

On the Path of the Perfecting Caregiver

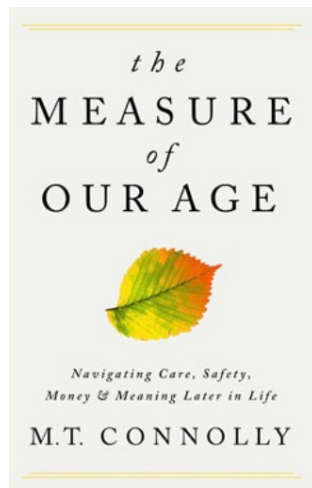
Quotes of Relevance from Books Read 2023/2024

Ernest L. Pancsofar
Affiliated with
Communitas, Inc.



Quotes of Relevance

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“We can work to make the world better, but we can only live in the world as it is.” (p. 84)

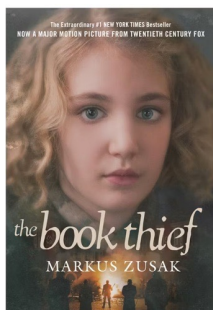
“Old is that age we are not yet.” (p. 286)

Be cautious of statistics in health care:

“It was a perfectly good place and got the maximum number of stars. But none of those stars told you if you’d be treated like a human being or a chair.” (p. 57)

“We also need to re-envision how we define ‘success,’ how we dole out money, and measure both based more on how residents define their own well-being.” (p. 100)

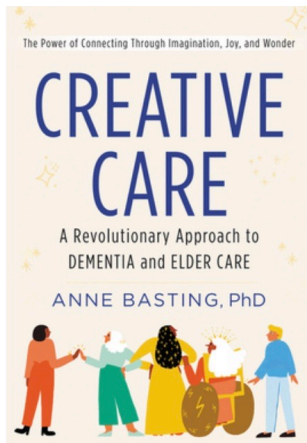
“ ... I read books I haven’t read for decades and they seem very different now than how I remember them. The books haven’t changed, but I have.” (p. 294)



I just finished this book and would certainly rate it among the more poignant and enriching of the historical fiction I have read. In its true form, historical fiction involves a contrived story set among historically accurate settings and events. I highly recommend it. (12/25/24)

“Don't be afraid to fail. I fail every day. I failed thousands of times writing The Book Thief, and that book now means everything to me. I had many doubts and fears about that book, but some of what I feel are the best ideas in it came to me when I was working away for apparently no result. ”

“Failure has been my best friend as a writer. It tests you, to see if you have what it takes to see it through.”



“Dementia brings me and my family to that deepest place of meaning, where our human frailty and our unique human capacity to imagine entwine. Where we can experience breathtaking beauty and heart-wrenching sorrow simultaneously. Dementia brings us to creative care.”

“... The creative care approach invites us to shift away from the temptation to focus so heavily on losses and instead train our eyes and hearts on the strengths that remain.” (p. 11)

“You can also echo gestures or movements for people who do not communicate verbally. Think of this as dancing, but you are letting the person with communication challenges lead.” (p. 100)

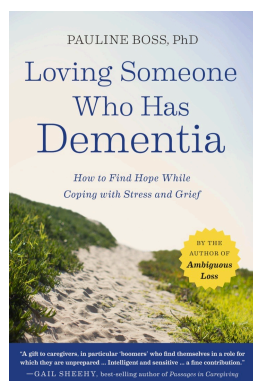
“What I keep being reminded of is how everyone who is alive has both disabilities and abilities.”

Helen Kivnick as quoted by on p. 193

Code of Ethics for Student Artists in Residence (SAIR)

- ❖ *“Be flexible, patient, humble, and dependable.*
- ❖ *Create an infectious sense of fun and discovery.*
- ❖ *Express gratitude and graciousness.*
- ❖ *Don’t underestimate the capacity of elders.*
- ❖ *Create time for just being present in people’s lives.” (p. 204)*

I discovered this book on our trip to Goodwill this morning. I wonder what wisdom may be found within its pages. There is mention of The Penelope Project, which seems interesting to investigate. (4/4/2024)

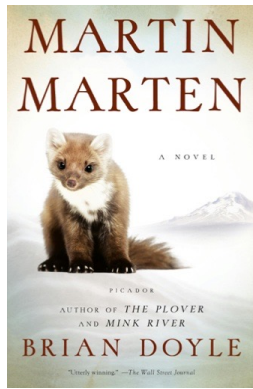


On my reading list as recommended by facilitator of on-line support group.

