

The recovery journey involves learning the daily dance of balancing losses that mental illness can bring, with persistent hope for improvement. In this section, we offer a way of managing what can be an almost overwhelming sense of loss arising from the discovery of a relative's mental illness, by drawing upon hope as a source of strength.

“Traditionally, we have considered that the “flight or fight” response was the standard reaction to stress. Now it is possible to hypothesize that hoping is a useful alternative response....Hope appears to be a crucial antidote to fear.”

*Jevne, 1993*

### Two Partners In The Dance Of Recovery: Loss And Hope

In recovery, families embark on a journey of accepting limitations and losses within a new world of possibility. Recovery is a balancing act between expectations and capacity, between finding a path to a better future and accepting the inherent difficulties that lie ahead on that path.

In a paper entitled, “Recovery and the Conspiracy of Hope” (1996), Patricia Deegan explains that recovery is not an end point in itself but rather an ever-deepening acceptance of limitations from which spring unique possibilities. She says, “This is the paradox of recovery — that in accepting what we cannot do or be, we begin to discover who we can be and what we can do.”

This is the “dance” of recovery

“Hope is always set in the context of time. It draws on the past, is experienced in the present, and is aimed at the future.”

*Jevne, 1993*

“The challenge of recovery is to maintain a balance between over-expectation and under-expectation....to encourage progress without fostering failure.”

*Lefley, 1997*

## Loss

Dealing with mental illness will likely involve dealing with changes in your ill relative—including changes in personality, behaviour, and in ideas of “what they could have become”—and with subsequent changes in family relationships.

Depending on the role of your ill relative within your family, their illness can alter how family members relate to one another. For example, mental illness can exacerbate existing relationship problems but it can also draw family members closer together.

Losing the way your ill relative was and life the way you knew it poses challenges for all of the family. When mental illness walks into your family, life is different and the future often looks less bright and uncertain.

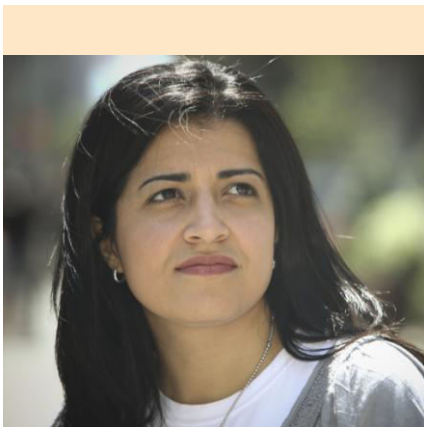
The losses incurred through mental illness are sometimes termed “ambiguous” since our society does not recognise them. Unlike other losses, such as a death in the family, there is no ritualised ceremony during which mourners receive support from others, followed by closure of some kind. With mental illness, the caregiver and other close family members suffer the ambiguous losses, unmarked by a date or by outside recognition, which can make the losses seem very isolating and unshared. It is therefore important to acknowledge your feelings of grief and loss and to share them with someone you trust—a family member, friend, counsellor, support group, for example.

In her book, “Ambiguous Loss: Learning to Live with Unresolved Grief”, Pauline Boss describes how mental illness presents a form of ambiguous loss in the sense that the ill relative is still present in body, but not in mind. She explains that the goal for the recovering family is to balance grief over what was lost with anticipation in what is still possible.

“This mother’s comment shows how her hope for recovery in the future is held in opposition to the grief for what has been lost to the illness:

I just want him to be what he was like....Just being able to work and having a full life, that’s what I hope for, for my son. I even have a picture in the lounge room, a picture I sit in there. It’s a picture of him when he was younger, when he was laughing and so I’m going to leave it there because that is what I’m going to see in the future”

*Bland & Darlington, 2002*



## Hope

To balance these losses emerges the partner, hope. There remains great hope for recovery and the return of your ill relative to a meaningful and productive life. In his paper, “The Holding of Hope: Exploring the Relevance of the Recovery Vision for Families” (2006), Peter McKenzie explains that many caregivers have shared with him their hope to “intervene or lessen the suffering that mental illness inflicts on their loved one and support them in moving towards regaining a sense of wellbeing and participation in life.”

“Recovery means the “holding of hope” on behalf of the family member, particularly at times when they are unwell. Contained in the “holding of hope” for the caregivers was the wish that their family member would be able to be “involved”, “contribute”, and “grow” even with the constraints of the illness.”

*McKenzie, 2006*

“Everything that is done in the world is done by hope.”

*Martin Luther King*

## Maintaining Hope And A Positive Attitude

Families can be torn apart by mental illness and it is necessary to nurture the realistic hope that members will be able to come back together again as a whole family, and to work towards that goal. Some families find that dealing with the illness can lead to an enriched relationship with the ill relative. Others have reported self-growth that they have found strengthening and valuable. There is also a strong possibility of increasingly close relationships between family members as they undertake the journey of recovery together.

