

Caregiving *with* Strength

Raising Self Care to New Heights

By Acknowledging the Losses

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INTRODUCTION

Family caregivers of the chronically ill are at risk of becoming ill themselves if they do not maintain their resiliency. They are providing care while witnessing the debilitating changes occurring due to the illness, which can unquestionably result in a depletion of the family caregivers' energy and well-being. The health risk to caregivers is the reason they require a strength-building regimen for maintaining their resiliency.

I invite you into this cocoon that is in the form of a book offering potential personal growth and strengthened resiliency. A cocoon is the protective silk covering that caterpillars make in their growth stage prior to transforming into a butterfly. This book serves a similar purpose, providing a strength-building regimen that can potentially empower you – as a care provider – to transform your thinking, attitude, and behavior. Pertinent elements of the regimen serve to prevent burnout and allow for optimal functioning.

The juggling regimen for building strength involves the elements of care provision, self care, and grief facilitation.

Processing loss and grief is presented as a pivotal element of the regimen, featuring an approach that I developed to specifically address caregiver loss and

grief. The components of the approach entail *acknowledging* the losses, *assessing* impact, and *assisting* strategies in order to strengthen well-being and ability to provide care.

On a personal note, my interest in the topic of grief emerged during my academic years in university. Where did this curiosity about grief come?

My parents were Holocaust survivors...

Being a child of Holocaust survivors, it was difficult, as a young child, to understand my insidious exposure to the impact of the trauma that my parents survived, the extermination of six million Jews. Practically all of my mother's and father's family members, including their parents, perished in the Holocaust. As a young child, I was disheartened because I did not have grandparents, and I was unable to grasp the reason that I did not have grandparents.

I experienced this traumatic loss as a second-generation offspring growing up in an environment where the Holocaust was not spoken of, but I felt the remnants of the situational loss and embedded grief in every corner of our home. As an adult, I now marvel at my parents' ability to carry on with whatever energy they could muster, to bring up my brother and me after what they had lived through. Also I understand that it was my brother and me who gave them strength to build a new life together.

Dr. Judith Kestenberg, one of the most prolific psychological writers of the Holocaust, was sitting

on a panel at a Holocaust conference. A member of the audience asked, “When you consider the multiple murders within families, physical annihilation of communities, persecution, uprooting, loss of a whole way of living and everything precious, how can survivors ever grieve all this? Is it not an insult to even expect them to go beyond the Holocaust?” Dr. Kestenberg replied:

It may be for the subsequent generations to grieve...

Such is the case in my experience where I believe the transmission of grief began at a young age. I was especially sensitive to my mother who was emotionally affected by the Holocaust, shedding tears but not willing to speak a word about it. The lack of communication and my young age made it very difficult to understand that I was reacting to a trauma I personally did not experience, thus demonstrating the complexity of grief.

Over the years as an adult, I have worked through the pain and have come to a place of peace. I am not looking for closure, accepting that closure is not attainable. Rather, I realize that I will continue living with a lingering grief – at times more intense than others – that has played a part in shaping me into who I am today.

That is my grief story...

It was my personal history that prompted me to study grief academically and continue to study it independently. Professionally, I apply a grief

approach in my social work practice. One might assume that I would seek out work that involved grief counseling. My interest, though, is in loss and grief that are not death-related. I pursued another interest, going into mental health counseling, practicing from a loss perspective. I could see loss in each client's situation and a large part of the counseling they received included addressing that loss.

For many years, I was a community outreach social worker, assisting families in dementia care. In addition to professionally drawing from a strong academic grief background in *assisting* the family caregivers, I could also draw from personal experience, having been the primary family caregiver for my father, Hershel Silverberg. As though Hershel had not lived with enough torment in his life, having lost a wife and two sons in the Holocaust, my father spent his last four years going through another "living death" after receiving a diagnosis of dementia.

I found it particularly "gut-wrenching" to move my father out of his "pride of ownership" home into residential care. The day my brother, Jerry and I moved my father out of his home into residential care was one of the hardest days of my life. After several months, Hershel settled in. Nevertheless, my guilt feelings remained as I witnessed my father's decline, feeling that in some way moving him out of his home caused the decline.

For nearly a year, I lived with the uneasiness and guilt until one day I spoke with a gentleman who

knew Hershel as an acquaintance. I do not even know his name but this gentleman changed my thinking. I recall him saying to me with conviction, “Do you really think you made that decision? If your father was healthy, he would never have moved into the residence. He made that decision, not you!” Regardless whether his words were fact or fiction, I no longer felt guilty, which demonstrates that you never know where your *assistance* is going to come from!

Assistance is a component of the 3-A *Intervention and Self Monitoring Approach* that I developed to raise grief awareness and fill a gap in addressing the loss and grief that individuals experience while caring for a family member who has a progressive neurological or chronic mental illness. The components – *Acknowledge, Assess, Assist*® – are empowering tools that can be applied by family caregivers to address their losses and by professionals for providing compassionate, empathic intervention with family caregivers. There is a benefit for both family members and professionals to apply the same approach, allowing them to “speak the same language.” Better communication between the professional and the family caregiver assists in strengthening resiliency, better relations, and collaboration in treating the care recipient. Since the ongoing care for individuals with a chronic illness is largely carried out by the family members, applying the same approach serves to include the family caregivers as part of the health care team.

This cocoon in the form of a book is also available for professional caregivers who are not immune from grieving for the people they care for. The professionals may include nurses, personal support workers, social workers, social service administrators, and others who can get affected by the illness of their patients and clients. Many professionals also work double duty, caring for a chronically ill family member at home.

Loss and grief is experienced frequently by those working in long term care homes where they witness progressive losses on a daily basis and death is a regular occurrence. Rituals, such as funerals, are performed as a way of collectively *acknowledging* and *assisting* through death-related loss. Following is an account from one of my workshop attendees, the manager of a long term care home about a ritual that was created to *assist* the staff through the losses they regularly encounter:

Acknowledging caregiver grief is so important. In Long Term Care we have some residents for a long time before they die. Staff become very close to these residents. When a resident dies, staff were not given time to grieve the loss. Room cleaned and new resident admitted. Often staff were “angry” at the new resident. We have learned many lessons over the years and staff are now given the opportunity to have grief *acknowledged*. A picture is posted in Homes in a designated spot as an in memoriam. The bed is made and a rose is placed on the pillow. For the new resident coming in, this is a nice touch. For

the staff, it is a memory of the resident who dies. We also use a dignity quilt which is handmade to cover the body as it leaves the Home. By *assessing* how to *assist* the staff, we have managed to *acknowledge* everyone's grief.

Bobbie, Extencicare

This account demonstrates a means of addressing grief through rituals. There are several caregiver accounts and different scenarios in this cocoon which hopefully serve to help provide an understanding of the loss and grief facilitation process for family care providers. The accounts and scenarios will also provide more insight into the other elements of strength building – responsible caregiving and self care. Based on consent, the names used may or may not be real. In each section, I refer to several resources which can be found in the references at the back of the book.