calm down in a stressful situation. You can take these actions when you're overwhelmed. You can also take them when you know you're about to be triggered. This list could include listening to a favorite music playlist, stepping away from the situation, squeezing a ball, taking a brisk walk, or taking a three-minute stretch or breathing break. This list can help you reduce the cortisol levels in your own body, letting you relax. This may not fix the challenges long-term. But it can give quick relief.

For more information on strategies for self-care and dealing with burnout, see [Applying Trauma-informed Care as a Volunteer Supporter.](#)

ACTION STEPS FOR FAMILIES

This section shares recommended action steps for families involved in the CARE process. These can be a starting point for supporting a relative living with serious mental illness. Many of these action steps may be familiar to family members who have been supporting their loved one for some time.

Action Step 1: Work to foster a collaborative partnership with the CARE participant's mental health practitioners.

One recommended action step is to partner with the CARE participant's mental health practitioners. In a "triangle of care" relationship, the participant, their family member, and the participant's mental health providers work together. They do this to support the person's goals and concerns. The triangle relationship is built on mutual respect for the knowledge and understanding that each person offers. For example, the mental health provider may offer expert guidance and understanding of effective treatments and services. The family member may offer understanding of the participant's history, identity, preferences, and culture.¹¹ The CARE participant can offer what treatments they prefer (and why), their engagement preferences, triggers, and their overall goals and priorities.

There are other ways for family members to work effectively with the CARE participant's behavioral health/medical team:

- With the participant's consent, attend a treatment session with the participant and practitioner. You can discuss communication patterns and styles.
- Watch the person's behavior outside the treatment setting. You can share those observations with the practitioner. This can help inform the treatment planning.
- Work with the practitioner to find solutions for anything that gets in the way of treatment, effective use of medication, and recovery goals.

Partnering with the practitioner can be challenging for family members who do not have a direct relationship with the behavioral health team. This is especially true when the

¹¹ Information on the "triangle of care" adapted from [The Triangle of Care: Guide to Best Practice in Mental Health Care in Scotland](#). For more information, see [Partnerships for Meaningful Community Living: Rehabilitation and Recovery-Informed Practices](#).

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CARE participant has not consented to share health information with the family. Remember: HIPAA often stops providers from talking openly to family members. However, it doesn't stop families from sharing with providers.

Action Step 2: Support the individual with their goals and recovery.

Another action step is to help the CARE participant with their goals. A goal could be, "I want to live independently." This action step also includes supporting them in their recovery. For example, they want to manage their chronic symptoms well enough to resume working and social activities. Remember that the participant's motivation will likely increase if the goals are driven by their own needs and preferences.

The CARE treatment team would likely lead activities for solving problems and setting goals. But it can be helpful for families to also understand goal-setting strategies.

Families can start by asking about their relative's goals for recovery. They should try to understand and accept these goals. They can encourage their relative to pursue things that make them feel valued. For example, they can suggest reconnecting with old friends. They can also find other ways to support their relative with achieving the quality of life they want.¹²

Examples of Goal-Setting Approaches

These tools can be used with a clinician. However, a family member can draw from these models to use in their own interactions.

Backwards Planning Goal Setting ([example here](#))

Simple and tactile tool that highlights and values the person's priorities.

Strategy starts with identifying a clear end goal. Then, establish the steps to reach that goal in reverse chronological order.

Problem-Solving Approach

Prioritize goals. Brainstorm solutions and pros and cons of each. Choose a solution and commit to next steps.

¹² For more information on goal setting, consider the articles on [Treatment Goals in Schizophrenia](#) and [Goal Planning in Mental Health Service Delivery](#).

Action Step 3: Reassess communication and relationship patterns.

A third action step is for family members to reflect on the ways they tend to communicate with each other. Family members often say they feel a full range of emotions while providing support to their relative living with schizophrenia spectrum or other psychotic disorders. These emotions may include love, hope, grief, fatigue, and frustration. However, certain reactions can make someone's symptoms worse. These reactions create high levels of criticism, hostility, and emotional overinvolvement. We have outlined them below. For better results, family members can try a few techniques. They can express pleasant feelings more often. They can make more positive requests. They can practice active listening. And they can always express unpleasant or difficult feelings without blame.

What does this mean for family communication with people living with schizophrenia spectrum or other psychotic disorders? A few methods can help the CARE participant feel more supported. These include using a calm, encouraging tone; identifying the person's strengths; and making positive comments. This can increase their ability to thrive at home and in the community.

