

Session 4

Family Recovery Journey

Lived Experience & Recovery

Destination or Journey: What Does Recovery From Mental Illness Mean?

The concept of recovery from mental illness emerged in the mid 1980s. It has been variously defined as a process, as a vision, and as an outcome or goal. Most often, the metaphor of a road or journey is used.

Recovery is both a process and a goal – it is learning to successfully manage a disorder, having control over symptoms, and having quality of life. It involves overcoming the negative impact of a psychiatric disability despite its continued presence. It is about getting on with life in spite of having a mental illness.

Recovery is...

- A complex process, that takes time
- A unique, individualized experience
- About reclaiming hope and purpose
- Rebuilding self-esteem
- Developing strong support systems
- Aided by a range of treatment options and supports
- Recovering from the stigma associated with mental illness as well as the illness itself

Recovery is unique for every person and involves finding their own way to wellness. There may be ups and downs, hills and valleys, detours and occasional roadblocks, but the road continues forward.



What is the Evidence That People with Schizophrenia Do Recover?

“ Even without intensive treatment and rehabilitation, many studies have revealed longer-term outcomes that are better than expected.¹ ”

- About 20-25% of persons in these studies regain normal levels of functioning
- An additional 25-30% significantly improved

The pattern of recovery from psychosis varies, depending on where the person is on the schizophrenia spectrum, among other factors.

Dimensions of Recovery

- **Functions** - The ability to read, to sleep restfully, to work, to have coherent conversations, to raise children, to drive a car
- **External Factors** - A place to live, a job, a social life, recreational activities, family relationships, school
- **Internal States** - Feeling good about oneself, satisfaction, self-confidence, spiritual peace, self-identity other than “mentally ill”, and self-responsibility

Phases of Recovery

Phase 1: Overcoming Stuckness	Phase 2: Regaining What Was Lost and Moving Forward	Phase 3: Improving Quality of Life
Acknowledging and accepting the illness	Recovery as a process of learning and empowerment	Striving to attain an overall sense of well-being
Having desire and motivation to change	Recovery as a process of redefinition and self-transformation	Striving to reach new potentials of higher functioning
Finding/having a source of hope and inspiration	Recovery as a process of reaching a level of functioning that is acceptable to the individual	

Who Will Recover?

This is not always predictable, but certain factors suggest that recovery is likely:

¹ Spaulding, W.D., Silverstein, S.M. & Menditto, A.A. (2017) The Schizophrenia Spectrum. Toronto: Hogrefe Publishing.

History, Onset and Type of Symptoms

- Good adjustment prior to the start of illness
- No family history of schizophrenia
- Developing the illness at an older age
- Sudden onset of the illness
- Onset following a major life event
- Few cognitive symptoms
- Effective medication without distressing side effects

Personal Factors

- A good understanding of what has happened
- Physical well-being
- Sense of realistic expectation and hope about the future
- Sense of purpose or direction, feeling of contributing to society

Contextual Factors

- Strong social support networks
- Stable living conditions
- Safe and structured environment
- Someone to discuss experiences and feelings with and provide practical help

How Do People Recover?

Recovery requires active involvement

Pat Deegan, a pioneer in the mental health recovery field, completed a doctoral degree after years of coping with major mental illness, and now offers recovery resources through her company, Pat Deegan Associates (<https://www.patdeegan.com/pat-deegan>). She emphasizes that people with mental illness are not passive recipients of rehabilitation services. They do not “get rehabilitated” in the sense that cars “get tuned up” or damaged property “gets repaired”. Rather, they are courageous participants in a way of life that includes employment, social interaction, sports, community service, and other activities.

Activities that support recovery (www.heretohelpbc.ca)

- Opportunities to express one’s true feelings
- Social interaction with friends and colleagues with and without mental illness
- Opportunities to resume education and learn new skills
- Opportunities to join the workforce
- Participation in community events and volunteer activities
- Continued access to recovery programs, depending on need
- Sports and leisure activities

How Families Can Support Recovery

1. **Believe in Recovery** – hope is a key factor in the recovery process.

