Stumbling on Joy

Not Always a “Burden” of Care

Although the field of Alzheimer’s research rightly highlights the “burden of care,” this metaphor can obscure the “joy of care.” This article focuses on the latter. And although too many Alzheimer’s caregivers are burdened, when provided with proper respite and support, caregiving is often a joyful and beneficial experience for the one who gives.

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What lies behind us and what lies before us are tiny matters compared to what lies within us.

—Oliver Wendell Holmes

Over the years, we have all observed caregivers, both professional and familial, who seemed to have remarkable energy and joy in their activities. It does, of course, go without saying that “doing unto others” to overwhelming degrees can become stressful in itself and will have adverse health consequences, as in the case of those family caregivers of loved ones with dementia who are unable to find respite support or much meaning in what they do. The burdens of the caregiver who is stressed and exhausted are all too real, and the importance of getting professional help, eventually in the form of nursing home placement, in most cases, cannot be overemphasized. But under the right conditions, caring for the deeply forgetful can have many joyful moments. This article is intended to celebrate the ability of many caregivers who, under the right conditions, do much for the deeply forgetful in a manner that is grounded in joy and warmth. People with dementia so often have a sense for palpable expressions of warmth and respond more favorably as a result.1

Sometimes the caregiver’s joy is elicited by the joy in the person with dementia. If we set aside the distorted position that a person’s worth, dignity, and status as a human being are dependent entirely on cognitive capacity and independence, we may discover that they can teach us something about the warmth and love that is the essence of humanity.

The following is an example of such discovery from the voice of a caregiver included by Carol Bowlby Sifton, a family and professional caregiver, in her book Navigating the Alzheimer’s Journey: A Compass for Caregiving:2:

We can choose to lament, be lost and lonely, or we can choose to seek out the joy in what we do and let it renew our resolve. Sometimes joy finds us. It may take the form of a fleeting look of recognition and warm embrace from our loved one with Alzheimer’s. It may take the form of shared laughter from a silly mistake, shared words from a familiar prayer, or shared lyrics from an old song sung just off key. Sometimes joy is present but we are simply too busy

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2Well-being and being safe: finding a balance

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to recognize it. Take the time to see the joy. Maybe it’s in a garden on the way to the doctor’s office, in the eyes of a young child who is unencumbered by recollections of how things used to be, or in the simple pleasure of enjoying an ice cream sundae when it’s not Sunday. Sometimes joy seems elusive. Seek it out. Look for it in the beauty of a sunrise after a sleepless night, in the peacefulness of a sleeping loved one after a fretful evening, or in the closeness of an embrace after a precarious transfer. Those most likely to survive the voyage are the caregivers who are able to welcome joy aboard whenever it visits. Perhaps the one constant joy is in the opportunity to begin anew each day in the life of persons with Alzheimer’s disease. We can choose to embrace the persons, the days and the joys within them.

Finding joy in being attentively present with the deeply forgetful is enhanced for those who can have an appreciation for the ways in which the deeply forgetful can express positive emotions, offer a smile, and, in various ways, enjoy their lives despite cognitive losses.

I recall receiving a gift of joy some years ago, while visiting a nursing home in Chardon, Ohio. I read the little biosketch of a man named Jim who was in the special care unit for those with severe dementia. I sat down with Jim, looked into his eyes, and asked him how his sons were, expecting an answer as I always do, although I knew this was unlikely. As caregivers, we should talk even to the most cognitively disabled, calling them by name and expecting a response (which, sometimes surprisingly, may come). We should speak with a warm and calm voice, with a joyful facial expression, bending down to make eye contact, communicating with them rather than round them. We are not obliged to reorient them into our reality, but we are obliged to be an attentive presence in theirs. Jim did not respond verbally, but he smiled a huge beaming grin, and he gently placed a twig in my hands. If a joyful smile was electric, the unit would have been lit up. I handed the twig back after a minute and thanked Jim. I then asked the nurse to tell me about his twig. It turned out that Jim had grown up on a farm in rural Ohio, and that he loved his father very much. In his demented state, Jim has gone back in time to the one person he most associated with tender loving care, his father. For his father had given Jim a chore as a boy to bring kindling in for the fireplace. That twig was a symbol of the warmth and love that Jim experienced from his father, and in sharing this warmth with me, I felt immense joy, so much so that I have never forgotten the details of the event. Jim, in his own way, gave me a huge gift that morning, and I still possess it.