It is important for family members to step back and assess their own communication styles during the CARE process. They can do this by looking for these signs:

Examples of Warm, Friendly Communication:

- Using a tone that conveys patience and acceptance.
- Pointing out how the CARE participant contributes positively to the family.
- Smiling and speaking calmly when assisting the participant.

Expressed Emotion

Researchers call this approach to communication a family's "expressed emotion" or "EE." "Low EE" families have low levels of criticism. They also have low levels of hostility and emotional overinvolvement. In families with "low EE," their relatives living with schizophrenia spectrum or other psychotic disorders tend to feel better supported. Families with "high EE" have high levels of criticism, hostility, and emotional overinvolvement. Their relatives living with schizophrenia spectrum or other psychotic disorders are more likely to need emergency psychiatric care.

Information on expressed emotion adapted from [High Level of Expressed Emotions in the Family of People with Schizophrenia.](#)

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- Encouraging the participant to manage their own daily activities as best they can and offering help as needed.

Examples of Criticism, Hostility, and Emotional Overinvolvement:

- Using a tone of voice that communicates anger, rejection, superiority, or blame.
- Implying the participant is a troublemaker or burden.
- Showing annoyance when assisting the participant.
- Restricting the participant's daily activities. This could include not allowing them to cook their own food in the family's kitchen.
- Controlling the participant's behaviors. This could include correcting them frequently for speaking too loudly or too much.

It may help to refer back to the strategies for self-care, like the SOS list when they are struggling with negative communication.

Action Step 4: Develop a deeper understanding of schizophrenia spectrum or other psychotic disorders and lived experience.

There is power in knowledge. The next action step is to develop a deeper understanding of schizophrenia spectrum or other psychotic disorders. This can include symptoms, available treatments, and the possible benefits and side effects of treatments. This also includes learning more about a person's experience living with these brain diseases. Family members might learn about the challenge of distinguishing reality from hallucinations and feeling stigmatized because of the illness. This information can help family members better relate to people living with schizophrenia spectrum or other psychotic disorders. It can also help family members better respond to their relative's needs for support.

For an overview of schizophrenia, see our training series on [Schizophrenia Spectrum Disorders & Evidence-based Care for Volunteer Supporters](#).

When a person is experiencing symptoms and complications, family members may not know what is going on. They may get angry and frustrated with the person's behavior. Understanding the symptoms and complications can help family members in a few ways. They may better understand their relative. They may collaborate better with their clinicians. And they may be able to work with their relative toward recovery.

There are many sources of information about schizophrenia spectrum or other psychotic disorders. See the section below on [Family Psychoeducation \(FPE\)](#). The National

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Institute for Mental Health's [website](#) has a [overview of schizophrenia](#) and material on other specific topics. Other reliable sources of information are included below in the section on **CARE-Specific Resources to Understand Schizophrenia Spectrum or Other Psychotic Disorders**.

Action Step 5: Plan together as a family support network.

Another helpful action step is planning together as a family support network. This network includes family members or other people chosen by a CARE participant as trusted supporters. This action step can include a variety of activities:

- Create a family caregiving plan. This plan will split support duties among family members and supporters. This division avoids putting support duties on just one or two people. For example, a family's caregiving plan might spread out who drives the participant to appointments. It could also include having different family members participate in activities the person enjoys, and creating a communication plan.
- Families can also work together to develop a mental health crisis plan. This is valuable to do *before* a crisis occurs. A mental health crisis plan can outline what to do in the event of an emergency. It can include resources, medication information, and directions or wishes. (See the links below for example templates.)
- Consider planning how family members can get support for themselves and practice self-care. Families can plan together or individually. Family members may experience secondary trauma and feel burnt out. The stress of caregiving may also impact their relationships with other family members. Family members may benefit from periodic breaks from caregiving. These breaks can be short or long. This is commonly known as "respite."

A psychiatric advance directive is a self-directed legal document. It includes a person's specific instructions or preferences for future mental health treatment. For more information, see the training on [**Psychiatric Advance Directives**](#).

To download the California Advance Health Directive Form, see the [**California Forms on the National Resource Center on Psychiatric Advance Directives**](#). For a psychiatric advance directive form, see [**SAMHSA's A Practical Guide to Psychiatric Advance Directives**](#).

