

## Situational Loss

**Wherever there is adversity, there is situational loss™. For those caring for a chronically ill family member, there are a number of losses stemming from the adversity of declining health status.**

Gilda Spitz, as an only child, was a dedicated primary family caregiver for her beloved father, Sam Schein, who has since passed away after a long battle with Alzheimer's disease. She had no siblings to assist but had a supportive spouse, Peter. Gilda attended a support group that I facilitated and would on more than one occasion relay her observation that, even in families where there was more than one child, the care demands often fell upon one of the siblings to take on the primary caregiving role, often without receiving any support from siblings.

After her father passed away, Gilda, a writer by profession, proceeded to write a blog, a series of articles created in his memory, containing a historical account of her father's illness. Following is an excerpt from Gilda's blog, *Sam's Alzheimer Highway* that follows the decline over the years.:

Is a picture really worth a thousand words?

Over the past year, many people have asked me how long my father had suffered from Alzheimer's Disease. There are actually two answers to that question: almost six years or almost thirteen. Why? Because it depends on whether I count from when he was diagnosed, or when symptoms began to appear.

Little did we know how long the disease had been secretly progressing on Sam's Alzheimer highway. Just by looking at him, you certainly couldn't tell.

1997 The first clue occurred seven years before diagnosis and over twelve years before his death.

...In 1997 my friend Karen had asked Sam to officiate at her son and daughter's combined Bar /Bat Mitzvah, and he had agreed. But when I called him the day before the big event to make arrangements to pick him up, he informed me that he had made other plans – and he really didn't care that he had left my friend in the lurch or embarrassed me.

I was furious. His lack of courtesy was totally foreign to his normal personality, but it never occurred to me that there was a particular reason for his rudeness. That incident was probably our earliest sign that something was seriously wrong.

But just looking at him, you never would have known. Here's a photo of Sam with our son Adam around that time, looking perfectly normal.



2000 Three years later, there was a second big sign. Sam was at fault in an automobile accident and was utterly unable to describe what happened. He hadn't been injured, but he couldn't remember where the other vehicle came from or which side of his car had been damaged. At the time, I attributed his confusion to simple shock, but I didn't pick up on the big clue.

Again, it would have been impossible to guess at the true story by looking at him. Here's a photo of Sam taken that same year with our son Bryan, still looking like his old self.



2005 Even a year after diagnosis in May 2004, Sam still looked like his normal self. True, he was now walking with a walker, and true, he couldn't tell you what he had for breakfast. But he could still sing all his Hebrew and Yiddish songs, pray at Sabbath services on Friday afternoons, and carry on normal conversations during visits with his family. And he was still his cheerful self in this photo with my husband, Peter.



2006

But a year later, the disease that had slowly been wreaking havoc on the inside for almost ten years was starting to make itself visible on the outside. In this photo, there was a vagueness in his eyes that we had never seen before.



The following summer, the physical changes were even more dramatic. Sam was now refusing to wear his dentures, which significantly changed the shape of his face, and had progressed from walker to wheelchair. And he could no longer respond to requests to smile for, or even look at, the camera.



There's an old saying that a picture is worth a thousand words. Is it true? With Alzheimer's Disease, only after many years of stealth attacks behind the scenes.

The pictures showing the changes in Gilda's father, Sam as the illness progressed are more telling than a thousand words, portraying the debilitating effects of a progressive nonreversible neurological illness. The visual changes show that a gradual situational loss was occurring, with Gilda and her family witnessing as the disease slowly robbed Sam of his functioning ability. It can begin insidiously with unusual behavior such as when Sam did not show up to sing at the friend's bar mitzvah, leaving Gilda angry, disappointed and baffled. At that time, the behavior was not associated with the slow decline due to a cognitive illness. Slowly the cognitive decline affected Sam's ability to remember, communicate and walk, altering his personality, appearance and ability to carry out activities of daily living like dressing and bathing.

It was distressing for Gilda to witness her father's disease progressing while managing his care. However, Gilda was not in a state of "distress," the term used by the Canadian Institute for Health Information (CIHI) in research they conducted to identify family carers who were unable to meet the care demands. They identified caregiver distress as "the overall impact of physical, psychological, social, and financial demands of caregiving." Although recognizing the impact of the care demands, the CIHI made no mention of the impact of the losses that the family members experience. Not only are family members, like Gilda, facing the challenges of the care demands, they also face the challenges of the losses that tug at their heart strings.

In healthcare, the focus is predominantly on those who are ill and require care. It is, then, not surprising that the caregiver strain gets associated more to the high care demands than the grief that impacts from the situational losses caregivers experience.