“... dementia does not destroy everything. Often something remains that is still wonderful. Out of the fog comes surprising wisdom.”

“People with dementia need our touch and the sound of our voices even if they don’t always know who we are.”

“No one has ever faced your particular situation before, so feel free to improvise. Just do what comes to you as the right thing to do.”

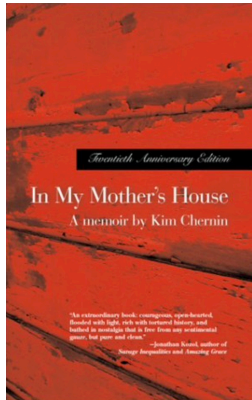


***“They attend.
They see.
They witness.”*** (p. 249)

“He leaned back and sat as still as he possibly could and waited for the world to present itself.” (p. 17)

“But isn’t it often the case that when we cease to move and think, we see and hear and understand a great deal?” (p. 100)

“People are stories, aren’t they? And their stories keep changing and opening and closing and braiding and weaving and stitching and slamming to a halt and finding new doors and windows through which to tell themselves, isn’t that so? Isn’t that what happens to you all the time?” (p. 152)



I found the following exchange very poignant between a daughter and mother, who is experiencing a brain changing illness:

“Do you know how much I love you?”

Oh Mama, I do know.

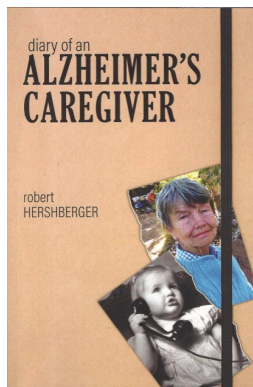
You can have no idea.

Well, I sure do feel how much you love me.

You can’t imagine. You cannot imagine how much I love you.

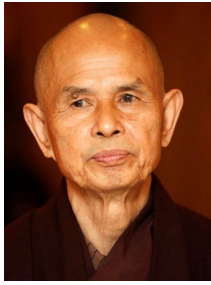
I love you too Mama.

Of course, you love me. I’m your mother. But do you know how much I love you?” (p. 432)



I have started this book and, already, I can note some parallels in the author’s experiences and my own. (9/2/2024)

“It was clear to me how Dee, her essence, is still here. Her feelings and emotions are as strong as ever. Dee is still the wonderful, caring, loving person at her inner core.” (p. 109)



Thích Nhất Hạnh

“The present moment is the only time over which we have dominion. The most important person is always the person you are with, who is right before you, for who knows if you will have dealings with any other person in the future? The most important pursuit is making the person standing at your side happy, for that alone is the pursuit of life.”

Found in: The Miracle of Mindfulness

“You and your loved one are here together. You have the chance to see each other deeply. But if you are not fully present, everything will be like a dream.” (p. 65)

“Perceptions often tell us as much about the perceiver as the object of perception.” (p. 148)

“When the person we love is happy, happiness comes back to us right away. We give to her, but we are giving to ourselves at the same time.” (p. 195)

Found in The Heart of the Buddha's Teaching: Transforming Suffering into Peace, Joy, and Liberation

“Breathing in, I calm body and mind. Breathing out, I smile. Dwelling in the present moment I know this is the only moment.”

“Life is available only in the present moment.” Found in: How to Relax



“There are mysteries that may never be solved, no matter how hard we try. And if we try too long trying to solve them, we may miss what’s right in front of us.”

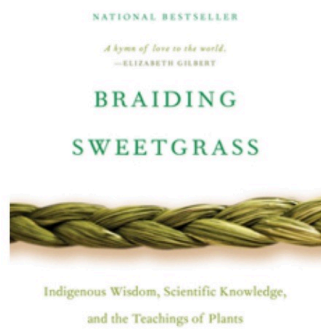
Mr. Parnassus – (p. 114)

“I'm afraid I don't have magic.

You do, Mr. Baker. Arthur told me that there can be magic in the ordinary.”

“It's the little things, I expect. Little treasures we find without knowing their origin. And they come when we least expect them. It's beautiful, when you think about it.”

“Home is where you feel like yourself . . .”



“Balance is not a passive resting place – it takes work, balancing the giving and the taking, the raking out and the putting in.”

“A Cheyenne elder of my acquaintance once told me that the best way to find something is not to go looking for it.”

“Maybe there is no such thing as time; there are only moments, each with its own story.”