FAMILY PSYCHOEDUCATION (FPE)

You can learn more about schizophrenia spectrum or other psychotic disorders by participating in a family psychoeducation (FPE) course. FPE is a structured, educational intervention. A clinician, peer supporter, or another facilitator will lead multiple sessions. Families of people living with schizophrenia spectrum or other psychotic disorders meet to learn about their relative's disease. They can also learn how best to help their relative. Sessions often have themes. For example, a theme could be communication skills for better relating with people living with schizophrenia spectrum or other psychotic disorders. Another theme could be promoting a person's engagement in mental health treatments.

What is discussed in FPE?

- Information about schizophrenia spectrum or other psychotic disorders as a brain disease and its treatments.
- Skill building, such as communication, problem-solving, and coping.

How is FPE structured?

- Usually offered in 8 to 12 sessions but can continue longer.
- Meetings occur in a series.
- Each meeting may have a specific topic for discussion.

Who is included in FPE?

- Can include a single family or a group of 8 to 12 families led by a facilitator.
- Includes individual in recovery for most or all educational sessions.

Participating in FPE sessions is not the same as other services. These could include attending family therapy, family meetings, or other mental health treatment. FPE is often an effective *addition* to those services. FPE's goal is to improve how family members help their relatives living with schizophrenia spectrum or other psychotic disorders. FPE can strengthen the family relationships and improve outcomes for people living with schizophrenia spectrum or other psychotic disorders.

What to Expect from FPE Participation

FPE programs vary in the number of sessions and whether they occur in person or online, but programs have a similar approach. Families are partners in care with people in recovery and their providers. They share their observations and other information about the person living with schizophrenia spectrum or other psychotic disorders with the teams that provide care. They work collaboratively and supportively with their relatives and the providers. They have the same goal: preventing relapse.

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FPE programs also use these principles:

- Help family members pay attention to the needs of their relative living with schizophrenia spectrum or other psychotic disorders. These include both clinical and social needs.
- Teach family members how to best support a relative's adherence to a treatment plan. This includes medication.
- Explore family members' expectations of their relative's mental health treatment programs and progress with recovery.
- Assess the strengths and limits of a family's ability to support their relative.
- Teach family members to respond sensitively to others' emotional distress. This can resolve conflict.
- Help family members create crisis plans. Also, help them identify supports for handling mental health emergencies.
- Teach methods for improving communication among family members.
- Train family members in structured problem-solving techniques.

Evidence for FPE

Research has shown how effective FPE and other family interventions are. These interventions can help prevent people living with schizophrenia spectrum or other psychotic disorders from suffering setbacks or relapses in their recoveries. They may also help people avoid returning to a psychiatric hospital. There was a 2022 overview of 90 previous research studies with more than 10,000 individuals. It found that family interventions helped prevent these setbacks. They did so more than other types of interventions. Of all the family interventions studied, FPE had the lowest 12-month relapse rate. It was 9.7%. The other rates varied. They ranged from 16.3% for systematic family-oriented intervention to 37% for usual clinical care.

Other research studies have shown that FPE reduced rates of symptom relapse requiring hospital readmission. It also improved social and occupational functioning. FPE has also been linked to better medication adherence.

Data on FPE's impact on relapse taken from [Family Interventions for Relapse Prevention in Schizophrenia](#).

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Connecting with FPE Providers

There are many resources to help families support people living with schizophrenia spectrum or other psychotic disorders. These include training webinars on the [CARE Act Resource Center](#) and FPE resources from NAMI and other organizations.

NAMI's Family-to-Family curriculum is the largest FPE program in the United States. It is a free, eight-session educational program. The program is for family members, significant others, and friends of people with mental health conditions. There is also a pilot of a four-hour [Family and Friends Seminar](#) being offered in California (in-person only).

FPE is an evidence-based program that covers various topics. These topics include communicating effectively and solving problems; offering support with compassion; handling crises; and the impacts of mental health conditions, including treatments and therapies.

Family members can find the NAMI Family-to-Family program nearest to them on [NAMI's website](#). If a program is not available in their area, they can [contact their local NAMI affiliate about starting one](#). NAMI's website also has [resources for family members and caregivers](#).

There are NAMI CA affiliates statewide; [click to find a NAMI affiliate near you](#).

RESOURCES FOR FAMILIES

Connecting with Additional Resources

FPE offers a structured learning environment for family members, but it may not be an option for everyone. There are other resources to learn about supporting people with serious mental illness. There are also resources to learn about the CARE Act broadly.

