

Keeping It Together

(K.I.T.)

How to Cope as a Family Caregiver without Losing Your Sanity

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WHAT THE CATERPILLAR CALLS THE END OF THE WORLD,
THE MASTER CALLS THE BUTTERFLY

-- *Richard Bach*

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THE ESSENCE OF *KEEPING IT TOGETHER: A SELF DEVELOPMENT GUIDE* A MESSAGE FROM THE AUTHOR

We can't live with them, we can't live without them. The vital role that family plays in our lives becomes increasingly apparent when a spouse or parent becomes chronically ill. The shortage of human resources in the healthcare system leaves us with most of the responsibility of providing care for a chronically ill family member who can no longer manage independently. We are required, by obligation rather than by choice, to step up and manage the care of serious conditions such as Alzheimer's, Parkinson's, Huntington's disease, Acquired Brain Injury. This is a challenge that no one signs up for. Some appear to take on the challenge willingly. Turning away from what is asked of us is not really an option. For the most part, whether willingly or not, we are most likely to step up with firm commitment to assure our family member is receiving the best care possible. Often at the risk of losing ourselves in the process.

Keeping It Together: How to Cope as a Family Caregiver without Losing Your Sanity is a product of the insight I obtained since writing my first book *Caregiving with Strength*. Both are cocoons, offering refuge to reflect and work towards making change for potential growth. My first book was written for both the family and the professional caregiver. Based on the feedback I received and my continued work with family caregivers, I came to see that you, as a family caregiver require a book that is written just for family caregivers. This book is more practical, intended for you to feel you are being heard, offering appropriate tools and exercises that can be helpful in moving you forward with 'renewed purpose'. It is not intended to replace any work you are doing with your present counselor, doctor or therapist. It may be beneficial, though, share this book's content as you see fit with the professional you're working with.

Some of the many ways in which you provide care includes:

- Shopping for an aunt
- Taking your spouse to medical appointments
- Reminding your grandmother to take her pills
- Paying the bills for your parent
- Assisting with bathing, dressing and feeding
- Providing relief for a caregiver



As our population ages, you will see an increase in the number of people who step into a caregiving role for an older family member living with a chronic and progressive illness. Often this will be by default rather than choice. It may be in small or large doses. Just as there are no two trees that are exactly alike, there are no two caregivers that are exactly alike. Most often, it is an adult child for a parent, a spouse or a parent for an adult child who is taking on the bulk of the responsibilities. The level of care and the impact of caregiving are based on several factors including the care recipient's needs, caregiver's health, whether the caregiver is living with the recipient, and the amount of available

supports. The reference section at the end of this book, provides a resource for you listed under this chapter. It is a short questionnaire that I devised for information purposes entitled 'Am I a Light, Middle or Heavy Weight Family Caregiver?'™. Your responses serve to inform about the weight you are carrying as a caregiver and to help in *acknowledging* that caregiving is work. You may take for granted that the weight from the caregiving can impact on other areas of your life and on your health.

If you have recently started your caregiving journey, this is a good time to be proactive and open to the material presented in this book serving to energize, prevent burnout and identify that you are more than a caregiver. On the other hand, if you have been providing care for several years, perhaps 10 years or more, you may have heard enough, be at your wits end and do not believe that anything is going to help. You may be burning out, feeling trapped without a way out. If you are reading this and *acknowledge* feeling this way, it could be the first step to feeling better. This book can help you but my advice in cases of burnout is to work first at feeling stronger and then go through its content when you feel ready. Depending on how you are feeling, it may be recommended going through it with the support and *assistance* of a qualified professional.

Any caregiver who is open to considering making change for their welfare can potentially reap the benefits in reading this book. We can all learn from Victor Frankl, psychiatrist and holocaust survivor. He made peace with his circumstance living under unbearable conditions in the work camps during World War II. He found meaning and purpose living under those conditions which helped him survive. While in the work camp, he passionately developed his psychotherapeutic method with the objective of sharing it with the world after the war – and that is just what he did. He wrote and published his book *Man's Search for Meaning* in 1946. His strong message relayed that we cannot avoid suffering but we have the choice on how to cope, finding meaning and moving forward with renewed purpose. Frankl died in 1997 but his monumental work and strong message live on: "When we are no longer able to change a situation, we are challenged to change ourselves."

It is my hope that this book can serve you as a family caregiver who wants *assistance* in enhancing your strength, bringing in new life for the sake of your own health and the health of those you care for.

About The Author:

Eleanor Silverberg, BA Psych, MSW, RSW lives in a northern suburb of Toronto, Ontario in Canada, and works as the managing director of Jade Self Development Coaching. She specializes in strengthening resiliency and burnout prevention and recovery for caregivers of the chronically ill. Eleanor can assist you through offering individual coaching in her community or online based on the *Keeping It Together* juggling regimen. The coaching includes training on applying the components *Acknowledge, Assess, Assist*® of the 3-A Approach she developed specifically for care providers. She facilitates groups and is also available for speaking engagements and professional training workshops. This is her second book, the first one being *Caregiving with Strength* in 2014.

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INTRODUCTION

“I am NOT a Caregiver” - a statement I have often heard from those caring for the chronically ill. People caring for family members with progressive illnesses such as Alzheimer’s, Parkinson’s, MS, and Stroke see themselves more as dutiful daughters, sons, nieces, spouses, and so on. Although true, what potentially gets missed is that they have taken on a job that becomes increasingly demanding over time... ..