Much research has been done on the importance and meaning of hope for family members of people with mental illness. Robert Bland and Yvonne Darlington’s Australian-based study, “The Nature and Sources of Hope: Perspectives of Family Caregivers of People with Serious Mental Illness”, investigated issues such as how family members define hope, what they hope for, and their sources of hope. Their research confirmed the enormous importance of hope in the path of recovery and showed that hopefulness appears to be central to a family’s coping with the impact of mental illness.

## Sources of Hope

Families in Bland and Darlington's study identified a range of sources of hope. Some were external, in the form of other people, whether professionals, support groups, family members, friends, or the ill relative themselves. Others reported hope as coming from within, mostly from their own religious beliefs and practices.

Bland and Darlington's study revealed that there is a reactive quality to hopefulness—loss of hope is linked to times when the relative is most ill and hope is recovered as the person becomes well. The bolstering effect of a support group can be extremely beneficial during acute illness. Equally, sharing the message of hope during periods of wellness offers an invaluable gift to family members whose hope may be faltering.

Some families in the study used hope-inspiring self-talk and positive thinking. They learned to recognise and emphasize improvements and successes. Some cited a sense of humour as a useful alibi in maintaining hopefulness. Journaling was used by one family as an outlet when talking was difficult.

Sources of hope highlighted in this study include:

**Family and Friends:** The ongoing support, encouragement, and sense of connection/belonging provided by family and close friends is cited as a common source of hope. Spending time with others who remain hopeful and who believe in recovery can help to sustain caregivers' ability to carry on, especially during the tough times.

**Professionals:** Mental health professionals play an important role in the complex relationship between hope and loss, having the potential to support or diminish hope. Those who are able to work sensitively and patiently with family members can sustain them through the subtle phases of illness and recovery by encouraging appropriate hopefulness while accepting the family's need to grieve for what has been lost to the illness.

**Support Groups:** Having a safe place to vent and share difficulties as a caregiver and to receive the support of others who maintain hope and believe in recovery can bolster hope.

**Religious Beliefs:** Religion or spirituality can be a significant source of hope for families.

“Whenever I was in serious crisis, I went back to a support group. I always ended up laughing and having fun.”

*Bland & Darlington, 2002*

**Inner Strength:** We all hold differing levels of self-confidence, assertiveness, self-esteem, perseverance, and patience. Each quality contributes to our overall “inner strength”. Developing these qualities enables families to overcome the obstacles and difficulties arising in the care of their ill relative and to take constructive action. Being able to move forward in a positive, constructive fashion provides the fuel for hopefulness while maintaining realistic expectations.

**Medications and Advances in Treatment:** While there is still no cure for mental illness, significant progress has been made in the past 50 years in diagnosing, treating, and helping people recover from it. Dramatic findings have been made about what contributes to mental illness and biomedical and clinical research is ongoing in areas such as genetic predisposition, molecular biology, brain imaging, and environmental factors. Families have every reason to remain hopeful as these new findings continue to work towards making recovery from mental illness a real possibility.

**Achievements:** Hope is grounded in achievable reality and involves a sense of goal-oriented determination. Recognizing when goals, small or large, are achieved can have a cumulative effect on caregivers’ sense of what further can be achieved, encouraging realistic hope.

**Positive Attitude:** As explained more fully in Section 3 (Thinking Traps), thoughts can be powerful evokers of feelings and actions and there are techniques you can use to avoid getting trapped in a negative circle of unhelpful thoughts, or “thinking traps”. Avoiding the pitfall of becoming frozen in “illness talk” and focus on practicing “recovery talk” allows more room for hopefulness.

Below are examples of self-talk and thoughts that families in our focus groups used to help them maintain their strength in dealing with their relative’s mental illness:

“We will get through this, we always survive, we can do this.”

“I can recover”

“I’m not in charge of the universe.”

“What happens is not my fault.”

“This too will pass.”

“Appreciate and have gratitude, seeing how I affect others. If I’m happy, I will affect others.”

“There’s nothing I can’t handle.”

“Could be worse.”

“There’ll be something good at the end.”

“I never actually gave up hope that things would get better. I think it’s my own inner strength that propelled my hope the most, that gave me the most hope.”

*Bland & Darlington, 2002*

## **Summary**

Recovery is a process undertaken by the whole family. It becomes a new way of life for everyone affected by the illness. Hopefulness is central to this new way of life in which the family attempts to cope with the present grief and loss associated with mental illness and to maintain hope for the future.