

When End of Life Care is Ongoing:

Assisting Families to Transform from the Embedded Grief by Eleanor Silverberg

Contributing Chapter to *Journey's End: Death, Dying and the End of Life*

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How do we endure an “ongoing funeral” or “living death” while caring for a family member stricken with a lengthy, progressive, debilitating illness such as Parkinson’s, MS, ALS, Acquired Brain Injury, Alzheimer’s/Related Dementia, etc? We often hear that to endure and maintain resiliency, it is best to keep up a healthy lifestyle which includes a good diet, rest, education, and utilizing available supports. What we do not hear often is about the series of losses that family care-givers experience while on the end of life path. These losses can impact their well-being, affecting their ability to carry out the care-giving role. Making conscious effort to *acknowledge*, *assess* and *assist* in addressing the losses and grief can contribute towards moving forward with strengthened resiliency.

Experiencing the “living death” and “ongoing funeral”, caring for a progressively ill family member raises other questions as well. When does End of Life Care begin? Does it begin years prior to the actual physical death? If this is the case, when does the grieving process begin for the families providing care, travelling on the path alongside those afflicted?

It is prudent to start early in addressing the family member’s loss and grief stemming from having a chronically ill parent, spouse or child. Processing the grief from situational losses that stem from the illness plays a big part in strengthening resiliency. The grief can easily get overlooked since the losses are ambiguous and the grief is disenfranchised, buried under the care demands. Overlooked also due to the fact there has not been a physical death.

We live in a culture where grief is automatically associated with death. In addition, our tolerance of grief is low. Tears and emotional display are discouraged, considered a weakness and many people are uncomfortable with it. We are expected to “move on” shortly after the death. As a result, the emotional turmoil brought on by loss gets easily buried and repressed.

If the grief experienced following a death is only *acknowledged* as a brief encounter, how can the disenfranchised grief that caregivers experience get any *acknowledgement*? It can be detrimental to possess such a narrow perception of grief since there are so many circumstances of loss that are not death related – loss of a job, a relationship, finances – all of which can also occur stemming from the loss of family members to chronic illness. By broadening our perception, we gain access to the tool of grief intervention. Intervention entails processing the grief can bring back the hope and faith that may have been lost due to the struggles being faced.

In order to *assist* in raising awareness and addressing caregiver grief, Eleanor Silverberg developed the 3-A Approach: *Acknowledge, Assess, Assist*. These components operate simultaneously in identifying the losses, grief reactions and coping behaviors. By being cognizant of the loss context, one can intervene using this approach to work through it, *assisting* caregivers or ourselves as caregivers to make the changes required to move forward with strengthen resiliency and well-being.

There are three guiding assumptions related to applying the 3-A Approach. The first assumption is the notion that wherever there is adversity, there is situational loss. The situational losses begin from diagnosis or the time when the adverse symptoms are noticeable. According to the Mosby's Medical Dictionary (9th Ed.),

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 and environment.

As family members, we are experiencing the loss of a significant person's loss of health and the implications that go along with this including loss of the role that the afflicted will no longer be able to play in our lives. As adult children, we may be impacted from losing the parent who always gave wise advice or the parent who traditionally hosted the holiday get-togethers. With the driver's license being taken away, we, as spouses may lose our time and freedom for other activities replaced with new chauffeuring duties. A quality that is lost in many chronic illness situations is loss of control in making it all better. The future loss of residence, moving into long-term-care can be an issue as early as the time of diagnosis when families commit to always take on the care and keep the care recipients out of a long-term-care residence. Making such a commitment is easy to do early on in the illness when the care recipient is high functioning, becoming increasingly more difficult as the illness progresses which can be years later after the caregivers' energy has been depleted.

The second guiding assumption of the 3-A Approach is that grief is a reaction to situational loss. Grief processing is a means of coping with the adversities and addressing the losses. A n issue with processing grief is that getting to the light often requires going through a long, dark tunnel of grief symptoms that are painful, often uncomfortable to bear. We may be crying daily, feeling sad most of the time, agitated, withdrawing socially. Since the symptoms stem from the illness that is ever present with losses faced daily, the remedy is not a quick fix. We generally tend to be more attracted to remedies that offer a quick fix. In order to cope, it is not unusual for family caregivers to resort to medication such as anti-depressants prescribed by their doctor. It does get the job done of relieving symptoms brought on by the care demands and the grief. Also, this course of action fits well with our emotionally restraining culture.