“A gift comes to you through no action of your own, free, having moved toward you without your beckoning. It is not a reward; you cannot earn it, or call it to you, or even deserve it. And yet it appears. Your only role is to be open-eyed and present. Gifts exist in a realm of humility and mystery – as with random acts of kindness, we do not know their source.”

“Isn’t this the purpose of education, to learn the nature of your own gifts and how to use them for good in the world?”

“This the fundamental nature of gifts: they move, and their value increases with their passage.”

“To learn again, you really have to listen.”

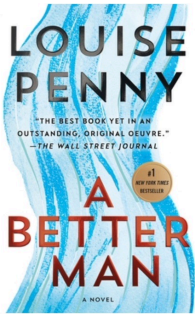
“I like the ecological idea of aging as progressive enrichment, rather than progressive loss.”

“Respect one another, support one another, bring your gift to the world and receive the gifts of others, and there will be enough for all.”

“A teacher comes, they say, when you are ready. And if you ignore its presence it will speak to you more loudly. But you have to be quiet to hear.”

“If there is meaning in the past and in the imagined future, it is captured in the moment. When you have all the time in the world, you can spend it, not on going somewhere, but on being where you are. So I stretch out, close my eyes, and listen to the rain.”

2024 will be memorable as the year I read all 19 books currently written by Louise Penny from the Three Pines series.

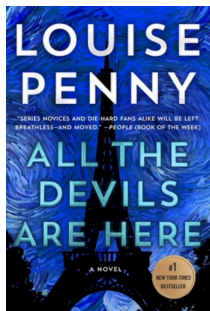


“Consider these three questions prior to speaking:

Is it true?

Is it kind?

Does it need to be said?” (p. 231)



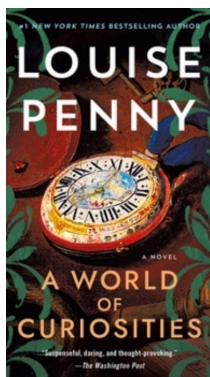
“With patience comes choice, and with choice comes power.” (p. 4)

“It had taken Beauvoir years to see the power of pausing. And of patience. Of taking a breath to consider all options, all angles, and not simply acting on the most obvious.” (p. 222)

Gamache is speaking to Beauvoir about the four statements that lead to wisdom:

- *“I’m sorry.*
- *I was wrong.*
- *I don’t know.*
- *I need help. “*

(p. 19)

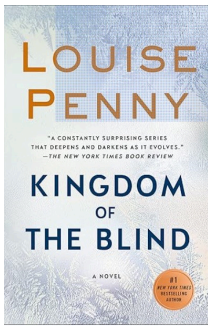


First Nations Blessing

*“Now you will feel no rain,
For each of you will be shelter to the other.
Now you will feel no cold,
For each of you will be warmth to the other.”
(pp. 233-234)*

“... beginning to understand that believing something was even more powerful than knowing it.” (p. 377)

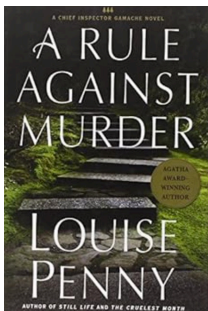
Louise Penny (continued)



“The memory of the heart was far stronger than whatever was kept in the mind.” (p. 3)

“We're all blessed and we're all blighted, Chief Inspector,” said Finney. “Everyday each of us does our sums. The question is, what do we count?”

“Life can be cruel, as you know, but it can also be kind, filled with wonders.”

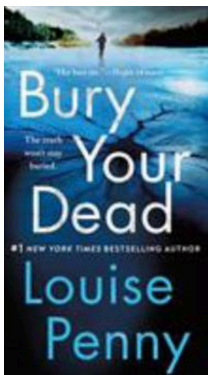


“ ‘The mind is its own place, monsieur.’ said Reine-Marie. ‘Can make a heaven of hell, a hell of heaven. This is heaven. Always will be.’

‘This place? Manoir Bellechasse?’

