



Strategies for Supporting a Young Person with Early Psychosis Pt 3:

Caring for the Carer

Toni Gibbs-Dean, PhD

Yale SCHOOL OF MEDICINE



This talk...

- The care and support offered by caregivers is pivotal for the success of the patients' recovery
- But what caregivers of people with early psychosis go through is highly challenging and has huge implications for their own lives
- This talk is about how we look after the caregivers and support them to continue to make such an important difference in the lives of their loved ones



What is psychosis?

Psychosis is a medical syndrome that can be diagnosed based on a cluster of characteristic changes in thinking, feeling, and behavior.

During an episode of psychosis, individuals can **struggle to differentiate what is real from what is not** and may come to believe false explanations for their experiences.



Common Signs and Symptoms



Positive - **add to** or **distort** an individual's normal functioning, perception or behavior

- Hallucinations, delusions, paranoia, bizarre behavior, disorganized communication...with **limited insight**



Negative - a **reduction** or **loss** in an individual's normal functioning, perception or behavior

- Decreased motivation, energy and speech, social withdrawal, flat affect, no enjoyment, poor hygiene, decline in functioning



Cognitive

- Executive functioning decline, attention, working memory, learning, preoccupation, thought blocking, reduced abstraction ability



Mood

- Fluctuations, anxiety, depression, suicidal ideation

More common than you think



Psychosis impacts approximately 100,000 **youth and young adults** each year – often living at home or only recently independent



For every person with a severe mental illness, including psychosis, around 5 to 10 family members and carers may be directly affected

The ripple effects of psychosis can extend well beyond the individual experiencing the condition



The caregiver...

How is “caregiver” defined?



Generally, an informal role – i.e., not paid



Tend to assume roles that have previously been performed by professionals



Examples: Emotional support, financial management, service access, treatment adherence, housing, shopping, meal preparation, transportation, paperwork, respond to crises

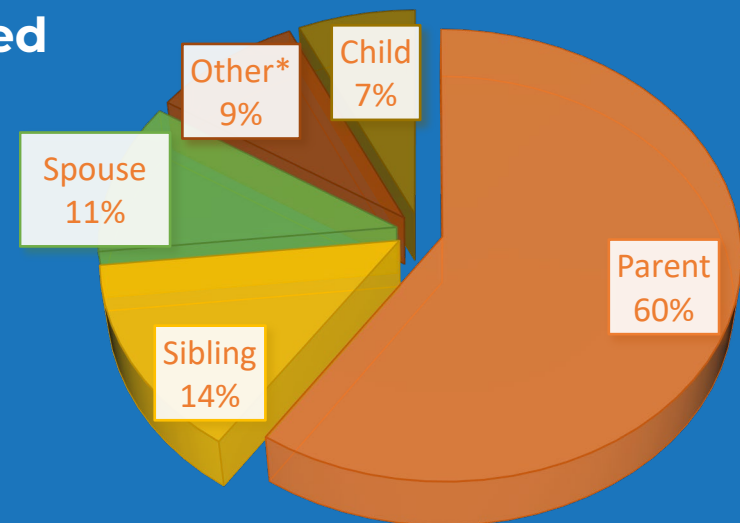
Common characteristics of caregivers

Age. Carers can be of any age, but a significant proportion are **middle-aged adults**

Gender. Predominantly **female**

Relationship. Over half are **parents**

SES. varied – however more impact on lower income families



*Other relative, friend or

Parenting AND the “carer” role

| | Parenting | Carer role |
|---|--|--|
| Behavioral management | Not typically complex | <ul style="list-style-type: none"> • Complex Mental Health Needs • Treatment Compliance • Crisis Management |
| Emotional and Psychological Impact | <ul style="list-style-type: none"> • Stress related to balancing parenting responsibilities with other life demands • Often societal support | <ul style="list-style-type: none"> • Need for constant vigilance and the potential for crises • Stigma and Isolation |
| Caregiving Skills and Strategies | General parenting strategies and resources to support their child's development and address behavioral issues | <ul style="list-style-type: none"> • Specialized Knowledge required • Coordination with Healthcare Providers |
| Legal and Financial Aspects | Costs are generally predictable | Costs can be significant and unpredictable |

Why are caregivers so important?

Research shows that caregivers play a **pivotal** role in improving **future outcomes** for the patient

- Increased medication adherence
- Fewer relapse episodes
- Better recovery rates over a shorter period
- Fewer hospital admissions
- Shorter inpatient stays
- Overall improvement in quality of life
- Better work and role performance
- Reduced substance use
- Potentially reduced mortality



Why are caregivers so important?