If a quick fix of symptoms is available, why should we even bother taking the painful, slow route of processing the grief? Just consider that while the quick fix dulls the pain, dulling the pain also lowers the chances of validating and dealing with what has caused the pain. The pain would commonly get attributed to the care demands. If the losses are not *acknowledged* and *assessed*, grief processing does not even get considered as a treatment option. In this article, awareness of the losses is being raised with grief processing presented as a treatment option

Providing the care for family members afflicted with a progressive chronic illness is on its own 'grief work'. Taking on the care-giving role is a form of instrumental grieving - a means of problem solving, taking action in response to adversity – like a funeral ceremony and burial is arranged after a death. On the online radio program, *Instrumental Grief and Caregiving*, Dr. Kenneth J. Doka, who contributed in devising the term in the death context, explained that after a

death, there are family members who “feel” the grief intuitively and/or “do” the grief instrumentally through taking action and problem solving. He goes on to describe the “doing” action of instrumental grieving as perhaps taking on the funeral planning or setting up a scholarship fund.

Similarly, instrumental grieving has been brought into the care-giving context through the application of the 3-A Approach components. *Assistance* is provided when there is conscious *acknowledgement* and *assessment* for spouses or adult children to dutifully transition from their spouse/daughter/son role prior to the illness into a care-giving role. This transition is an instrumental means of taking action and addressing the losses. They are carrying out instrumental grieving assuring that, on a positive note, the best possible care is provided. It is a form of *assistance* in that they are maintaining whatever control they can have in a situation that is for the most part out of their control.

The third guiding assumption of the 3-A Approach is the reason for raising grief awareness, and insights such as the notion of caregiving as instrumental grief work.

There are potential benefits of grief processing such as personal growth and strengthened resiliency.

Taking the path of grief processing provides us access to *assisting* strategies that specifically address situational loss. One such strategy is partaking in rituals. In death-related circumstances, the funeral ceremony is a ritual that helps the mourners through the loss. Religious groups have their own respective rituals. For instance, in the Jewish tradition, there is the Shiva, where the immediate family gathers together for seven days after the death. They do not partake in any of their regular day to day activities. The Shiva is an opportunity for self-introspection, for friends and extended family to visit, provide comfort and pay their respect.

Since the losses are commonly overlooked, there are no defined rituals to soften the situational losses involved while caring for a family member with an ongoing chronic illness. Therefore, rituals can be created to accommodate the situation. For instance, Mr. J developed Parkinson’s while he was employed. As the disease progressed, he had to stop working which created a financial situational loss. Mr. and Mrs. J had to downsize to an apartment. Moving unwillingly out of the home where they raised their children, with over 30 years of memories was difficult for them. As a ritual to *assist* in moving them forward, they made a family dinner in the house prior to leaving. The gathering gave them each the opportunity to talk about the memories they had while living there.

The objective of grief processing is to resolve, potentially providing the peace, hope and meaning that is so often sought. Restoring hope and meaning allows for us to move forward stronger in carrying out the important care-giving role. The rewards are genuine in working through the many losses that occur stemming from having a chronically ill family member, many of which we may have not been consciously aware of.

In the book, *Caregiving with Strength*, restoring hope and meaning is expressed as relevant, relayed through the monumental work of Victor Frankl, *Man’s Search for Meaning*. Frankl tells

his, true, compelling story of survival, finding hope and meaning while being imprisoned in a concentration camp during the Holocaust years. His words can ring true for many difficult circumstances: “When we are no longer able to change the situation, we are challenged to change ourselves.”

Restoring hope and meaning was also a theme in the Mayo Clinic’s article *Use Grief over Alzheimer’s Loss to Transform Yourself*. An important message was relayed in this article:

Grief is the most powerful resource for human transformation.

Each of us has the opportunity to transform our grief, yet the transformation does not come without anger, pain, loneliness, and sometimes terror. I see this transformation unfolding when caregivers begin to work on what they can change and begin accepting what they can’t.

I observe a shift in caregivers from “saving” their loved one to finding hope and meaning in other ways. This may be in discovering creative ways to offer the best care they can to be fully present with their loved one, and finding joy in everyday happenings. Others discover qualities about themselves they didn’t know they had, including patience, resilience and even humor in the most challenging of situations. Some caregivers find ways to help others who are experiencing similar pain or advocate for laws that support persons with Alzheimer’s disease and their families.

The key I believe is to avoid feeling helpless. With incredible tenacity, many caregivers transform a heartbreaking situation into one of hope and meaning.

Restored hope and meaning can provide a tremendous amount of strength to families. *Assisting* with grief intervention strategies can as well. The loss and grief process starts early for those of us who have family members with progressive, chronic illness. The journey can be a long one. *Assisting* by *Acknowledging* and *Assessing* the situational losses and grief reaction along the way is important so that we are consciously aware in providing *assistance*. Transforming from the “ongoing funeral” and “living death” allows us to have a stronger quality of life while caregiving and beyond.

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