‘No,’ she put her arm around him. ‘This place.’ ”

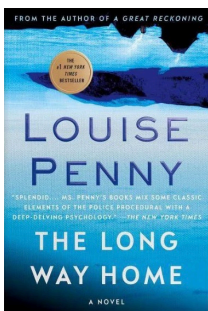
(pp. 73-74)



“ ... we're all so fascinated with history. We're in a rowboat. We move forward, but we're always looking back.” (p. 108)

A Brief Note to Louise Penny:

I thank you for providing me with hours and hours of reading pleasure as a care partner for my wife who lives with dementia. Your personal connection with this condition endears me to your writing. You have provided needed respite during stressful times as I am immersed with the characters you develop throughout the sequence of your novels. (sent to U.S. publisher)



An Inuksuk (plural inuksuit)

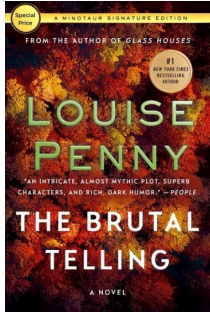
... a figure made of piled stones or boulders constructed to communicate with humans throughout the Arctic.

(from Canadian Encyclopedia)

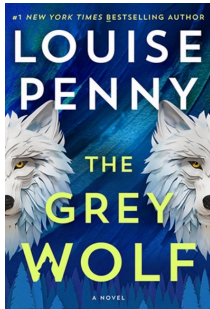
“These may be works of art, but more than that, they were markers, signposts. Pointing out where he'd been and where he was going. The route he was traveling, artistically, emotionally, creatively.”

Each entry of my weekly journal is like a rock in an inuksuk, describing my journey. (ELP)

Louise Penny (continued)

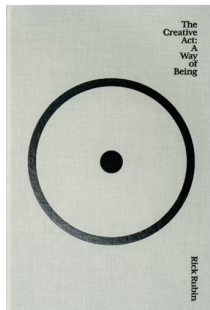


“The leaves had fallen from the trees and lay crisp and crackling beneath his feet. Picking one up he marveled, not for the first time, at the perfection of nature where leaves were most beautiful at the very end of their lives.”



“In many ways, in every way that mattered, feelings were more real, more powerful than thoughts. They were the engine of perception, which drove thought, which became words and prompted action.”

(p. 319)



“The heart of experiment is mystery.” (p. 151)

“Tomorrow presents another opportunity for awareness, but it’s never an opportunity for the same awareness.”

“Do what you can with what you have. Nothing more is needed.”

“The goal of art isn’t to attain perfection. The goal is to share who we are. And how we see the world.” (p. 177)

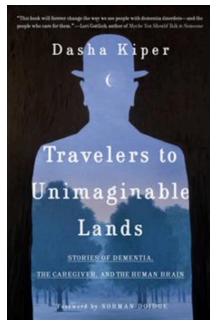
“Each new project is another opportunity to communicate what’s coming through you. It’s another chance at bat. Another opportunity to connect. Another page filled in the diary of your inner life.” (p. 196)

“We can only flow with the challenges as they come and keep an open mind, with no baggage, no previous story to live up to. We simply begin from a neutral place, allow the process to unfold, and welcome the winds of change to guide the way.” (p. 286)

“As Arn Anderson once noted: ‘I’m both a professor and student, because if you’re no longer a student, you don’t have the right to call yourself a professor. ’ ” (p. 332)

“These transmissions [messages from our environment] are subtle: they are ever-present, but they’re easy to miss. If we aren’t looking for clues, they’ll pass by without us ever knowing. Notice connections and consider where they lead.”

“More often than not, there are no right answers, just different perspectives.” (p. 112)



Caregivers ... have to view patients as both sufficiently different from themselves, the better to stop perceiving intention, and yet sufficiently similar, so as not to lose sight of their humanity. It's a fine, nearly impossible, line to walk. (p. 142)

Even when we know our decisions are for the best, denying a person's right to choose still feels like a moral violation as long as we continue to see an essential moral self. (p. 157)

I chuckled at the following account as I encounter a slightly different version when Marsha asks, “Why didn’t you tell me about my appointment with Dr. C_____?” or a similar future event.

“One evening, as Sam helped his father get into bed, Mr. Kessler looked up and said in a kindly tone: ‘Who are you?’

Startled, Sam replied, ‘Your son.’

‘My son?’ Mr. Kessler said wonderingly. ‘How long have you been my son?’

‘Well, I guess sixty-two years now,’ Sam said, feeling both alarmed and amused.

Mr. Kessler’s eyes widened. ‘Sixty-two years you’ve been my son and only now you’re telling me?’

Sam laughed. ‘Well, sometimes it slips my mind.’

