

section 6: transitioning away from mental illness

Throughout this resource, we have emphasized the importance of a recovery perspective. One of the main achievements of the recovery model is its emphasis on a more holistic view of the person, recognizing that people who experience mental illness are more than just a host of symptoms to be treated.

With hope as the foundation, a recovery-oriented approach respects a person's lived experience and expertise, promotes decision making, choices, self-responsibility, and independence.

In this section, we offer some ideas and suggestions for families to enable them to promote recovery for their ill relative. We offer a word of caution, however. In reviewing the literature, we found a wealth of information about family support in the early stages of mental illness, but very little with respect to later stages. We therefore feel it is important to seek out further information and talk to others who believe in the recovery process.

To help families visualize the recovery process, we have created a chart that breaks recovery down into five stages. (See the "Stages of Recovery" chart in the Appendix B.) Some of the main needs of both the ill relative and family are covered for each of the stages. Keep in mind that each family's experience will be unique and that the stages are only guideposts.

Caregiving And Support During Recovery

In his (2004) article, Dr. Crabtree suggests that the goal of caregivers is to provide "help that helps" rather than "help that hurts". Your ill relative will likely need a greater amount of your help during the early stages of their recovery. Assisting with the majority of their needs may be necessary during periods of acute illness, but as your family member begins to feel better, they will likely need less of your help. As they regain their strength and mental health, the extent and nature of the help they need will change in order to enable opportunities for growth. Some types of caregiving can be very helpful at one stage of recovery but unhelpful at another. There will be a point where it will be more helpful to start backing off and begin the transition from caregiver to supporter.

Dr. Crabtree warns that, *"Helping a person with psychiatric difficulties, however, can lead to patterns of caring that quietly foster an exclusive reliance on the family."*

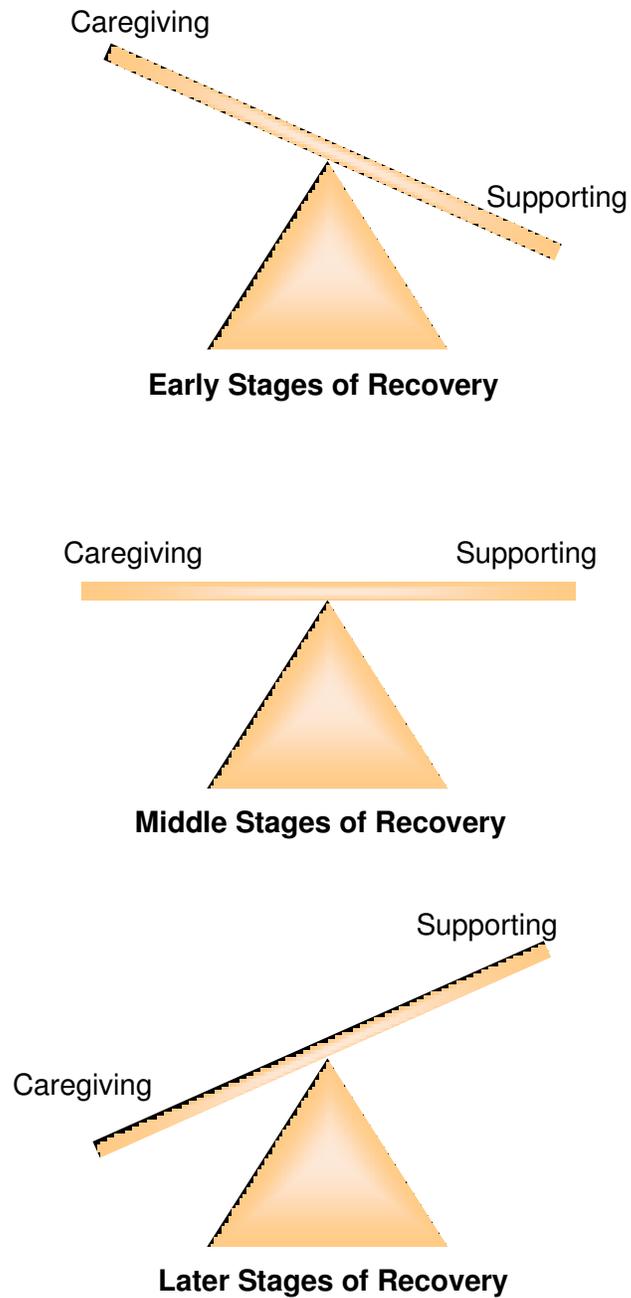
Your challenge is to recognize when you need to change the type of help you provide in order to prevent your well-intentioned help from becoming an obstacle to recovery and to your own mental (and physical) health.

