

Grief Toolkit

A resource guide for our community to utilize when assisting others in managing their grief process.



Table of Contents

EXECUTIVE DIRECTOR WELCOME LETTER	3
EXECUTIVE DIRECTOR WELCOME LETTER	3
INTRODUCTION	4
Vision	4
Mission	4
What We Do	4
About this Guide	4
GLOSSARY OF TERMS	5
MODELS OF GRIEF	6
Kubler-Ross Model	6
Four Tasks of Mourning	7
GRIEF MYTHS	8
HOW TO SUPPORT OTHERS	
AS A MENTOR ANGEL & BEYOND	9
How to Listen	11
Language	12
Actions/Activities to Help	13
THE TRAUMA-INFORMED MENTOR ANGEL	14-15
WRAP-UP	16
RESOURCES	17
Organizations	17
Books	17
ACKNOWLEDGEMENTS	18

Executive Director Welcome Letter



Dear Imerman Angels' Community:

The truth is, there is no simple or sufficient way to sum up grief. I would like to provide an allpurpose, full-service guide to understanding, coping and supporting the grief process. But as those of us who have lived with grief know, there's no one-size-fits-all approach.

All of us at Imerman Angels hope this toolkit provides some useful thought starters, ideas and ways to manage through the grief process. Additionally, we believe this guide will help you better support those experiencing grief and loss.

Your feedback encouraged us to create this toolkit. As people impacted by cancer, you experience grief in a myriad of ways. Anticipatory grief, secondary grief and death-loss grief are all complicated issues our community confronts daily. Grieving for tangible things, such as life and body parts, and intangibles, such as body confidence and relationships, are real issues community members feel reluctant to discuss.

As you move through your own grief, and support others addressing theirs, we hope this document provides the same kind of comfort Imerman Angels provides in our peer-to-peer support program. Please let us know if you have thoughts or ideas of how to best support you and other cancer fighters, survivors, previvors and caregivers in their cancer and grief experiences.

Warmly,

Stephanie Lieber Executive Director

Introduction

VISION

Imerman Angels envisions a world where cancer is not a solitary experience.

MISSION

Imerman Angels provides comfort and understanding for all cancer fighters, survivors, previvors and caregivers through a personalized, one-on-one connection with someone who has been there.

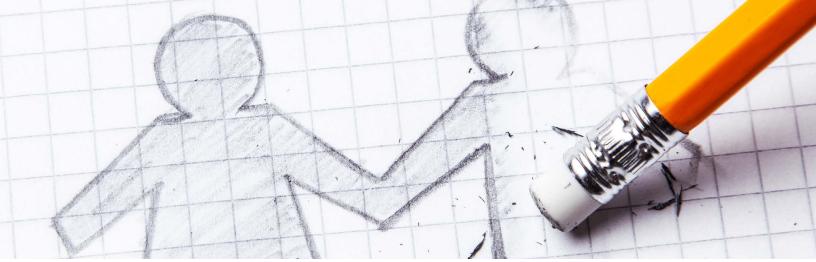
WHAT WE DO

Through our unique matching program, we partner anyone, anywhere and any cancer type seeking support with someone just like them – a "Mentor Angel." A Mentor Angel is cancer survivor or caregiver who has faced the same type of cancer and provides a light in the dark room of cancer.

These one-on-one relationships give a cancer fighter, caregiver or previvor the opportunity to ask personal questions and get support from someone who has been there. Mentor Angels can lend support and empathy; and help cancer fighters and caregivers navigate the system, determine their options and create their own support systems. Frequently, caregivers experience feelings similar to those of the person facing cancer. Mentor Angels can relate while being sensitive to the experience and situation. Reflect on a time you supported a grieving person in the past. What went well? What questions were you left with?

ABOUT THIS GUIDE

The one-on-one relationship between a Mentor Angel and a Support Seeker is the heart of Imerman Angels. As Mentor Angels you have the opportunity to utilize your experience to support someone as they navigate their cancer diagnois. This role is precious, vital and rewarding. Yet, as you know, the cancer experience is one that can be filled with grief and loss. Our community came to us craving resources for themselves and others as they manage the grieving process. This guide is a concise but powerful tool to assist you in understanding, navigating and processing grief. Throughout the guide you will find prompts that give you quick reflection questions to assist you in your role as a Mentor Angel. Thank you for your service to Imerman Angels.