Seeing his son laugh caused Mr. Kessler to laugh as well.” (p. 17)

I found Dasha Kiper’s insights to be quite profound and useful as I journey with my wife who lives with Alzheimer’s disease. I have come to realize the uncertainty and duality that exists in my relationship to her and realize that my current understanding had to evolve from a stage of ignorance, followed by information through the “contented Involvement” curriculum/ workshops to my current understanding of why I may be reacting and responding to my wife’s confusion with her world between the now and what she remembers it used to be. Interestingly, I had a career working on behalf of individuals with intellectual disabilities and I wonder if this preparation was a foundation for my current reactions and support. There are certainly great differences in approaches, but I am comfortable with my conversations and interactions and try to honor her interests, oddities, eccentricities and companionship. The author has a keen ability to combine her knowledge of the intricate workings of the brain and the everyday interactions between caregiver and family member. I am pleased that one of my daughters recommended this book and I would do, as well, to all family members who have a loved one with Alzheimer’s.

Submitted as a Goodreads book review.

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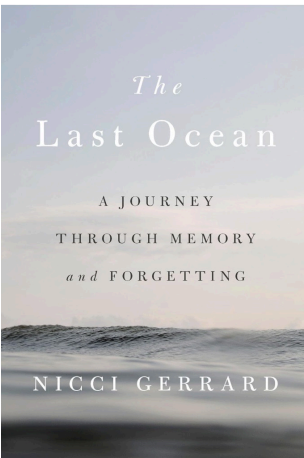
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Quotes of Relevance from Books Read 2025

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There was something that endured beyond language and recollection, a trace perhaps, like grooves that life had worn into him the way a river carves into rock. He still had his sweetness; his past lived on in his smile, his frown, the way he raised his bushy silver eyebrows. It lived on in us. He might not have recognized us, but we could recognize him. I don't know what the word for this indelible essence is – once, it would have been 'soul'. (p. 3)

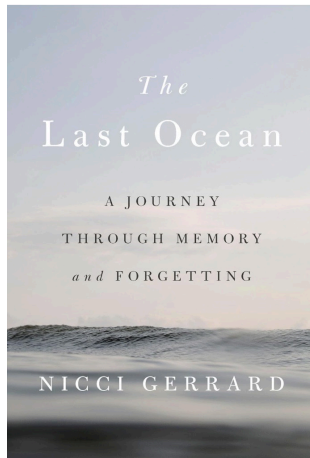
We are attached to our past selves because we have been them and they are still lodged within us. All our infinite, shifting versions are contained by the present self – moment after moment, now and now and now, unquantifiably small fragments of experience piled up in the complex formation of the self. (p. 61)

Tim Dartington, who looked after his wife, Anne, and kept her at home during her last years, told me that what happened with his wife 'transformed my whole way of thinking who I was, what I was doing, what my values were. It changed everything, I was a better person for it ... ' (p. 117)

But kindness isn't easy; it's never just kindness. It involves a scrupulous vigilance to individual needs; a nimble, improvisatory imagination; a common-sense and patient determination to find the unique and precious person who may be obscured by their dementia. (p. 189)

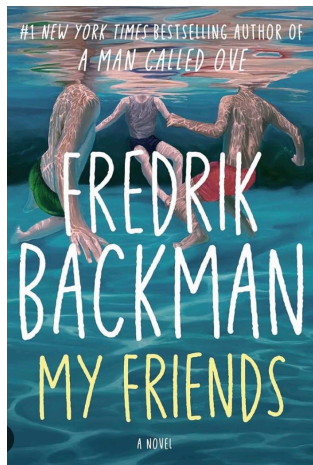
Completed reading this extraordinary account of the author's reflections as she witnessed her father's decline in the later years of his life with dementia. There were numerous parallels in the chronicles of these experiences with which I could readily relate. ELP

Jenni Dutton's tender, unsqueamish relationship with her mum has much to teach us as a society. Somehow, she found the wisdom and humanity to look steadfastly at what it is to be a failing mind inside a wasting body and feel nothing but compassion, love and joy. Indeed, she seemed to be able to see her mother more clearly and value her more dearly as capacity fell away. She didn't mourn what she had lost but embraced what she had become: 'That little soul!' (p. 111)

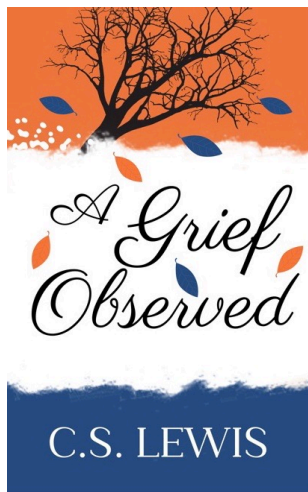


(continued)