Situational loss is the loss of a person, thing or quality, resulting from alteration of a life situation, including changes related to – in addition to death – illness, body image & environment.

The definition of situational loss™ fits well, describing the circumstances where caregivers experience loss related to their family members' "illness," "body image," and "environment." For instance, changes in environment would include living arrangement such as moving to assisted living or into long-term-care. The definition also includes everything that could possibly be lost. In addition to losing the "person," there are "things" and "qualities" that are lost as well. In addition to losing her parent to the illness, Gilda lost freedom due to the time required to provide care. She lost communication and the pleasure of hearing her father sing. She also lost the quality of a close, loving relationship, especially in the latter stage when Sam became distant like a stranger.

*Acknowledging* her situational losses, Gilda once blurted out to her father while visiting him at the long-term-care home, "I miss you!" receiving no response from the man who had thought the world of her. Despite his physical presence, the father Gilda knew and loved was no longer present.

The combination of the loss experience and providing care can take its toll. While experiencing situational losses that tugged at her heart strings, Gilda had to make difficult decisions on her father's behalf, such as moving him out of his home into long-term-care.

Gilda's account of her father's progressive illness also brought to light the reality that, in the early to middle stage of the disease, afflicted individuals can live their lives with the illness going undetected and undiagnosed. It is often close family members who first notice and experience the loss due to changes such as missed medication doses, forgotten medical appointments or getting lost in familiar places. Additional strain is put on family members when they *acknowledge* and *assess* loss that no one else *acknowledges* and *assesses*. In cases like this, the loss can remain ambiguous.

Ambiguous Loss is a loss that is not clear. One type of ambiguous loss is physical presence and psychological absence. The person you care about is psychologically absent – that is, emotionally or cognitively missing. Such ambiguous loss can occur from Alzheimer's disease and other dementias; or physical illnesses that take a loved one's mind or memory away.

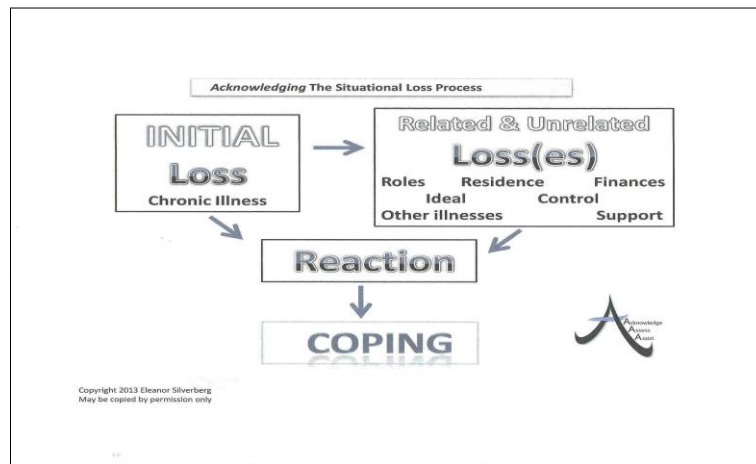
*Pauline Boss*

Individuals with illnesses such as Alzheimer's, Parkinson's, Acquired Brain Injury, and Schizophrenia have not died. They are changing while still physically present. "He or she is here but not here." The awareness of what is happening in the early stages may be different from one family to the next. For instance, in some families, the adult children may be *acknowledging* the loss of a family member to illness and bring it to the attention of the parent who is living with the ill family member but not *acknowledging* it. Another scenario is when the spouse living with the ill person *acknowledges* the loss but the adult children who are not living with it do not *acknowledge* it.

*Acknowledging, assessing and assisting* through situational loss helps in raising awareness, unmasking and clarifying unclear losses, removing the ambiguity by associating reactions to life-altering situations related to illness. It is difficult enough just to be experiencing loss without having others not *acknowledge* that loss is occurring.

Equally important to *acknowledge* is that family members are required to cope in order to provide care despite the high care demands and the reaction to situational loss. It would be of benefit to *acknowledge* the losses, *assess* the reaction and *assist* if required in order for family care providers to be able to cope.

The diagram of the situational loss process below shows that coping in the caregiver role is affected by the losses experienced and the reaction to the losses.



The flow chart illustrates the situational loss process with the illness identified as the initial loss. Losses stemming from the illness are identified as subsequent losses. There is a reaction that family care providers experience to both the initial and subsequent situational losses that can impact on their well-being and ability to provide care. Many of the losses include “things” and “qualities” related to what the chronically ill person represented, and the effects of the illness on the caregiver. Past losses that have not been resolved may resurface as well.