

Ambiguous Loss

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By Pauline Boss, Professor Emeritus, University of Minnesota

What is ambiguous loss?

Ambiguous loss is a loss that remains unclear, often for years, even forever. There are two kinds, with the first being *physical*. A family member is physically gone but kept psychologically present because there is no certainty of loss. With no body to bury, funeral rituals don't fit, so families are left alone without the usual supports for mourning. Examples of physical ambiguous loss are: loved ones lost at sea; family members lost in the Holocaust, 9/11; soldiers gone missing in war; airplane explosions; kidnappings; or family members swept away by natural disasters. Gone, but not for sure.

The second type of ambiguous loss is *psychological*. A family member is physically present but gone cognitively or emotionally. Examples are Alzheimer's disease and the many other illness that cause dementia, autism, addiction, depression, and other chronic mental illnesses. The person is here but not here.

Origin of the Term

I coined the term, ambiguous loss, back in the 1970s as I studied with Carl Whitaker at the University of Wisconsin-Madison. In family therapy, it seemed in the 1970s that fathers were "there but not there". Their minds would wander away from the child issues that brought the family to therapy. Fathers would ask why they needed to be there because the children were their mother's business. I saw this phenomenon first as "psychological father absence in intact families" but then realized it was about more than fathers. *Anyone* in the family could be ambiguously lost.

The Connection to Complicated Grief

Historically, the idea of ambiguous loss has not been discussed except in the arts where it has for eons been the topic of plays, poems, and paintings. In psychology, only the pathology of complicated grief was mentioned. Today, ambiguous loss is known as a complicated LOSS that causes complicated GRIEF. The lack of closure is a normal reaction to an abnormal kind of loss.

Ambiguous loss theory then provides a new lens for understanding a more nuanced type of loss. Having a name for what one is experiencing allows coping –and grieving– despite unknowing. But meaning and hope can be discovered when families as well as professionals can embrace more fully the imperfections of absence and presence in human relationships.

Article based on Pauline Boss' books:

Ambiguous Loss (1999, 2000-paperback; Harvard University Press)

Loss, Trauma, and Resilience: Therapeutic Work With Ambiguous Loss (2006, Norton)

Loving Someone Who Has Dementia: How to Find Hope While Coping with Stress and Grief (2011, Jossey-Bass).



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Building resilience

Building resilience, personal strengths and hope

Ambiguous loss and grief are integral parts of the dementia caregiving experience. Understanding and getting support for your grief allows you to move forward by making informed choices and taking actions to build resilience, personal strengths and hope that life can continue in a new way.

To restore energy and balance, despite limited time and resources, you can make a variety of positive self-care choices and changes. Stay physically active and eat healthily. Remain mentally active and socially involved. Engage in stress management and relaxation activities. Work with your doctor to treat conditions such as depression, and tend to your spiritual health. Any one, or even a combination of these elements can have a major impact in boosting your overall wellness and resilience.

Listening to positive feedback and comments on your personal strengths from supportive friends and family, Alzheimer Society staff, or peers in a support group can be a powerful confidence and morale booster.

Hope can be renewed each time you make a positive adjustment to the challenges and changes in the person with dementia and your own situation. You may experience tremendous personal growth by taking on new roles and responsibilities, acquiring new skills and knowledge, building new support networks, and finding different ways to connect with a person with dementia.

The profound transformations that occur amid the losses and grief can give rise to new hope, purpose and meaning your life.

“Group support and listening to other people’s stories is the best type of support. You know you’re not alone and you can just let the fears go.” -Marylin, Caregiver.

“My way of dealing with the disease is looking at the cup half full rather than half empty. I look at what my mother can do, instead of what she can’t do. I focus on the skills she still has and accept whatever she is able to do”. -Sharon, caregiver.

