

Navigating the Transition into Caregiving

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Caregiving often calls us to lean into love we didn't know possible. --Tia Walker



Sign at Occupy Portland, October 21, 2011. Flickr/K.Kendal via Wikimedia Commons. CC BY 2.0.

Personal transformation is usually an experience we actively seek out - not one that hunts us down. But in the twenty-first century, becoming a caregiver is a transformation that comes *at* us because today the 'call to care' is at odds with the imperative of work and the call to individual achievement. Being a caregiver is not something most people think or dream about, let alone prepare for, even though it's a role many of us will inhabit, since there are approximately 43 million informal caregivers in the United States and 6.5 million caregivers in the United Kingdom.

When a loved one becomes a caregiver everything changes, including responsibilities, beliefs, hopes, expectations and relationships. Caregiving is always different than we imagine it to be, largely because so few of us think through our care roles in advance. The disorientation associated with these roles can be deep, intense, and isolating because it entails a series of paradoxes, including an ongoing tension that becomes difficult to reconcile: this is a relationship you may not want but feel you must accept.

In the resulting process of transformation, your loved one's story, your story, your relationship story, and the 'cure' story you have mapped out in your head can betray you when what happens isn't what you thought would happen - or should. It's as if someone steals the script you have been working from your whole life through.

Unlike the taken-for-granted script that leads you to believe that willpower and love and desire can change almost any situation, your caregiving exists in the overlooked spaces of life where the language of doing and action are confronted by the ongoing realities of care, realities that require you to change the way you think and talk about your experiences.

Our interviews with caregivers across the care spectrum reveal an unexpected change in how they perceive support from those who once - pre-caregiving - provided comfort and reassurance. Suddenly there is a growing awareness that you feel alone. Troubling questions emerge such as, *Why is it that the more time, energy, and attention I provide to my loved one in need, the less comfortable I feel interacting with family and close friends? And why do I feel so frustrated and out of place in the company of people I used to enjoy?*

Although the friends and relations who surround you may be familiar, something is different. They are still recognizable, but the ways in which you interpret what they are saying (or not saying) may no longer make sense. If a caregiver could write a truthful letter to family and friends explaining this experience of disorientation, it might read like this:

I see when you've called, but I don't have the energy to even listen to a voicemail message. It's not that I don't want to. It's just that I feel like I can't right now. I'm here, but I may not even answer the door if you come by. It's not that I don't want to. You want to help and for that, I am deeply grateful, but caring so deeply for someone I deeply love is changing me in

ways I don't know how to explain. I want to be called. I want you to text. I want you to want to come by, even though when you do I may not answer.

You may hear me and think I sound the same, but I don't. I didn't choose this way of looking at things; it feels like it chose me. You may hear me and think I sound the same, but I don't because I'm not.

When the people you most want to understand your care roles can't or don't, it can feel like a betrayal. When the loved one you are caring for can no longer be an audience for you in the ways they once were (as a spouse, parent or child), you can feel trapped by a desire to share, but painfully reminded that you can't or don't know how to disclose what you most want them to know and understand.

Relationship confusion is what can happen when care roles ask caregivers to act in ways they feel are inconsistent with preexisting relationships. Talking to a friend the way you once did - filled with references about future vacations and plans - may no longer be possible in ways that make you or your friend comfortable.

Simply bathing a spouse you are caring for can change how you think about your relationship. This act of care can become charged with meaning that threatens relational identity. No longer is physical intimacy and touch designed to enhance your relationship. Rather, the caregiver role changes the meaning of physical intimacy, from enhancing closeness to fulfilling a need. Over time, this can create confusion and resistance because it unsettles the way you once viewed your relationship as a spouse or partner.

In these moments you can feel desperately lost in a relationship you've been in for years. No one gives you permission to make sense of your experiences. After doctors, nurses, physical therapists, family and loved ones drive away, hang up the phone, close the office door or send an email or a text, you are still living deeply inside the situation. Other people won't find value in your experiences in ways that make sense to you. They don't have to - yet - but you must, and now.

Only by reaching beyond your existing networks into relationships with other caregivers will you be able to try out new stories that make it possible for you to see your experiences from different perspectives. Multiple vantage points can grant you the freedom and permission to be

self-compassionate in ways that only others in similar circumstances and relationships can promote and sustain.

Reaching out and connecting with people who share common caregiving challenges is vital to the process of shaping personal growth and voicing experiences that allow you to explore meanings that may make no sense to your existing networks, but which are necessary to your evolving caregiver identity - meanings that move beyond good or bad, sadness or happiness, cure or recovery.

The changes that accompany the shift from loved one to caregiver can also invite new ways of understanding yourself and your evolving purpose. The care roles in which you find yourself require a reclaiming of a mindset that allows you to think about yourself and your experiences in sustainable and authentic ways.

Although others may use values like ‘perfection’ and ‘outcomes’ to guide them, these things make no sense in terms of caring. Instead, caregivers must lean on values that are consistent with their experiences. Connection and mindfulness, not perfection and outcomes, are more appropriate markers because they emphasize the value of the care role *and* how this role may change how you think about yourself.

In the 21st century, caregiving isn’t simply a set of obligations. Rather, it’s a radical re-envisioning of the self-in-action. Care can’t be accomplished in isolation, but only with and through others. Caring for each other occurs within nested dependencies. The outer nest is society, while the innermost is an individual with health needs, or oneself. Giving and receiving flows back and forth between individuals and groups within these layered ‘nests’ of family, community and society. Caring itself is the foundation of our individual and collective wellbeing, but it cannot thrive without support.

Often however, support is hard to come by because caring is mistakenly conceived as a private set of activities. Instead, caregiving is an integrative way of being with others that leaves no room for specialization or prefabricated boundaries. It requires fluency in participation, negotiation and innovation with others who are both similar *and* different, close *by* *and* far away, face-to-face *and* online, intersecting the formal and informal spaces of our lives that cannot be quarantined from one another,

whether at home or at work, in the community or in the world of hospitals, care homes and hospice.

Caregiving requires a laser-like focus on the needs of another person. But the aspect of caregiving that others too often forget, but carers know intimately, is that care also requires a radical opening-up to others, a willingness to connect with those you know are in the midst of struggle too. This awareness, born from personal transformation, can be the beginning of a new way of seeing and being ourselves, entwined with the lives of those we love.

Donna Thomson and Zachary White's new book is [The Unexpected Journey of Caring: The Transformation from Loved One to Caregiver](#).

This article originally appeared in the Transformation section of [OpenDemocracy](#). It is republished here with permission. Donna Thomson is the author of ["The Four Walls of My Freedom: Lessons I've Learned From a Life of Caregiving"](#) and blogs at [The Caregivers' Living Room](#). Dr. Zachary White is an Associate Professor of Communication at Queens University of Charlotte and blogs at ["The Unprepared Caregiver."](#)