The following resources may be helpful for family members:

- NAMI CA's [resources \(including short training videos\) on the CARE Act](#)
- NAMI's [resources for Family Members and Caregivers](#)
- NAMI's [resources for Finding Mental Health Care that Fits Your Cultural Background](#)
- Caregiver Action Network discussion forum for [Loved Ones with Mental Health Issues](#)
- Caregiver Action Network's [10 Tips for Family Caregivers](#)

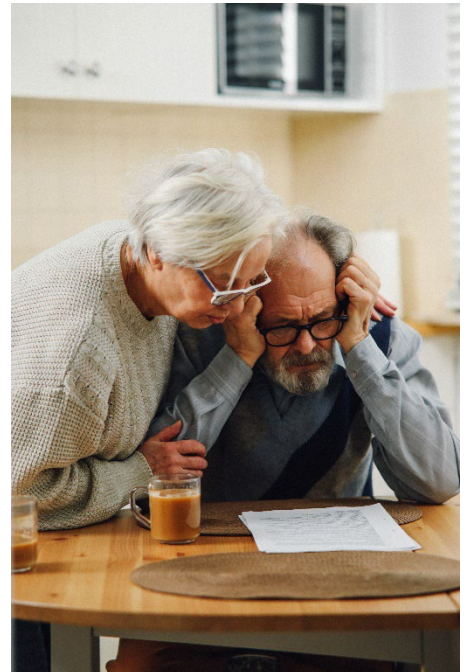
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- Family Caregiver Alliance resources on [Caring for Yourself](#)
- Very Well Mind's information on [Caregiving for Schizophrenia](#)
- [Treatment Advocacy Center](#) resources on SMI/AOT
- Families Advocating for the Seriously Mentally Ill ([FASMI](#))
- Schizophrenia & Psychosis Action Alliance's [Caregiver Toolkit](#)
- LEAP Institute [Resources](#)
- [CalHOPE](#) mental health support for youth, young adults, and families

Developing a Support Network

Many families find it helpful to connect with others who share their experiences. Families can help provide validation. They can discuss tools to support resilience. And they can share resources and strategies to navigate systems. Possible ways to develop a support network include:

- Connect with religious or faith-based organizations. Houses of worship often give extra support. They do this individually or in groups for their members.
- Find local organizations or support groups that are responsive to your family's cultural needs.
- Connect with a peer organization or an individual with lived experience.
- Consider starting your own local support group. This can be an informal group. Some city and county governments provide grants to start support groups.



County-Based Programs

Many county behavioral health agencies offer support. This can include resources, support groups, lunch and learns, mobile crisis, and peer support for families. The CARE Act Resource Center lists a [county directory](#). It shows counties with active CARE websites.

Connect with your county behavioral health agency to see what resources, programs, and support groups are available for families in your county.

National Alliance on Mental Illness (NAMI) California

[NAMI CA offers support groups](#). Some are for people with mental health conditions. This is called a [NAMI Connection](#) group. They also offer support groups for family

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members, significant others, and friends of people with mental health conditions. This is called a NAMI **Family Support Group**. NAMI Family Support Groups are led by family members with lived experience in supporting a loved one with mental health conditions. These conditions can include schizophrenia spectrum or other psychotic disorders. They can also include other serious mental illnesses. The groups follow a structured model. This ensures all participants have an opportunity to share their story and find the help they need. Groups meet on a regular basis. They often offer virtual options. This allows people across the country to get support no matter where they are. **Find a NAMI Family Support Group near you**. If one is not available, **contact a local NAMI affiliate** about starting a group for families and/or people living with schizophrenia spectrum or other psychotic disorders.

Schizophrenia & Psychosis Action Alliance

The Schizophrenia & Psychosis Action Alliance offers options to meet virtually. They have meetings every day of the week. You can **register on their website**.

Support Groups on Social Media

Other support groups are available on social media apps, including:

- **Families of Schizophrenia Support Group** (Facebook)
- **Parent Support Network** (virtual; account required)
- **Support for Family and Caregivers of Love Ones with Schizophrenia** (Facebook)
- **r/SchizoFamilies** (Reddit)

Support Groups for Related Diagnoses

Support groups for related diagnoses can be beneficial too. This is because they have similar features and challenges. Also, many people will go through multiple diagnoses. For example, the **Depression and Bipolar Support Alliance** (DBSA) has support groups. They are both in-person and online. Many are designed for families.