Glossary of Terms

GRIEF

n. The anguish experienced after significant loss; usually the death of a beloved person. Grief is often distinguished from bereavement and mourning. Not all bereavements result in a strong grief response, and not all grief is given public expression (see disenfranchised grief). Grief often includes physiological distress, separation anxiety, confusion, yearning, obsessive dwelling on the past, and apprehension about the future. Intense grief can become life threatening through disruption of the immune system, self neglect and suicidal thoughts. Grief may also take the form of regret for something lost, remorse for something done or sorrow for a mishap to oneself.¹

MOURNING

n. The process of feeling or expressing grief following the death of a loved one, or the period during which this occurs. It typically involves apathy and dejection, loss of interest in the outside world, and diminution in activity and initiative. These reactions are similar to depression but are less persistent and are not considered pathological. Other mourning reactions may include anger (e.g., toward the deceased for dying); a sense of relief (e.g., that the deceased is no longer suffering); anxiety about the repercussions of losing someone upon whom the bereaved may have depended; and physical signs (e.g., fatigue, loss of appetite).

BEREAVEMENT

n. The condition of having lost a loved one to death. The bereaved person may experience emotional pain and distress and may or may not express this distress to others (see mourning; disenfranchised grief); individual grief and mourning responses vary.

ANTICIPATORY GRIEF

n. Grief that occurs before death, is common among people who are facing the eventual death of a loved one or their own death. Yet, while most people are familiar with the grief that occurs after a death (conventional grief), anticipatory grief is not often discussed. Because of this, some people find it socially unacceptable to express the deep pain they are experiencing and fail to receive the support they need.²

DISENFRANCHISED GRIEF

n. Grief that society (or some element of it) limits, does not expect or may not allow a person to express. Examples include the grief of parents for stillborn babies, of teachers for the death of students and of nurses for the death of patients. People who have lost an animal companion are often expected to keep their sorrow to themselves. Disenfranchised grief may isolate the bereaved individual from others and thus impede recovery. Also called hidden grief.

¹ https://dictionary.apa.org/grief

² https://www.verywellhealth.com/understanding-anticipatory-grief-and-symptoms-2248855

Models of Grief

A note about the stages of grief: The grief process is messy and unpredictable. You may experience all or none of the phases listed below. The stages of grief are not mandatory or linear. They are merely frameworks to give language to the variety of psychosocial phases endured after loss.

KUBLER-ROSS MODEL

Denial

In an effort to minimize emotional pain, the person denies the loss. Everyday reality has shifted and it may take some time to adjust. Denial is our brain's natural attempt to slow down the grieving process and to mitigate feeling overwhelmed.

Anger

Anger is a normal emotion to experience during the grief process. Some may rely on anger as an emotional outlet more than others. Some may find anger to be more socially acceptable than to display true vulnerability but this, in turn, creates isolation.

Bargaining

During the grieving process it is normal to desperately want life to return to "normal." Sometimes people will bargain with their "higher power," for example, "I will quit smoking if you bring my son from war" or "I promise to attend church if I can get my friend back." Bargaining is an awareness of a person's helplessness and inability to change the current reality. It is also common during this time to reflect on your grief, have regret or wish things had played out differently.

Depression

During this time, the brain is ready to begin to process reality. Bargaining no longer feels like an option, and the person is faced with the truth. At this phase the loss feels the strongest emotionally. This phase is difficult, but a natural response to loss.

Acceptance

This phase does not signal the absence of pain, but rather accepting the situation and no longer resisting reality. Sadness can still be present but aspects of denial, bargaining and anger are minimized.

Meaning (later added by David Kessler)

Kessler writes "meaning comes through finding a way to sustain your love for the person after their death while you're moving forward with your life. Loss is simply what happens to you in life. Meaning is what you make happen." Some people have described not being able to "stop" at acceptance but instead wanted to do something positive with the pain they had experienced. This can manifest in many ways: celebrating loved ones through service, donating to causes, renewing personal spirituality, reconnecting to family or supporting others on their grief journey.

> Think about a time you were grieving. Did you move through the phases of grief? Skip stages?



ACCEPT THE REALITY OF THE LOSS

Although many people intellectually know they are experiencing loss - and can make arrangements to deal with the loss - they have not accepted it emotionally or spiritually. Example: A person loses a beloved pet and arranges for the pet to be buried. Months later the person sees a dog park and momentarily forgets their pet has passed. This person has gone through the motions of their pet passing, but has not fully accepted that they are no longer present. Acceptance is not easy or simple. Each day you must build a "new" normal. People shift internally and externally after any type of loss. As the person embraces and creates new routines, frameworks and expectations they will begin to accept the loss.