Several years ago, I was in a large department store, running late, looking for things I couldn't find, hot and feeling a bit frazzled and itchy and out of sorts. As I was hastening along an aisle, a woman came hastening towards me. She was quite a bit older than I was, scrawny, and looked distressed and in a state of substantial disarray. As I drew closer, I saw her shirt was wrongly buttoned. I put up a hand to prevent her bumping into me, and she put up a hand as well, smiling anxiously back at me. I stopped. She stopped. We stared at each other with a kind of pity. And with a sudden rush of mortification, I understood that she was me. I was looking at myself in a mirror. Usually, we prepare ourselves for our reflection. Here, I was caught unawares and my self-image shattered and lay in pieces around me. I stood face to face with the self that others see. (pp. 30-31)



- *The painter Ragnar Sandberg once said that art should be without purpose, and irresistible. You have to paint like the birds sing.*
- *Art is what we leave of ourselves in other people.* p. 221
- *She (Fish) said it didn't matter if we lived to be eighty years old, because that's only a billion different nows, and one really good now is enough.* p. 222
- *Isn't it like totally unbelievable that we even exist? So it won't be a tragedy when we don't exist anymore! It's just cool, really cool, that we happened at all.* p. 233
- *It's a funny thing. The person we fall in love with, we hardly ever call by their name. Because it's somehow just so obvious that it's you I'm talking to, that it's you I'm always thinking of. Who else?* p. 361



Recommended by a member of an online support group of which I am a participant.

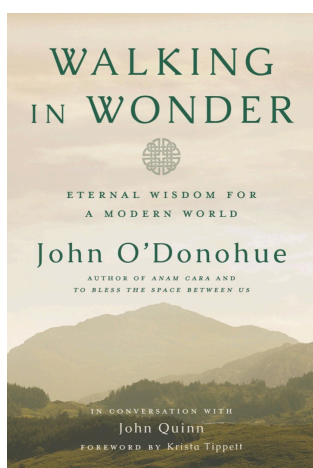
- *For in grief nothing stays put. One keeps on emerging from a phase, but it always recurs. Round and round. Everything repeats. Am I going in circles, or dare I hope I am on a spiral?*
But if a spiral, am I going up or down it?
- *Still, there's no denying that in some sense I 'feel better,' and with that comes at once a sort of shame, and a feeling that one is under a sort of obligation to cherish and foment and prolong one's unhappiness.*
- *Kind people have said to me, 'She is with God.' In one sense, that is most certain. She is, like God, incomprehensible and unimaginable.*
- *Once very near the end I said, 'If you can -- if it is allowed -- come to me when I too am on my death bed.' 'Allowed!' she said. 'Heaven would have a job to hold me; and as for Hell, I'd break it into bits.'*
- *The best is perhaps what we understand the least.*
- *For a good wife contains so many persons in herself.*
- *... the ultimate purpose of God's love for all of us human creatures is love.*
- *Sorrow, however, turns out to be not a state but a process. It needs not a map but a history, and if I don't stop writing that history at some quite arbitrary point, there's no reason why I should ever stop. There is something new to be chronicled every day.*
- *If you think of this world as a place intended simply for our happiness, you find it quite intolerable: think of it as a place of training and correction and it's not so bad.*



I am going to seek a great perhaps.

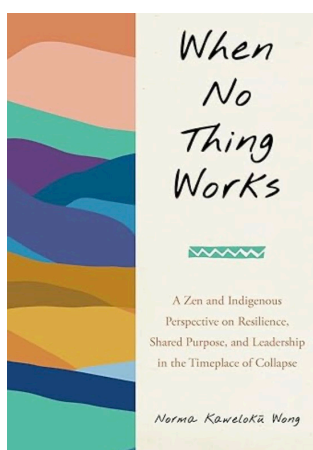
François Rabelais

(as cited in *Looking for Alaska* by John Green)

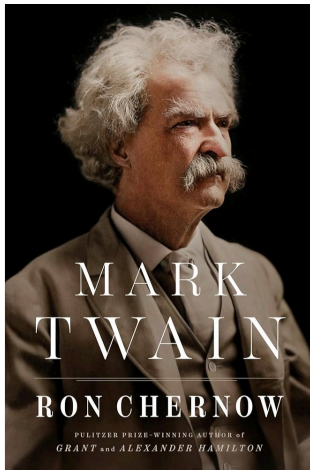


I was looking for my next book to read and remembered Krista Tippett's interview with John O'Donohue. This also encouraged me to find some suitable quotes by this author that are compatible to my current life's journey.