2. **Have a Strengths Perspective** - In a strengths perspective, we believe that people are doing the best they can with what they know. Instead of focusing only on their problems, we actively look for their strengths, and aim to draw out and build upon strengths.
 - > **Examples of strengths:**

 - > Personal qualities, traits, skills, talents, virtues

 - > Beliefs and attitudes – hope, faith, spirituality, values

 - > External factors – supports, low-stress environments, structure, supported housing

3. **Recognize** that recovery is not a linear process, and can occur whether one views the illness as biological or not

4. **Be supportive**
 - > Be as supportive, understanding and patient as possible. Express your love for the person and your belief in their abilities

 - > Give support and encouragement to help your relative feel more comfortable and included in social situations

 - > Take notes or keep a recovery journal

 - > Look after your own health and family recovery

 - > Encourage your loved one to stick to a treatment regime, and keep track of medication side effects (see links on page 6 for information about medications)

 - > Encourage your loved one to develop a relapse prevention plan (see next pages)

 - > Join a family/peer support group

Moving from a Problem or Deficit Orientation...	To a Strengths Orientation
Instead of focusing on my relative's problems, symptoms and deficits....	I am primarily concerned with what they want, desire, and dream of.
I don't spotlight my relative's pathology and difficulties...	I seek to understand and build upon their positive talents, skills, knowledge and abilities.
Rather than see my relative as a diagnostic label...	I see them as a unique human being.
Instead of letting others' perspectives guide and sometimes limit my ability to give my relative choices...	I honour my own standpoint, values and beliefs about recovery and choices. I know that my relative's life holds many possibilities and they can choose a positive direction. My relative also has the right to learn and grow from their mistakes like everyone.

I don't believe that my relative's past predicts a negative future...	I am concerned with the here and now, and moving towards a positive future.
Rather than focusing on the things they cannot do...	I know that my relative has many abilities. They have made it this far and I know that they will make it in the future.
Rather than making their problems the focus of my life, so my own life seems limited and stagnant...	I am actively learning, growing and changing. I am focusing on my own needs and happiness. I can be a role model for my relative.
I don't let people around me focus on my relative's limitations...	I seek relationships, role models and helpers who support and encourage our family in our recovery journey.

Adapted from: Pathways to Recovery: A Strengths Recovery Workbook (2002) by Ridgway, McDiarmid, Davidson et al.

5. Recognize Your Limit

- > Decide what level of support and care you are realistically able to provide. Explain this to the friend or relative with the mental illness as well as the health professionals involved in his/her care. This will ensure that the type of support you are unable to provide can be arranged in another way.
- > Discuss options for future care with health professionals and other family members and friends. This will ensure continuity of care when you are unable to fulfill your role as a caregiver.

6. Encourage a sense of structure

- > Develop predictable routines: for example, regular times to get up and eat; introduce gradual changes to prevent boredom.
- > Break tasks into small steps: for example, encourage someone to shower more by helping them put out towels and choose clean clothes.
- > Try to overcome a lack of motivation: for example, encourage and include the person in activities.
- > Allow the person to make decisions: even though it can sometimes be difficult for them to do this and they may keep changing their mind; try to resist the temptation to make the decision for the person.
- > Understand that your loved one may wish to spend time alone

7. Maintain a calm atmosphere in the home

- > Avoid excessive stimulation, such as having frequent company, loud music, violent television programming, etc.
- > You and your loved one may discover and practise calming activities (e.g., playing quiet music, reading, or gardening).

Setting Goals & Expectations

Families function smoothly when expectations for each person are clear and consistent. Decide with your family member on appropriate routines, and keep routines simple

It is important to review and compare your goals and expectations with your loved ones. This process will help keep your relationship positive and healthy and provide you with some direction on how to best support your loved one in the pursuit of their goals.