PROCESS THE PAIN OF GRIEF

Grief must be processed emotionally, intellectually, physically and spiritually. There is no set timeline on how long it takes for someone to grieve. It is important to process grief with your support system and, in some cases, with a mental-health provider or support group.

Four Tasks of Mourning³



READJUST TO THE WORLD POST LOSS

Adjustments can occur both internally and externally. Externally, a person may remove or add items into their home to aid in acceptance. Internally, a person will need to adjust to their identity. Spiritually, a person will need to make meaning of the loss. Mindfulness, or the act of being singularly focused on the present moment, can assist in being present and attune to your needs (see page #13).

FIND A BALANCE BETWEEN HONORING THE LOSS AND MOVING FORWARD WITH YOUR LIFE

In the process of grief, it is vital to find a balance between honoring what you have lost and pushing forward to your new reality. Honoring what has been lost can aid in the grieving process and help bring parts of the past into a new reality. For example, this could be purchasing a ring to remind someone of the person they were and who they are today, or after someone has passed, doing something they loved on their birthday to honor them. Connection to others and sharing in memories is beneficial to finding balance.

3 Worden, J. W. (2009). Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner, Fourth Edition, Springer, N.Y.)

Grief Myths

GRIEF IS A SIGN OF MENTAL ILLNESS

Grief is a healthy response to the loss of something you love. It is a symbol of how much you cared and is part of the natural healing process to adjust to your new reality. Grief can become "complicated" when it is denied or avoided. In these instances, the grief process can cause depression, anxiety, etc.

THE STAGES OF GRIEF ARE LINEAR

When the Kubler-Ross model was originally formed, it was built in a linear fashion. We now know that the stages of grief can vary some people may begin with bargaining or depression. Others may skip certain stages. The stages of grief are designed to give language to a healing process, as opposed to something to track or follow over time. In addition, grief can emerge again several years after a loss.

ONCE YOU HAVE ACCEPTED THE LOSS, THE GRIEF CYCLE IS OVER

There is no timeline for grieving; some people will experience a level of grief for the remainder of their lives. Grief does not go away for everyone, but rather it changes and dulls over time.

"I'VE NEVER GRIEVED"

If a person deeply cared about what was lost, they cannot avoid grief. People can repress or ignore their grief temporarily but grief will reemerge if there is no space to cope.

YOU CAN ONLY EXPERIENCE GRIEF WHEN SOMEONE HAS PASSED

Whenever a person loses a part of their everyday life, they grieve. Yes, this can be a person, but it can also be your hometown, a piece of your body, a friendship or even an image you had in your mind of how life would be.

GRIEF ISN'T JUST FOR DEATH. IT'S ALSO FOR:



Friendships that have ended

2

Losing your community

3

Missing the certainty you once had

4

Questioning your judgment

5

Releasing who you once were

6

Feeling lost and unanchored

7

Losing traditions you loved

How to Support Others As A Mentor Angel & Beyond

Your commitment to serve as a Mentor Angel and share your experience can create support, connection, guidance, and hope for someone on their cancer journey. There is a line between the support a Mentor Angel can provide and what a mental health professional can provide.

AS A MENTOR ANGEL

You do not need to bear the responsibility of your Support Seeker's wellness but as a Mentor Angel, there are numerous ways you can help:

- You do not need the perfect words, but, rather have the courage to sit in uncomfortable spaces with them and listen.
- Share resources and tips with your mentee that were helpful to you.
- Be a listening ear help your mentee speak freely and be understood.
- Share about your personal experience what you have overcome, learned, and/or advice you want to share.
- Commit to being consistent and present with your mentee.
- Assist the person who is grieving: see if you can research information for them, aid in communicating with loved ones, brainstorm ways to commemorate their loved one moving forward, or do things together (watch a movie, reflect on a book, take a virtual walk).

It is important to note that grief can look different based on socioeconomic status, gender, religion, race, ethnicity, sexuality, and ability.⁴ Although you may share similarities with your mentee, how they choose to grieve and engage in the Mentor Angel/Support Seeker relationship may vary. Remember that supporting their journey is the key factor - and allow them to dictate the relationship and how they engage with recommendations.