Caregiving Versus Supporting

Caregiving and supporting are not mutually exclusive and families provide both, at various points in their family member's lives. The challenge is to find the right balance.

The following diagram shows the balance between caregiving and supporting at three stages of recovery:

Transitioning from Caregiving to Supporting



The Risk of “Helping Too Much”

There are obviously situations during crisis and the early stage of recovery when your extended help in caring for your relative is legitimately needed. However, as recovery progresses, your relative’s needs will change and they will transition away from their dependence on you as a caregiver. This means that the types and extent of support you provide to your relative will change as they become more successful in managing their illness and getting on with their life.

Caregiving and supporting need to be based on an attitude of mutual respect for the needs of yourself and your ill relative. Everyone needs to have the freedom and responsibility to grow, regardless of disability. Part of this process involves supporting your ill relative to begin to solve their own problems and make their own decisions.

“There is sufficient scientific evidence to conclude that strategies that enhance the caregiving capacity of family members and other people involved in the day to day care for people with mental disorders have a clinically significant impact on the course of major mental disorders...”

Falloon, 2003

Backing Off Is Easier Said Than Done

There can be significant challenges involved when moving from the caregiving to the supportive role. You might wonder why you should put yourself through the stress of risking change when the current pattern feels safe and gets things done.

Other concerns expressed by families include:

- “If I let go of them, I might lose them.”
- “If I stop trying to fix and change them, they will no longer need me and will leave me.”
- “There must be a way to make things better and I can't give up yet.”
- “What if they fail or fall flat on their faces?”
- “If they lose or fail, it will reflect badly on me.”
- “I would feel so guilty if anything bad happened to them.”
- “What would others think of me?”

The journey of recovery may involve changing your perspective from

“How do I deal with this illness?”

to

“How can I best support my relative in their recovery?”

The response to these concerns comes back to the need to avoid the type of “help that hurts.” As hard as it may be to change the family pattern of help, a gradual shift from caregiver to supporter can greatly assist your ill relative’s progress toward regaining control of their own life. Gradually allowing them to problem-solve and accept responsibility for themselves will assist in gaining greater self-sufficiency, developing relationships outside the family, self-growth, and may even release capabilities that would otherwise lie dormant and undetected.

Helpful Hints for Stepping Back

Transitioning away from dependence is not a matter of the family giving up its role in recovery entirely. While individuals are supported to take personal responsibility for their own self-care and self-advocacy, recovery is not viewed as a solitary process. Rather, it is a complex, dynamic, social interplay between the person with the mental illness and the social and physical environment within which they live.

In fact, most people who have recovered from a mental illness credit the steadfast encouragement and support of another person who they say believed in them— a therapist, teacher, counsellor, nurse, or family member.

Stepping back and letting someone regain control over their life is a gradual process. It involves taking inventory of both the ways in which you currently provide help and what your relative is capable of doing for themselves. You may want to start by creating a list of all the caregiving tasks you currently provide and giving some careful thought around what can be “handed back” to your relative.

There will likely be a period of testing to see how much responsibility the person is actually able to take on. It is advisable to begin with simple things and gradually allow them to regain more control. Engaging in a process of careful drawing and re-drawing of boundaries will assist your relative in moving towards independence with a sense of achievement and growing self-esteem.

“People who are recovering talk about the people who believed in them when they did not even believe in themselves, who encouraged their recovery but did not force it, who tried to listen and understand when nothing seemed to be making sense.”

Anthony, 1993

Families in our focus group told us that transitioning for them meant moving from solving the problem or doing the task themselves to stepping back and not taking over. Some of their comments include:

- “When the issue came up in the past, I would have come up with a solution. Now I give it back to him to discuss with his social worker or psychiatrist.”
- “Let him test the parameters a bit more.”
- “Give a little more responsibility for more things.”
- “Do less for him.”
- “I tell him I have other caregiving burdens and that he must be responsible for his own recovery.”

Your Role As A Supporter

Below are some ideas on helpful supports you can provide to your relative, the goal of each being to foster self-empowerment:

Offer encouragement: Lack of motivation can be part of mental illness and your relative may need gentle pushing to get them back on their feet. Encourage your relative to manage their health, learn new skills, re-learn old ones that were lost, find ways to engage in social activities, and when ready, prepare for education, work or volunteer opportunities. Taking steps towards independence requires great courage and strength on the part of your relative. Acknowledging this can help to boost your relative’s confidence in themselves and their ability to take hold of their life.