- *No one else can see the world the way you see it. No one else can feel your life the way you feel it.*
- *If you allow yourself to be the person you are then everything will come into rhythm.*
- *Mendoza asks Gabriel Garcia Márquez, what did he think of his wife, Mercedes? Márquez, who has been with Mercedes for forty years now, said to Mendoza, 'I know her so well now that I haven't the slightest idea who she is.'* ”
- *The question is the place where the unknown becomes articulate in us. A good question is something that has incredible grace and light and depth to it. A good question is something that always, in some way, plows the invisible furrows of absence to find the nourishment and the treasure that we actually need.*
- *An interesting question to ask yourself at night is, What did I really see this day?*
- *We do not need to grieve for the dead. Why should we grieve for them? They are now in a place where there is no more shadow, darkness, loneliness, isolation, or pain. They are home.*
- *Everyone that leaves your life leaves a subtle trail of connection with you; and when you think of them, and miss them and desire them, your heart journeys out again along that trail towards them in the elsewhere that they now find themselves.*



- *While we may hesitate, not knowing many things, it is the unknown that holds the most powerful possibilities. So, take a breath. Take a step.*
- *... leaping is transformative evolution in which there is evolving transformation.*
- *... internal resolve to weather the most confusing and chaotic days without losing our way and ways.*
- *Thus, it can be said our beingness both precedes and permeates our doingness.*
- *... interdependence, a way in which each person is important to every other person for collective existence and thriving. Norma Wong*



Like many writers before him, Twain discovered that the past recaptured was often more poignant than the past actually lived.

Chernow, Mark
Twain, p. 234

I don't know anything about the hereafter, but I am not afraid of it. The further I get away from the superstitions in which I was born & mistrained, the more the idea of a hereafter commends itself to me & the more I am persuaded I shall find things comfortable when I get there. Mark Twain

As I continue to read a biography of Mark Twain, I am at the part when his friend Charles Dudley Warner (CDW) dies in 1900. Here is a quote from CDW:

Perhaps nobody ever accomplished all that he feels lies in him to do; but nearly everyone who tries his power touches the walls of his being.

When I was younger, I could remember anything, whether it happened or not, but I am getting old, and soon I shall remember only the latter.

After reading a biography of Mark Twain by Ron Chernow

Married Olivia Langdon

Author Extraordinaire

Renowned Orator

Kept chasing pipe dreams

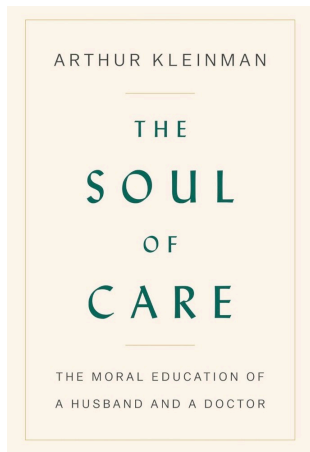
Troubled relationships

World traveler

Angelfish fixation

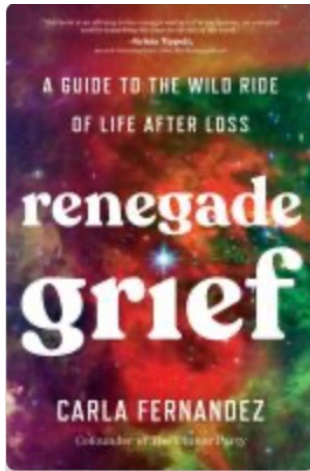
Icredible Wit

Naive in business matters

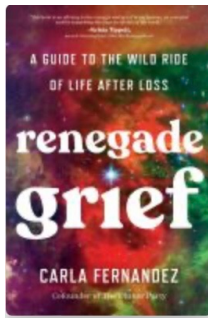


Courtney Martin
recommended this book
and I found several
quotes worthy of
including on this page.