CARE-Specific Resources to Understand Schizophrenia Spectrum or Other Psychotic Disorders

It can be helpful to learn about schizophrenia spectrum or other psychotic disorders, treatment options, supported decisionmaking, creating psychiatric advance directives, trauma-informed care, and other information on interacting with people living with schizophrenia spectrum or other psychotic disorders. The [CARE Act Resource Center](#) has recorded webinars and training materials. These cover helpful topics.

NAMI's Family-to-Family

A NAMI peer education program for family members of adults with mental illness.

This program is an evidence-based program (EBP). For more information on the research base for the program, email namieducation@nami.org.

Training	Description
Introduction to Family Psychoeducation (link)	Defines family psychoeducation. This includes outcomes and research on family psychoeducation in schizophrenia spectrum or other psychotic disorders.
Role of the Family in the CARE Process (link)	Discusses how family members can participate in the CARE process. This includes participation as the petitioner, volunteer supporter, or through informal support. Details action steps that families involved in the CARE process can consider.
Supported Decisionmaking for Volunteer Supporters (link)	Defines supported decisionmaking (SDM) and highlights key concepts. Outlines how to support the CARE participant to make their own decisions under an SDM framework.
Maintaining Neutrality as a Volunteer Supporter (link)	Discusses the relationship between the supporter and the CARE participant. Reviews the importance of fully supporting the CARE participant's self-determination. Scenarios are used to illustrate how different relationships may pose challenges to the supported decisionmaking process.
Psychiatric Advance Directives (link)	Reviews the background, purpose, and evidence of psychiatric advance directives (PADs). Discusses the when, who, how, and what of PADs in the CARE process.
Series: Schizophrenia Spectrum Disorders &	<ul style="list-style-type: none">• Part 1: Schizophrenia Basics: Provides an overview of schizophrenia. Discusses the when and

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Training	Description
Evidence-based Care for Volunteer Supporters (link)	<p>how of a schizophrenia diagnosis. This also includes an overview of related disorders, associated diagnoses, and complications.</p> <ul style="list-style-type: none"> • Part 2: Evidence-based Practices in Schizophrenia: Introduces approaches and practices used to treat people with schizophrenia. These include a person-centered approach, assertive community treatment, and medications. • Part 3: Supporting People with Schizophrenia: Introduces concepts to consider while supporting a person with schizophrenia. Provides helpful strategies. These include how to react to hallucinations and delusions; using a trauma-informed approach; building rapport; and meeting them where they are at. Reviews the recovery and supported decisionmaking models that can be applied to this population.
Series: Trauma-Informed Care for Volunteer Supporters (link)	<ul style="list-style-type: none"> • Part 1: Foundations of Trauma-informed Care: Defines trauma and trauma-informed care. Identifies factors that are common causes of trauma. Provides an overview of how trauma can trigger responses and impact the brain and behavior. • Part 2: Goals and Principles of Trauma-informed Care: Outlines the goals of trauma-informed care and principles. These include safety; collaboration; trustworthiness and honesty; empowerment; and positive peer and natural supports (e.g., friends, members of social networks). Additionally discusses cultural, historical, and gender issues. • Part 3: Applying Trauma-Informed Care as a Volunteer Supporter: Overview of tools to help a supporter de-escalate situations using a trauma-informed approach. Discusses how to promote resiliency for those supporting CARE participants.

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Resources to Understand the CARE Process

It can also be helpful for families to understand the CARE process. These trainings can help you understand what to expect.

Training	Description
Overview of CARE Process for Supporters (link)	Background on the CARE Act, roles within the process, and a high-level description of the court process.
Overview of CARE Agreement & CARE Plan for Volunteer Supporters (link)	Provides an overview of and compares the three main paths to services in the CARE process. These include voluntary engagement, CARE agreement, and CARE plan. Discusses elements of a CARE agreement and CARE plan. Also, the importance of individualizing the CARE agreement and CARE plan to the person's needs.
Housing, Services, & Supports Available Through the CARE Act: Training for Supporters (link)	Provides an overview of the volunteer supporter's role with regards to housing and community supports in the CARE Act. Details housing and supports that may be included in the CARE process. These include the housing first approach, snapshots of the housing continuum for CARE participants, and elements of the CARE agreement and CARE plan specific to housing and community supports.
The Supporter Role in the CARE Act (link)	Explores the role of a volunteer supporter through a case study. Also, outlines the CARE Act volunteer supporter responsibilities, requirements, and components.