Crucially, how caregivers (and those close to the patient) respond has considerable influence on illness course. For example...

High levels of...

- critical comments
- hostility
- emotional over-involvement

Have been linked to...

- More frequent relapses
- High rates of hospital admissions
- Higher burden of care for the carer and less adaptive coping strategies

The impact on the caregiver...

Psychological impact

- Approximately 30-50% of parents report that their mental health has been negatively affected by the caregiving role, experiencing chronic **stress** and **emotional strain**.
- Clinical levels of **depression** identified in 40-60% of caregivers
- **Burnout and emotional exhaustion**, at equivalent levels to those reported by paid psychiatric staff
- Studies indicate that caregivers of individuals with psychosis, experience **higher** levels of stress compared to caregivers of individuals with other chronic conditions.



Social impact

Family Strain. The caregiving role can strain family relationships. Research indicates that up to 50% of families with a member who has a severe mental illness report experiencing increased family **conflict** and **strain**.

Social Withdrawal. Parents often experience social isolation as a result of their caregiving role. Studies suggest that **up to 40% of caregivers report feeling isolated** from friends and family due to the demands of caregiving and the **stigma** associated with mental illness.

Financial impact

Financial Costs. Parents may face costs related to **medical treatment, therapy**, and sometimes **lost income**. Research has shown that families may incur **out-of-pocket expenses** that can exceed several thousand dollars annually.

Workplace Challenges. Around **20-30% of parents** report having to make significant work-related changes due to their caregiving responsibilities, which can include **reducing work hours**, taking **unpaid leave**, or **leaving their job** entirely.

The caregiver's experience...

Common roadmap

Pre diagnosis

- Loved ones may experience **worry, fear** and **confusion** until the psychosis is recognized.
- **Anger, frustration, despair** can also be common.

Diagnosis

- Loved ones may experience **relief** and a sense of **hope**
- However, rapid **learning** about services and medication management often required

Recovery

- Patients enter a recovery period – often not a straight line and may require a **longer-term adjustment**
- Caregivers need to go through their own recovery where the events are processed, **understood** and **accepted**

Common experiences

- **Mourning** the loss for self /and/or young person / or relationship
- Because these disorders were misunderstood for a long time, some families feel **responsible** for their young person developing psychosis and wonder what they did wrong.
 - Psychosis is not caused by parenting, or by other familial relationships.
- Difficulty adjusting to having young newly independent adult children having to become more dependent once again
- **Advocacy** - relatives' fight with the mental health 'system'
- The **learning curve** – medication, services, provision
- **Isolation** - 'Is anybody listening? Does anyone understand?'

Common stress response

Caregiver stress and burnout

- Anxiety and worry
- Tired and rundown
- Difficulty sleeping
- Focus and concentration limited
- Short fuse and Anger – fear/frustration



Negative cycle

- Carers tend to cut back on key **self-care** behaviors e.g., ***"there isn't time", "I'm too tired"***
- This can lead to -->
 - Being unable to fulfill the caring role, mental health problems, relationship break down

What carers have found helpful

Supporting your own wellbeing – SELF CARE

- Access individualized and/or group **therapy**
- Engage in **stress management** – **exercise, diet, sleep**
- **Talk** to your friends and family to ease the burden
- Take things **one step at a time** – **marathon not a sprint**
- Taking care of **YOUR OWN NEEDS**

Take back control of (some of) your time

- Take time to enjoy activities and **hobbies** for yourself
- Accept help, delegate, and give yourself a break
- Proactive **planning** and prevention **strategizing**

Empowerment

- **Education** – illness, medication, services
- Skills building – patient focused, **self focused**
- Building positive relationships with services

Skills training and resources

Practicing Acceptance

What do we mean by acceptance?

Accepting the reality of your loved one's diagnosis, your caregiving role as a **choice**, and the changes this may bring

Why is acceptance important?

- **To support emotional resilience.** Acceptance helps carers to acknowledge and manage their own emotions without becoming overwhelmed by them and start to see the silver linings
- **Reducing Avoidance.** Confronting the reality of the situation can help in finding practical and emotional ways to cope with the demands of caregiving.
- **Improving Relationship Quality.** By accepting their situation and their own emotional responses, carers are better able to maintain positive and supportive relationships with the person they are caring for.