Clarify Your Expectations

- Your loved one needs to be clear about their expectations for friends and family members. For example, ask them to identify what type of support they expect to receive from family and friends (e.g., to live with parents or a sibling; to be able to depend on someone for transportation or financial support).
- **Negotiate** - not all expectations can be met. Discuss what is realistic and do-able.
- Consequences for failure to meet expectations should be clear and appropriate.
- State what you expect from your loved one. For example, tell them how you want them to contribute to the home (if living with you), how you expect them to behave, and your expectations regarding self-care (e.g., taking medication as prescribed and attending regular appointments with health care providers).
- Be prepared to review the expectations periodically as things may change.

Keep in mind that expectations should be positive and achievable. Positive and reasonable expectations serve to provide guidance, create faith, establish hope, and promote self-confidence and self-esteem.

Avoid common unrealistic expectations, for example:

- That the recovery will be speedy
- That the person will never again be hospitalized or have a relapse

Establish realistic short-term and long-term goals

- Discuss goals with your relative. Their interests, wishes, and level of functioning need to be considered in any plans that are developed.
- Use the LEAP approach to Agree and Partner.

Relapse May Be Part of the Process

Relapse refers to a return of acute symptoms. Even when taking medications, the relapse rate can be as high as 50%. So it makes sense to expect, and be prepared for, an eventual return of acute symptoms, even when the individual is doing fine.

Relapse can occur for a number of reasons, as well as for no apparent reason. An individual may feel discouraged after a relapse, and so it is important to remember that experiencing a relapse is not a “failure.” An individual who relapses can recover.

Possible Risk Factors for Relapse

- It may be that they have stopped taking medication, or that the dosage is not high enough to prevent that return of acute symptoms, or even that the medication has stopped working.
- The individual may have a poor doctor-patient relationship or may not be receiving enough support from community services.
- The individual may have recently experienced severe mental stress
- The individual is physically ill or exhausted or is using alcohol or street drugs to feel better.
- The individual may be experiencing anosognosia (lack of awareness of being ill).

Keep in mind: that the signs and symptoms of relapse tend to be constant for the individual, so the changes that announced the relapse last time are likely to be the same ones that will signal relapse next time.

Warning Signs of Relapse

Anxiety and tension

Trouble concentrating

Trouble sleeping

Restlessness

Depression

Not being able to remember things

Not being able to enjoy things (or loss of interest in things)

Being preoccupied with one thing

Denial of illness

Talking in a nonsensical way

Negative thoughts about oneself

Negative beliefs about others

Changes in expression of feelings (more hostile or increased episodes of euphoria; extreme moods)

Changes in personal care (stops bathing or changing clothes)

Changes in appetite (usually eating less)

Changes in level of activity (increases or decreases)

Changes in sexual activity

Changes in social activity (refuses to see friends or withdraw)

Relapse Prevention Planning May Include



- Getting more rest
- Reducing stress (work or other obligations)
- Exercising
- Structured routine
- Changing medication dosages
- Increased visits with the doctor or psychiatrist
- Education and awareness about relapse
- Developing and following an individual prevention plan

Resources

Recovery – Hope Changes Everything

Video: <https://www.youtube.com/watch?v=5Q2zkeirxK4>

Your Recovery Journey (The Schizophrenia Society of Canada)

<https://www.your-recovery-journey.ca/english.htm>

WRAP – The Wellness Recovery Action Plan

<https://www.wellnessrecoveryactionplan.com/living-a-family-wrap/>
or <https://www.wellnessrecoveryactionplan.com/bookstore/>

The Family Guide to Mental Health Recovery

<http://www.familyguidetomentalhealth.com>

Antipsychotic medications

<https://www.camh.ca/en/health-info/mental-illness-and-addiction-index/antipsychotic-medication>

Understanding psychiatric medications

<https://www.porticonetwork.ca/tools/client-handouts/client-handouts-mental-health>

Personal Relapse Prevention Plan

Signs of Relapse (List behaviours that indicate signs of relapse)	Strategies (List possible coping methods)