Meaningful relationships with persons with dementia provide renewal on a daily basis, as well as nourishing the spirit for years to come. Here is another example from Bowlby Sifton’s Navigating the Alzheimer’s Journey: A Compass for Caregiving, who tells about her experiences with John Angus:

John Angus, a sensitive and caring man, had earned his living from the land. It was more than a job, it was his life. The challenges of living with dementia meant that he could no longer stay alone on his farm nor even work with plants and the soil without a lot of help from others. Unfortunately, he was not always in a care situation where his deep need to be connected with the land was understood. This great loss and sorrow, combined with fading skills in using words, often led to very distressing situations between he and some of his caregivers. (pp32-33)

Perhaps because of Bowlby Sifton’s own deep ties to the land, she and John Angus became special pals. She offers some stories of how this wonderful person informed her life as a newly minted therapist, and still sustains her more than 20 years later.

John Angus spent many contented hours a week in various group activities: dining, breakfast club, sensory stimulation, reminiscence. While all these activities emphasized aspects of normal daily life, they by no means always involved activities with plants.
Even though he never once said “thanks,” or called me by name, I have absolutely no doubt that John Angus appreciated every minute of the time we spent together and that he ‘knew’ me.\(^{(p33)}\)

One morning in spring I had a happy time sharing some of the sensory delights of spring with John Angus and 6 or 7 other persons with advanced dementia. I had remained in the kitchen afterwards, working quickly to prepare for the dining group. I really needed some focused time to prepare, so that I could give my full attention to the people who were coming next. When I heard a knock at the door and looked up to see John Angus through the window I have to admit to rather ungraciously thinking “Now what, I just don’t have time for this now.” When I opened the door, I changed my attitude entirely. How humbling and absolutely overwhelming to open the door and be greeted not only by John Angus’s beaming face, but by his outstretched arm giving me the rather tattered, but very precious, bouquet of mayflowers that his daughter had brought a few days earlier.\(^{(p35)}\)

John Angus was able to express love and appreciation in a manner that inspired Carol Bowlby Sifton and showed her that even when cognitive capacities wane, the emotional and relation power of love can still remain powerful. It was especially meaningful when John and Bowlby Sifton would together more their fingers through lose soil, putting them both in touch with the land.

An Alzheimer’s caregiver who finds the right meaning in caring may find higher degrees of joy than would otherwise be the case. There are so many caregivers who think that the life a person with dementia still has dignity, that such persons can and should be respected, and who sees in caring a dynamic that goes with rather than against the grain of the universe. David G. Myers, a prominent happiness researcher, defines happiness, or subjective well-being, as a lasting perception that one’s life (or the current part of it) is “fulfilling, meaningful, and pleasant.” Myers states, “Happiness makes people less self-focused and more altruistic.” But it works the other way around too. Doing good makes us feel good. Altruism enhances our self-esteem. It gets our eyes off ourselves, makes us less self-preoccupied, gets us closer to the unself-consciousness that characterizes the flow state.\(^{4}\) In other words, caring for others creates a psychological momentum and a sense of self-competence that makes us happier. This can occur in the experience of the caregiver.