- *The most important thing offered by a caregiver is simply their complete presence.*
- *Care does end with death but involves actively caring for memories. I learned that caregiving entails moments of terror and panic, of self-doubt and hopelessness – but also moments of deep human connection, of honesty and revelation, of purpose and gratification.*
(pp. 3-4)
- *One must retain honest humility when offering advice. Caregiving is about relationships above all else, and troubled or failed relationships are rarely a promising source of successful care, even when supported in other ways.* (p. 173)
- *You do it because it is there to do. It was part of the deal – you know, the marriage vows, the way you lived your life together over the decades. You do it!* (p. 177)
- *There are no simple conclusions, and no universal answers. All we can do is dig deeply into each illness experience to identify and cherish what matters most to each individual and in each relationship.* (p. 179)
- *I could never have undertaken the unrelenting tasks that make up dementia care if the person needing that care had not been the core of my life and my world. I felt a deep moral and emotional responsibility to repay the life-enhancing gift of care Joan had given me for so long.*
But it wasn't a sense of obligation that drove me; it was my instinctive desire to see her happy and comfortable, or at least not unhappy and not uncomfortable. (p. 151)
- *Caregiving made me feel both stronger and better about myself in my relationships with others.*
(p. 169)

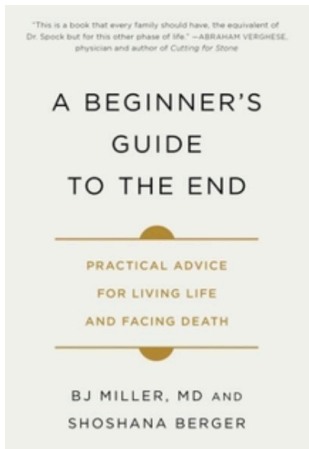


- *Being renegade means we're working to become less independent and alone in our grief, and more interdependent; restitching a social fabric where we're not afraid to ask, "What was their name?"; where we are comfortable sitting with someone's story, knowing that what they're experiencing can't be optimized or solved, knowing that avoiding the discussion because of its inherent discomfort is avoiding life itself. (p. 11)*
- *This path that I'm on – one marked by grief and goodbye – is not actually what I would have chosen if I had my pick, but it is the road I am on. And now that I'm here, he [Carla's dad] reminds me to approach it with an open mind, curiosity, and focused energy for this version of a challenging time. (p. 12)*
- *Over time, we grow to accept that the one constant of being in a relationship with our grief is that it'll evolve and change. (p. 41)*
- *But by expressing our experiences, we get a chance to examine more fully what happened, to consider the variety of ways we can narrate our own story to others and also to ourselves. (p. 42)*
- *Each time we look in the rearview mirror, we revisit the wisdom that's there for us, and it mirrors back our own transformation in the miles we've traveled. We've grown, and our relationship to the past shifts and deepens. We learn how to use our rearview mirror as a tool to navigate our loss; yet our gaze never fully rests there, lest we miss the exit on the road ahead. Because once we've spent time sitting with the histories and relationships and realizations of the past, it's time to tend to our grief in the present tense. p. 79*
- *The question "Where are you at with your loss right now?" is really an invitation to be present. It requires us to not only listen to other people, but to more thoughtfully listen to ourselves. p. 82*
- *Nature is chock-full of grief wisdom, protocols, and offers of support. For some, their deepest companion and counselor in grief is the ocean or bodies of water. p. 133*
- *... we often miss the chance to really distill down the learnings, not just from someone's death, but from their life; and to honor the person or people, who were here before and who mattered. p. 144*
- *We can find sanctuaries not just in physical buildings, but in patterns of motion, not just in places but also states mind. p. 147*
- *Hope Edelman wrote a beautiful book called The AfterGrief where she describes a "phase we enter after the most acute elements of grief – shock, numbness, helplessness, sorrow, despair – start to subside. It's where we reenter the larger flow of humanity, where we discover all the ways we're still ourselves and also all the ways we've been fundamentally changed." p. 162*



(continued)

- ... you might very well ask, *What is there to celebrate? To which I'd answer that you're celebrating the person who was here, as well as the person you are becoming in this wild time.* p. 181
- ... by spending time with *their objects or telling their story, and continue coming into presence, to not ignore the range of emotions related to your grief, but to get curious about what lessons it has to offer; the importance and privilege or resting, of listening to your dreams, of looking to nature, and finding the people who can be present with you too.* p. 185



- *Caregiving can narrow your field of vision in the day-to-day, but a grander sense of perspective will also take shape. You might come to see just how long the list is of things not to worry about: the pettiness of office politics; the nightly news; the traffic. Now you might find yourself more moved by silence or morning birds or small signs of kindness. You care, you show up, you face reality with someone, you touch the limits, and maybe you learn something about yourself.*
- ... the pain of loss stems from the power of love. *If you didn't care, this would all be easier.*

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