4 https://www.cancer.net/coping-with-cancer/managing-emotions/grief-and-loss/understanding-grief-within-cultural-context

MENTOR ANGEL PROVIDES:

Resources

Community

Guidance navigating medical system

A listening ear Sharing of experience

Presence

Affirmation Support

THERAPIST PROVIDES:

Diagnosis

Mental-wellness strategies

Referrals

Client-centered support

Therapeutic theory



HOW TO LISTEN

LEAD WITH NON JUDGMENT

When talking to a mentee, being non judgmental means not holding any evaluation towards your mentee - positive or negative. Being non judgmental creates a balance between Mentor Angel and the Support Seeker. This allows the Support Seeker to process freely without concern of the Mentor Angel's perception of their grief.

BE EMPATHETIC

Empathizing is "a concerted effort to gain an accurate perception of another's experience, and then to share that perception in one's own words, style and manner." This involves being present with another person and "putting yourself in their shoes" - understanding grief from their perspective. To understand the concept further, watch the short video "What is Empathy" by Brene Brown (https://youtu.be/1Evwgu369Jw).

FOCUSING ON FEELINGS

Encourage your Support Seeker to share their feelings with you. Sometimes people have a difficult time verbalizing their grief. Allow mentees to share their feelings when they are ready. If you are concerned about the feelings your Support Seekers express, contact Imerman Angels.

REMIND YOUR SUPPORT SEEKER -CARE IS UNCONDITIONAL

Reminding your Support Seeker that care is unconditional assures them that they deserve to be seen, respected and heard. You, as their Mentor Angel, demonstrate this by being consistent and present with your Support Seekers regardless of what they share. Showing unconditional support allows your mentees to process their grief in a safe and supportive environment.

LANGUAGE⁵

Although your presence is more vital than having the perfect words – there are some key phrases to avoid:

At least _____ or silver-lining problems.

• Often we attempt to put a positive spin on people's pain. In the moment this may seem helpful, but it minimizes and invalidates the person's feelings.

I had a friend who _____.

• By bringing up other people who have had similar experiences it takes the attention off the individual and brings it inadvertently back to you.

You are so strong, you look so well, you are holding it together.

• In essence, these are compliments but it does put pressure on the individual to maintain appearances.

It's part of God's plan.

 The heart behind this phrase is to give someone peace, but this can stir up anger, loss is never part of an individual's plan.

They're in a better place.

• Often, statements like "They are in a better place" bring more relief to the person sharing the sentiment than to the grieving.

ACTIONS/ACTIVITIES TO HELP⁶

Encourage mentees to honor those they have lost. Creating rituals and celebrations can increase a sense of control for the person grieving, assist in meaning-making and be a vehicle to carry the person with them in this next chapter of their life.

- Celebrate a loved one's birthday, anniversary or memorable moments.
- Create an altar that honors what has been lost - you can add photos, flowers, momentos, etc.

When you were having a difficult time, what did others do or say that was helpful?

SOME PHRASES TO UTILIZE INSTEAD

"I realize there are no perfect words for this situation, but I want you to know I am here for you."

"That sounds incredibly difficult, would you like to talk more about that?"

"I'm here for you."

"I am listening."

"What makes you feel supported?"

"It is ok to feel anything."

5 https://www.helpguide.org/articles/grief/helping-someone-who-is-grieving.htm

6 https://www.psychologytoday.com/us/blog/promoting-hope-preventing-suicide/201705/ring-theory-helps-us-bring-comfort-in

MINDFULNESS

Mindfulness is a state of mind focused on the present moment. Mindfulness can morph a distracted mind to a calm mind. A calm mind will benefit you and also grow your capacity.

Want to encourage your Support Seeker to practice mindfulness? You can suggest:

- Set a timer for five minutes and focus on your breathing and the present moment.
 If you become distracted, redirect your mind to the present moment.
- Walking meditation: walk around your neighborhood and focus on your fives senses, sight, smell, touch, taste and sound.
- Try an app like Headspace, Calm, Liberate (for women of color), Chill Anywhere or Daily Shine (for women).
 If you don't want to use your phone, you can look up guided meditations on YouTube.

In mindfulness, one is not only restful and happy, but alert and awake. Meditation is not evasion; it is a serene encounter with reality.

77

-THICH NHAT HANH



Being Trauma Informed

"The traumatized soul finds no rest in conditions of peace. It's forever questing for violence, for action, for the same combination of factors which gave rise to it in the first place."

- Matthew S. Williams

Trauma n.⁷

Any disturbing experience that results in significant fear, helplessness, dissociation, confusion or other disruptive feelings intense enough to have a long-lasting negative effect on a person's attitudes, behavior and other aspects of functioning. Traumatic events include those caused by human behavior, as well as by nature, (e.g., earthquakes) and often challenge an individual's view of the world as a just, safe and predictable place.