Caregivers can find happiness in helping other caregivers too. Anyone who attends caregiver support groups will see the huge amount of warmth and help that people give to one another. The human capacity to do “unto others” in unselfish love is profoundly alive in these support groups. Any one member of such a group spends a great deal more time giving support than receiving it. The therapeutic benefits of helping others have long been recognized by everyday people. This concept was first formalized in a highly cited and often reprinted article by Frank Riessman that appeared in 1965 in Social Work.\(^{5}\) Riessman defined the ‘helper therapy’ principle on the basis of his observations of various self-help groups, where helping others is deemed absolutely essential to helping oneself. These are grassroots groups that nowadays involve tens of millions of Americans. As the saying goes, “if you help someone up the hill, you get closer yourself.” Riessman observed that the act of helping another heals the helper more than the person helped. Members of such groups are deeply engaged in helping one another, and are in part motivated by an explicit interest in their own healing. These groups adhere to the view that people who have experienced a problem can help each other in ways that professionals cannot, that is, with greater empathy and more self-disclosure. The members of these groups are replacing negative emotional states with the positive state called “the helper’s high,” a pleasurable and euphoric emotional sensation of energy and warmth.

Joyful caregivers? External conditions and support levels can make the difference. But also, there are some caregivers who by nature and/or nurture seem to thrive, and
even maintain a palpable love for the deeply forgetful. There is little research that allows us to predict who will maintain such an affective affirmation of the imperiled, and the antecedents are surely complex. For those who have adequate support and can sustain a sense of meaning and purpose, caregiving can be relatively more buoyant.

And even when a person with dementia seems to lack warmth and may struggle with negative affect, there is still much good for the caregiver who discovers meaning and purpose through self-transcendence. The great French Canadian Catholic Jean Vanier founded L’Arche ("The Ark") nearly 40 years ago. In response to the miserable conditions in institutions that warehouse persons with developmental cognitive disabilities, Vanier invited 2 such men to live in his home. L’Arche communities now exist in 120 countries, using a model in which “assistants” (both short-term and long-term volunteers) live communally in group homes taking care of “members” (persons with disabilities). Here is one vignette sent to me by Vanier that captures the growth in an assistant named Pauline:

Just recently the mother of Pauline came to visit her daughter, a nineteen year old assistant living and working in one of our homes. Pauline has been in the home only four months. Her mother told me how her daughter has changed and been transformed. Before coming here she was unable to make choices, didn’t know who she was nor wanted for the future. Now she has discovered that she is giving life to the people with disabilities around her. She is loved by them and new energies of caring and of communion are flowing from her. People with disabilities have awoken her heart and what is deepest within her: her capacity to give life and to bring joy and hope to others.

Stories like this one abound in L’Arche. The assistants who stay on, sometimes for many years, are the ones who experience the joy of giving most powerfully, but almost all of them report that their experiences of giving enhance their happiness.

There are many caregivers who, despite dealing with every sort of behavioral difficulty in a person being cared for, seem to maintain a patience and delight in their activities. There are times when even the most buoyant caregiver will need to rely on dry duty alone. There are going to be Februarys, when the holidays are a distant memory, and spring is not yet around the corner. We go through the motions of caregiving without really giving care in the emotional sense. Running on empty, we feel that there is no nobility in what we do. Yet, these periods will hopefully pass. An ethics of care built on arid obligations, on “filial duties,” is unfulfilling and limiting, even though it is sometimes absolutely necessary and the only grounds for continuing on. With the right support, both practical and spiritual, a spring breeze will warm the air. It might be time for nursing home placement and a greater reliance on professions. It is important to get away and care for one’s own soul. But then return with a renewed desire to bring joy into the lives of the deeply forgetful and to be sensitive to the joy that they do often offer in countless small ways.

I recall vividly my grandmother, who died years ago of Alzheimer’s disease. I would spend time with her in my early 20s. She loved peanut M&Ms candy. She would suck the candy and chocolate off the nuts and place them back in the bowel. Whenever I saw her, she would offer me some candy from the bowel, as she had over the years offered candy to her grandson. I never ate those nuts, of course, but I took joy and delight in the fact that so deep into the disease grandmother, she still had the heart of a giver, still expressed love in this small way, and such love certainly brought delight to me. Her bowel of nuts always made me laugh, and that made being with her more joyful.

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REFERENCES


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