Strategies for living positively with ambiguous loss and grief

- Reflect on the losses that occur in the life of the person with dementia and in your own life as well. Acknowledge, express and share the grief you feel in response to those losses with a person or people whom you know will be supportive and understanding.
- Stay connected to family and friends, enhance existing relationships, and be open to building new relationships with others who can be supportive and enhance your life.
- Look after your own needs. Stay physically active, eat as well as possible, and do what you need to relieve stress. Take breaks from care. It is vital to your health and morale, and will help you to make better decisions and be more effective as a caregiver.
- Let your family and friends know how they can help, rather than assuming people know what you need.
- Seek out information about dementia and what to expect. Talk to others who are caregivers at different stages of the journey. This knowledge gives caregivers more ideas and information about how best to cope with the disease and plan for the future. Consider attending a support group.
- Seek out support from family and friends, professional organizations such as the Alzheimer Society or other professionals.
- Share advice from your own experience and contribute by helping others in a similar situation. Become a volunteer or advocate for people with dementia and other caregivers.
- Express grief in creative ways through writing, painting, photography or other art forms.
- Recognize and value your growth as a person, which resulted from caring for a family member with dementia. You may have learned new skills, such as handling finances, becoming more compassionate, or developing an inner strength and resilience that you may not have realized you had.

Dealing with guilt

As a caregiver, you are likely to feel a wide range of emotional responses to your situation –both positive and negative. This is because, although caring can be very rewarding, it is also hard work and can be extremely stressful. Some of the emotions that arise, such as frustration and anger, are healthy responses to challenging circumstances. They can be useful, helping people to move forward. But other emotions, such as guilt, can be more difficult to deal with, and leave people feeling powerless or “stuck”.

While each person’s experience is different, guilt can be a very tiring emotion, consuming energy that you need for other tasks. If you have identified that you have feelings of guilt, you have already taken the first step towards addressing these feelings. The next steps are to:

- Work out where these feelings come from;
- Realise that you are not alone in feeling this way;
- And find ways to develop a more positive attitude and to be more forgiving of yourself.

Circumstances that often lead to guilty feelings in caregivers

Other caregivers seem to manage better than you do

Meeting up with other caregivers at support groups or reading about other people’s experiences might lead you to believe that other caregivers are coping much better than you are. You may feel guilty because you feel you haven’t matched up to your own expectations, or to the expectations that you believe other people have of you.

Remember that it’s alright to make mistakes –no one can get it right all the time. There is no such thing as the “perfect caregiver”, and it’s important not to be too hard on yourself.

Are you being realistic about what you can achieve?

If not, can you reduce any of the expectations you have of yourself, or get any more help? This help does not need to be from specific services.

Sometimes just letting family and friends know how you feel may give them the opportunity to help out.

How you treated the person before they were diagnosed

Many caregivers feel bad about how they behaved towards the person before they were diagnosed with dementia. You may have reacted with irritation or criticism, or you may wish that you had made more of

the time you spent with the person when they were well.

Try to remember that everyone gets frustrated with their partner or family member from time to time. You were not to know that they had dementia and you could not have foreseen what the future held.

Dementia can have a profound effect on a person’s behaviour and without advice or guidance this can be very difficult to understand.

It may help to keep in mind that although you can’t change what happened in the past, you can still affect how the person you care for feels today.

You sometimes want time for yourself

You may feel guilty about having time to yourself. If you still enjoy things that you used to share with the person you are caring for, you may feel that you are being disloyal.

Everyone needs to recharge their batteries now and again, and it’s very important for caregivers to enjoy some time away from their caring role. Many caregivers find that giving themselves some time apart, and doing things that make them feel happy and positive, makes them more able to fulfil their role. This can improve their relationship with the person they are caring for.

If the person you are caring for can’t be left alone, ask friends or family if they can fill in or get connected with respite options in the community.

You feel you shouldn’t be accepting help

Many caregivers feel that they should be able to manage without any help. You may worry that the person with dementia will be distressed if you are not there all the time.

Looking after a person with dementia can be exhausting. You may be able to free up some valuable time by accepting respite care or a service like a day program. This will give you more energy and may enable you to go on caring for longer.

Even if the person with dementia is initially upset about others becoming involved, they may well come to terms with the idea. The first experience of separation often makes caregivers feel guilty and unable to relax, but in time you will probably both get used to it and see the benefits it can bring.

This information was provided courtesy of the Alzheimer’s Society UK

Ontario taking action to protect people with dementia

Alzheimer's safety campaign a step in the right direction



The Ontario Government, in partnership with the Alzheimer Society of Ontario, is launching a groundbreaking multicultural safety awareness program for people with dementia who may go missing. Finding Your Way, a new wandering prevention program funded by the Ontario Government, will help prevent people with dementia from “wandering” and going missing, and also help care partners and other family members prepare for such incidents, if they occur.