Your Support Seeker may be suffering from trauma or be trauma exposed. This is very common, but often misunderstood. Trauma can look like: irritability, insomnia, hypervigilance, having multiple triggers (places, words, objects that bring up painful memories), isolation, difficulty concentrating, etc. When working with Support Seekers, keep in mind the Universal Precautions approach to trauma:

The 5 S's:

SUPPORTIVE RELATIONSHIPS

People who have been exposed to trauma crave support which can be best displayed through stability. Allowing your mentee to know your relationship is stable and you will not easily be pushed away is helpful.

SAFETY

Trauma-exposed people crave safety. You can create safety by having predictable times to meet or talk and allowing them to create the parameters (where you meet, where you sit, the freedom to leave at any time). Safety can also be manifested with structure. It is important to set clear boundaries and expectations with your mentee. For example, "I prefer that you text me" or "I do not answer my texts after 10 pm."

SELF SOOTHING

Recognize "disruptive" behavior (doodling, getting up, tapping a pencil, constant bathroom breaks) could be self-soothing techniques. Working with a trauma-exposed population can be unpredictable and mentors can model positive coping mechanisms. Mentors should also support mentees when they display positive coping strategies (ie. taking time for walks, meditation, seeking therapy).

STRENGTHS

While someone is grieving, highlight to them the things they are doing well and the steps they are taking in their healing. Different from positivity, focusing on strengths acknowledges the difficulty of the circumstance while helping mentees acknowledge the progress they have made.

SELF CARE

Assist your mentee with focusing on their own wellness and self care. Grief is consuming, and self care is often the first thing that falls to the wayside. Talking with your mentee about their sleeping habits, nutrition, spiritual practices, relaxation and supportive relationships can help them prioritize self care.

In addition to the Support Seeker being trauma exposed, you have also had traumatic experiences. Working with Support Seekers may cause old feelings and memories to resurface. As with the Support Seeker, if you find this is the case you should focus on your own and connect with your support system or a mental health professional. If you feel your relationship with your Support Seeker is taking a toll on your mental health, please reach out to the Imerman Angels team.

9 https://sites.rutgers.edu/shp-shpri/trauma-informed-care-universal-precautions/

⁷ https://dictionary.apa.org/trauma

⁸ https://www.helpguide.org/articles/ptsd-trauma/coping-with-emotional-and-psychological-trauma.htm

Compassion Fatigue n.¹⁰

Stress-related symptoms experienced by caregivers and other helping professionals in reaction to working with traumatized people over an extended period of time.

As a Mentor Angel, it is important to notice if you are beginning to experience compassion fatigue (also known as Vicarious Trauma). compassion fatique is different from burnout. Burnout is often the accumulation of stress - typically after a busy season of life. This can be remedied by an extended break and relaxation. compassion fatigue is mental and spiritual. People may experience apathy, mood swings, trouble focusing, anxiety or even depression. compassion fatigue is best treated by focusing on self care/wellness, rekindling your "why" and drive for your service, and finding support through community or a mentalhealth professional. If you believe you are experiencing compassion fatigue and it is impacting your role as a mentor, contact the Imerman Angels team.

IDEAS FOR MENTOR ANGEL SELF CARE:

Journal

Journaling is a powerful tool to calm an anxious mind, reflect and set intentions for the future. On Google or Pinterest you can search "journal prompts for _____" and multiple writing prompts will be available.

Practice Mindfulness

See page #13

Calm Your Vagus Nerve

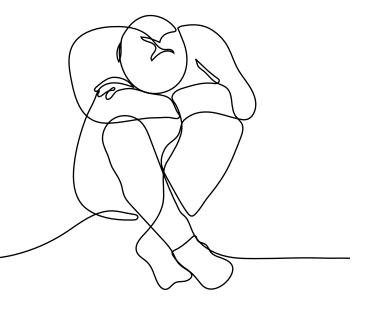
The Vagus Nerve is a nerve running throughout your body that becomes activated when we are overwhelmed, anxious or stressed. You can calm the Vagus Nerve instantly by pressing a cold compress on your chest, taking a cold shower or going out for a brisk walk around your neighborhood.

Create Routines

Having a morning and night time routine can signal to your brain that you are ready to start and end your day. Consistent routines can help ease stress and maintain your wellness. Search YouTube for "Morning or Night Routines" for ideas.