.... Just as in my first book *Caregiving with Strength*, this book *Keeping It Together* serves its readers as a cocoon 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. In yourdictionary.com, the words used to define a cocoon include ‘protective,’ ‘shelter,’ and ‘safe.’ In our developing years, parents maintained a ‘cocoon’ for us as children, providing food, shelter, and whatever else was needed for us to grow. As adults experiencing painful losses that turn our world upside down, we may regress, requiring comfort and safety, similar to the protection our parents provided when we were children. Like butterflies in their transformation who must break free from the cocoon by their own efforts so they may fly, this book’s content can provide you with refuge, insight and the *assisting* tools so you may transform on your own to a place of enhanced strength.....

You are about to enter a Cocoon for Family Caregivers



Before entering.....

The following are tips to help you get the most from this experience:

1. Enter with an open mind to new ideas.
2. Be willing to consider change.
3. Believe ‘Keeping It Together’ is possible.

THE SELF DEVELOPMENT K.I.T. REGIMEN

The self development regimen for 'keeping it together' is a juggling act of practice elements intended to strengthen resiliency and prevent burnout. The elements include:

- the practice of attending to the person who requires care
- the practice of attending to one's own needs outside of caregiving
- the practice of attending to processing the losses and grief stemming from the circumstances.

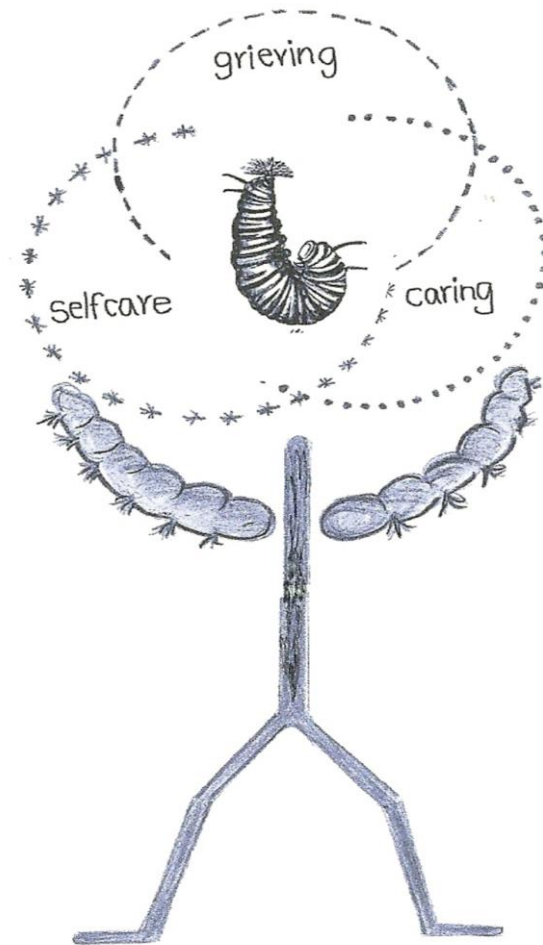
Raising awareness of the role that grief plays is pivotal, especially since research has shown evidence that grief is a major barrier for family members in providing care.

The remainder of this book takes you into the cocoon which is sectioned off by each practice element beginning with grief processing. I use the 3-A's from the 3-A Approach I developed to demonstrate how to address the losses stemming from the illness and to help you cope with the challenges. Throughout the book, Acknowledge, Assess, Assist® are applied as the 3-A tool components for 'keeping it together.'

There is a 4th 'A' being applied as well. The 4th 'A' was initially introduced by Dr. Kenneth Doka in the foreword of my first book, *Caregiving with Strength*. I have seen how helpful it is for family caregivers when they *allow* themselves to just be in the situation they are in rather than fighting it. Those who practice mindfulness are encouraged to be present and *allow* things to be just the way they are. The same is being encouraged now.

In the cocoon, you can unmask any shame due to stigma or painful feelings that make you appear vulnerable. You may be afraid that once you start releasing emotions, you are going to lose it. If that is the case, it is a good idea to have appropriate support as needed. By giving yourself permission, you are giving yourself the opportunity to reap the benefits of this book. It is a strength, not a weakness to *acknowledge*, *assess* and *allow* yourself to *assist* yourself or to seek *assistance* when required for the purposes of strengthening your resiliency and well-being.

I hope you are ready and willing to proceed into the cocoon in the form of a book. Some may be keen while others apprehensive, perhaps uneasy or uncomfortable. *Acknowledge* and *allow* how you are feeling and *assess* for yourself. Take your time and go at your own pace after entering. This book is NOT intended to be a Sunday afternoon quick light read. There are hands-on K.I.T. practice exercises available to *assist* and guide you towards moving forward feeling stronger. You may want to use a folder, binder or notebook to keep your exercise notes together. You may also choose to use your notes as a writing journal. Also, the beauty of this cocoon in book form is that you can refer back to it again whenever you feel the need.



THE K.I.T. PRACTICE OF GRIEF PROCESSING

Where's the grief? Family caregivers carry heavy emotional and physical weight from the care demands, their losses and the grief stemming from the illness. It is easy for the grief to get overlooked - invisible, buried under care demands; however it is beneficial to *acknowledge*, *assess* and *assist* since the embedded grief influences caregiving behavior and the caregiver's well-being.

To *assist* in understanding, the grief is now getting *acknowledged* and *assessed* through the lens of the following underlying assumptions:

- Assumption #1: Wherever there is adversity, there is loss. For those caring for a chronically ill family member, there are a number of losses stemming from the adversity of declining health status.
- Assumption #2: Grief is a reaction to significant situational loss that can manifest and impact on caregiver behavior in different ways. The experience is unique for each individual.
- Assumption #3: There are potential benefits to processing loss and grief, such as strengthened resiliency and personal growth.

.....End of Book Excerpt