Communicate: Families are often concerned about being direct with their ill relative, out of fear that it will stress them. Quiet, even communication is often best. Direct, honest, “say what you mean, mean what you say” communication can maintain mutual respect for your needs and those of your ill relative.

“I speak more directly to him. I don’t pussyfoot around”

Focus Group member

Offer choices: Choice leads to empowerment. Empowerment allows your relative to gain control over their life through access to meaningful choices and the resources to implement those choices. Allow them to make choices about all aspects of their life—treatment, personal goals, community activities, advance directives, etc.

“We try to make a mantra of “Find the good. Praise it.” Once we start looking for opportunities for genuine compliments, we generally will not have a hard time finding them.”

Friese, 2004 p. 973

“Instead of being the first one to look for the lost car keys, I step back and let it happen.”

Focus Group member

Find opportunities for them to do things for themselves: When someone has been ill for a while and unable to do things for themselves, it can be easy to fall into a pattern of “doing it for them”. Part of recovery for caregivers and families is learning to “step back” from doing for them so they can do it themselves.

Be a talent scout: Focus on your relative’s strengths and help them to uncover and explore their interests, talents, and skills. Focusing on strengths helps build confidence and self-esteem.

Validate: Recovery can be hindered by criticism or invalidation of the ill person’s choices. Respect for their choices aids in their journey toward self-care. Although you may not agree with them, it is important to respect your relative’s decisions and choices, provided they are not life-threatening or harmful to others.

“You may not agree with the decision, but if it is not life threatening or harmful, transitioning involves not judging his choices or second-guessing his decisions. “

Focus Group member

Be realistic: Devising realistic and achievable goals, responsibilities, division of duties, and so on, increases your relative’s chance of success. Gaining a sense of achievement will motivate them to continue to take risks and move forward in their recovery. Expectations that are too high can increase stress levels and may result in relapse of illness.

Be patient: Let your relative do what they’re able to do, even if it takes longer and is not how you would do it. Allow for mistakes and less-than-perfect results. Remember also that there is no set timeframe for recovery, that it is a non-linear journey including setbacks and challenges. It can be frustrating for families when the ill member appears to stop making progress and “plateaus” or has a relapse.

“I let him make his own mistakes so he can learn from them.”

Focus Group member

Take acceptable risks: Enable your relative to explore what they can do on their own. Remember that you cannot eliminate all risks without eliminating all opportunities.

Don’t take over when things go wrong: As recovery progresses, your relative will need opportunities to deal with the consequences of their choices. Experience is a great teacher!

Listen: Sometimes the best way to support someone is simply to stop talking and start listening. By actively listening to your relative’s concerns and successes you are validating what they think and feel. This can be one of the most powerful tools to aid their recovery.

“Instead of giving advice, I engage in more active listening, being there with him. “

Focus Group member

Promote trust: Trust is key to creating an environment that promotes recovery. Trusting oneself and others involves personal risk and is earned through caring and supportive relationships.

Be a good role model: Set a positive example of a balanced life. By modeling healthy choices, finding time for yourself, and engaging in social activities, you provide opportunities for your relative to develop a healthy lifestyle, both mentally and physically.

Provide feedback: While it is important for your relative to be the decision maker for their life, they may still value your input on some decisions. Moving from caregiving to supporting involves a change from decision *advisor* to decision *facilitator*.

Push past the fear: Moving away from dependence is likely to be a scary prospect for you and your relative—but do it anyway!



Summary

As a caregiver, your goal is to give your ill relative the power and opportunities to be in control of their own life as much as possible and to recognize that every effort they take to maintain independence is a victory for you as a caregiver.

We wish you all the best in your recovery journey.

Family Member Interest Chart

This chart can be filled out by your family member or created together. Invite your family members to come up with a list of activities that your ill relative enjoyed in the past. It can be used as a reminder and to encourage your family member as they begin to re-engage with life.

	How Often	Alone or With Company
Favorite Exercise		
Fun Activities		
Hobbies		
Social Activities		
Favorite TV shows		
Favorite Music		
Ways to Relax		
Types of Reading Enjoyed		
Computer Activities		
New Activities		
Other		

Reviewing Progress In Recovery

In the course of our daily lives, it can be difficult to see change. Often changes are quite subtle and evolve slowly. Periodically, it may be helpful to stop and review how your relative has improved. The exercise below can assist you to acknowledge the positive changes that have occurred and think about what would make life better.

On a scale of 1 to 10 how happy are you with how you and your family are dealing with the mental illness?

1 _____ 10

What could you do (a realistic activity) that would increase this rating by one or two points?

What's better now — even a little bit better — than it was last week/a month ago?

Who else has noticed this change? What would they attribute it to?