Nearly 200,000 Ontarians have dementia, an increase of 16 per cent over the past four years. By 2020, nearly 250,000 seniors in this province will be living with some form of dementia. Statistics show that three out of five people with dementia go missing at some point, often without warning. There is greater risk of injury, even death, for those missing for more than 24 hours. Having a plan in place and knowing how to protect the individual is a must for care partners.

The Finding Your Way safety kit contains information to help families create personalized safety plans. The kit includes:

- An identification kit with space for a recent photo and physical description that can be shared with police in an emergency
- At-home safety steps to help prevent missing incidents from occurring
- Steps to safeguard a person with dementia, such as using the Alzheimer Society of Canada’s MedicAlert® Safely Home® program
- Tips on what to do when a person with dementia goes missing and when reuniting after a wandering incident;
- The latest information on locating devices.

Information sessions	Date, Time & Location
Caregiver stress <i>Learn how you can cope</i>	Presentation by the Canadian Mental Health Association Monday, April 29, 2013 from 5:00 to 6:30pm Cost \$10 –Cornwall
Driving <i>Coping with changes and creating a plan</i>	Wednesday, May 8, 2013 from 1:30 to 3:00pm Cornwall
Understanding Alzheimer’s disease and related dementias	Tuesday, May 28, 2013 from 6:00 to 7:30pm Cornwall
When is it time to consider Long Term Care?	Tuesday, June 4, 2013 from 2:30-4:00pm Cornwall

REGISTRATION IS REQUIRED 613-932-4914 ext. 202

Mental illness and dementia

Mental illnesses (like schizophrenia, depression, bipolar disease) are disorders of the brain. So is dementia.

Disorders of the brain can cause problems in one or more of the brain's three main functions: how we move, think and feel. In the case of dementia, it is "cognition" -the thinking, knowing, problem-solving and judgement function of our brain –that is primarily affected.

Dementia and other mental illnesses share other important similarities:

- The family doctor is usually the first health-care professional that people see for help.
- People with dementia often experience depression, a psychiatric condition.
- People with dementia may face stigma, which involves isolation, disengagement and susceptibility to discrimination.

Mental illnesses, including dementia, tend to arise out of many complex factors:

- Genetic make-up (what you were born with);
- Biological (physical changes in the brain);
- Psychological factors such as problems with coping or self-esteem;
- External social and environmental factors (like isolation).

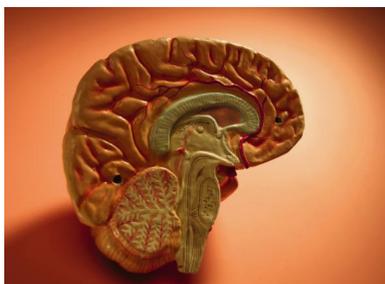
Can we do anything about it?

Information on understanding risk factors and ways to protect the brain is growing.

Risk factors can include high blood pressure, heart disease, history of traumatic brain injury or depression.

To protect the brain, it is important to eat well, exercise and stay socially and mentally active.

Can a person with dementia or other mental illness have good "mental health"?



A person diagnosed with a mental illness can maintain strong mental health. For example, a person with Alzheimer's can prepare for the disease, develop a

reliable support system and participate in meaningful activities to improve mental health and make the journey with dementia easier.

Why should we talk about dementia as a mental illness?

The barriers faced by people with dementia and other disorders of the brain are similar. Talking about dementia as a mental illness:

- Reduces stigma;
- Unites efforts to advocate for better diagnostic, treatment and support options;
- Gives health-care professionals common focus to improve the behavioural and psychological problems associated with mental illness, including dementia;
- And strengthens the research focus to improve understanding of causes and cure.

We know that education and prevention are critical. Good mental health combined with a physical and socially active lifestyle and a healthy diet helps reduce the risk of dementia and slow its progression in people who are already diagnosed.

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 Friday, April 26, 2013 at 6:30pm
 Knights of Columbus Hall in Cornwall
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- **Mother's Day Tea in Alexandria**
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 \$20 per ticket (613-525-4722)
- **Annual Golf Tournament
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