Connect

Connect with other Mentor Angels in the Facebook Group or with the Imerman Angels team to share and learn new strategies.



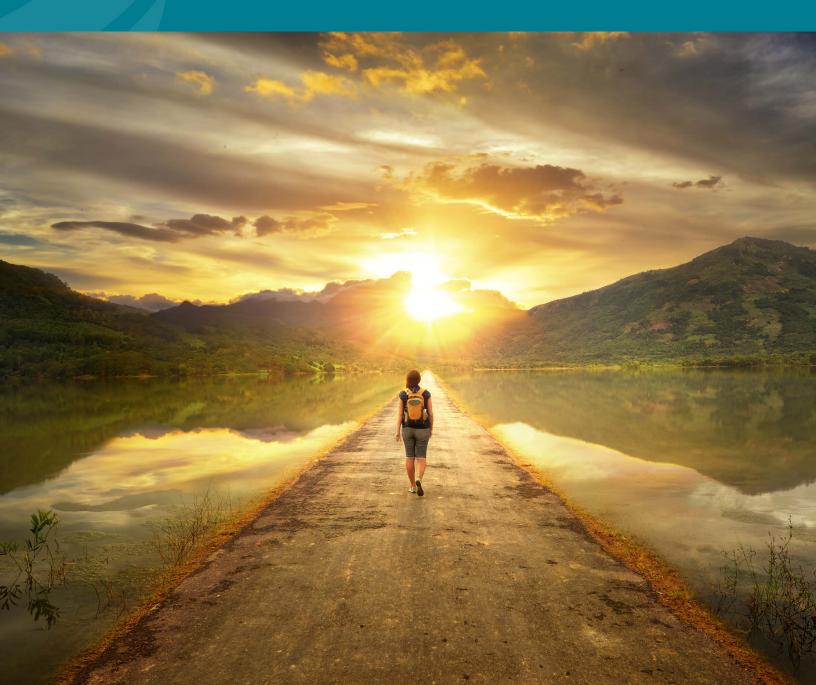
10 https://www.webmd.com/mental-health/signs-compassion-fatigue

11 https://sass.uottawa.ca/sites/sass.uottawa.ca/files/how_to_stimulate_your_vagus_nerve_for_better_mental_health_1.pdf

Wrap Up

The cancer community experiences grief and loss in different ways and for different reasons. We hope this toolkit provides a helpful framework for you as you navigate your grief journey. If nothing else, we trust you now know that grief is not linear and there is no right or wrong way to experience it. This toolkit is a living, breathing document and we encourage you to provide us feedback on how to make it more useful for our community. Please reach out to info@imermanangels.org with any thoughts or ideas.

Thank you again for your partnership with Imerman Angels.



Resources

We encourage you to check out the resources below to get more support or learn more about grief and loss.

ORGANIZATIONS

Refuge in Grief refugeingrief.com

Modern Loss modernloss.com

The Dinner Party thedinnerparty.org

Lantern lantern.co

Zen Caregiving Project zencaregiving.org

BIPOC Grief & Mental Health Database alicaforneret.com

BOOKS

How to Support the Loss of a Love by Peter McWilliams

On Death and Dying by Elisabeth Kubler-Ross

Finding Meaning: The Sixth Stage of Grief by David Kessler

Healing After Loss by Martha Hickman

When Breath Becomes Air by Paul Kalaninthi

Tuesdays with Morrie by Mitch Albom

The Year of Magical Thinking *by Joan Didion*

The Body Keeps Score by Vessel van der Kolk

Notes on Grief by Chimamanda Ngozi Adichie

It's Ok That You're Not Ok by Megan Devine

- INSTAGRAM
- <u>glitterandgrief</u>
 <u>whatsyourgrief</u>
 <u>griefshine</u>
- @ learningaboutgrief
- @ empowered_through_grief
- @ iamdavidkessler
- @ endwellproject
- @ imermanangels

Remember, you are our greatest resource. Thank you for extending yourself to this community.

Acknowledgements



Imerman Angels would like to thank the following organizations and individuals for their counsel, advice and support in the creation of this guide:

Dr. Ken Moses, PhD Evanston, Illinois

Zen Caregiving Project Roy Remer Naomi Stoll San Francisco, California

Dr. Timothy Pearman, PhD Chicago, Illinois

For more information about Imerman Angels:

imermanangels.org info@imermanangels.org 866-IMERMAN (463-7626)

The Grief Toolkit is made possible thanks to funding and support from AbbVie