Acceptance and commitment therapy (ACT)

ACT is a therapeutic approach that emphasizes accepting difficult thoughts and feelings rather than trying to change or avoid them.

Ways to achieve this...

- **Mindfulness and Self-Compassion:** Incorporating mindfulness practices can help carers become more aware of their own emotional state and cultivate self-compassion.
- **Value-Based Actions:** Both ACT and CBT emphasize acting in ways that are **consistent with personal values**. For carers, this might mean **prioritizing self-care, seeking support**, and maintaining a focus on the **well-being** of both themselves and the person they are caring for.

Processing difficult emotions

Grief, mourning, loss, guilt, trauma

It's important to have an outlet to work through difficult emotions – for your own sake and that of your loved ones

Taking the time to do this is **AS important as your caring role.**

Some top tips:

- Therapy
- Journaling/talking - get outside of your head
- Allow celebration of progress: try not to compare your loved one to how they were “before” the illness, rather measure progress from week to week, month to month.
 - o Common experiences: Pride, joy, deep bond
- Hold hope for recovery and your young person getting back to the things that are important to them and maybe even forging a new path that you did not expect.

Temporarily lower expectations, but maintain aspirations

Worry & problem solving

The problem

- Feeling overwhelmed, spending a lot of time worrying
- The problem feels unsurmountable

Practical solutions for worry

- Make a **dedicated time** to think about the problem to avoid rumination
- Write it down, talk to someone, try to **take the problem outside of your head**

Problem solving tips

- Use SMART goals: **S**pecific, **M**easurable, **A**chievable, **R**elevant, **T**ime-bound
- **Record keeping** – keep a record of all service interactions
- **Pre-plan** coping strategies with your family and the patient prior to important events e.g., Christmas

Planning: Early warning signs

Relapse signatures are unique to each individual but follow certain trends for example

- Pacing
- Restlessness
- Nervousness
- Medication non-adherence
- Increase in drug use
- Responding to unseen stimuli
- Mood swings

Work together with your loved one to identify their relapse signature

Make a pre-emptive plan of how you will both respond in this situation.

Reducing household tension

Try to maintain a calm home environment

Provide a **structured** and **predictable** environment and try to limit sudden changes

Try to keep the amount of **stimulation low** in the household

Try to take the emotional high road

Emotional **neutrality** – be non-reactive where possible

Suspend disbelief rather than denying their experience

Compliment the positives rather than focusing on problem behaviors.

Ignore troublesome behaviors that are not harmful.

Allow more time for responses. Psychosis can affect thought processes. It may be a bit longer for your family member to process what you have said and respond back.

Be **consistent** with your interactions

Try to build a collaborative (team) based relationship

Take advantage of calm moments to foster open conversations about how they are feeling, and what they are experiencing, **without judgement**

Problem solve together where possible – make plans and strategies of how you will together deal with future issues

Befriending – build on your shared interests and goal

Open communication

Family resources

Connect with an individual therapist

- <https://www.psychologytoday.com/>
- Ask your insurance provider for a list of in-network providers

Connect with others

- Support and Advocacy Groups – [NAMI Family Support Groups](#)
- Podcasts and videos of others with lived experience

Educate yourself

- [STEP LC Family Training archives](#) – educational trainings and tip sheets for family and providers

Learn skills to feel empowered

- [Self-Compassion for Caregivers - Dr. Kristen Neff](#) – guided exercises to cultivate self-compassion
- [Psychosis REACH](#) - Psychosis REACH teaches concrete, evidence-based skills to caregivers that are rooted in Cognitive Behavioral Therapy



- Screening for psychosis and rapid access to outpatient care
- Provider trainings
- Provider consultation
- Family and Community workshops
- Virtual Resources

Delivering safe, timely, and effective pathways to and through care for every young person experiencing first episode psychosis in Connecticut.





step
Learning
Collaborative

mindmap
a clear path to mental health

Thank you!

Providers direct questions to
our Consultation Service

STEPLC@yale.edu



203-200-0140



Search Mindmap CT

www.CTEarlypsychosisnetwork.org

www.mindmapct.org

The caregivers point of view...

Pre diagnosis

- Family and friends may experience worry, fear and confusion until the psychosis is recognized.
- Anger, frustration, despair can also be common.

Diagnosis

- Family and friends may experience relief and a sense of hope
- However, rapid learning about services and medication management often required

Recovery

- Patients enter a recovery period – often not a straight line and may require a longer term adjustment
- Carergivers need to go through their own recovery where the events are processed, understood and accepted