

## A Self-Assessment and Tool for People Who Serve as Caregivers for People with Dementia

### *Context*

Being a person who gives or coordinates care for a person with the set of symptoms termed "dementia" is a rare occurrence.

Currently, approximately 88% of the U.S. population aged 65 and older and 93-95% of the world's population aged 60 and older have not developed symptoms of dementia. Being a person who cares for a person with dementia is also a nearly singular experience, having some common and also unparalleled elements with other caregiver roles.

Rather than a diagnosis, "dementia" is the term for a set of symptoms resulting from brain-damaging diseases such as Alzheimer's and others. This damage to the brain results in reduction of memory, ability to recall and form words, ability to use logic and reason, ability to learn new information, and other disabilities.

As brain-damaging diseases begin to cause the set of symptoms termed "dementia," brain networks reroute to bypass the damage. As the damaged portions accumulate, brain networks can no longer bypass the extensive areas of damage. Mental and physical functionality declines. Intermittently, functionality may return due to unknown re-routings or temporary reconnections. The causal disease is difficult to determine and usually requires an autopsy to accurately diagnose.

Dementia, resulting from one or more illnesses, is progressive and irreversible. There is no effective treatment or cure.

Honoring the personhood of the individuals involved is inherent in the work that follows. For the sake of clarity and brevity, hereinafter, the person who offers care is termed "caregiver" and the person who receives care is termed "person." I define "caregiver" as a person who self-defines as a caregiver, either as a direct provider of care or a person who coordinates care or participates in care from a distance. Singular pronouns will be "they."

In caring for a terminally ill person without cognitive impairments, a caregiver witnesses the declining health of the person for whom they are caring. A person with degenerative cognitive impairment such as dementia experiences the erasure of personhood, as well as declining health.

The human brain has evolved to work effectively with the reality of its environment. Most people, most of the time, behave within a predictable range. When the very essence of what makes a person human deteriorates before a caregiver's eyes, and the person continues to live but speaks and acts in ways that seem inhuman, the experience for the caregiver can seem other-worldly, even horrific.

As a result of challenges to their reality created by this illness, caregivers can experience a devastating loss of connection with the self and the self's inner resources: losses in self-awareness, self-empathy, self-compassion, self-efficacy, invention and creativity, and inner wisdom.

On an on-going basis, witnessing the person's suffering, their abnormal words and actions, paired with experiencing the loss of connection with self, and connection with the person even though they sit or stand in front of them, can seem surreal, disorienting, harrowing, traumatic, and painful to the point of being torturous, calling into question the caregiver's own reality, the meaning of everything, even the very purpose of existence. The caregiver's suffering can be acute.

### *Purpose*

This assessment and tool attempt to synthesize research findings on the experience of people who serve as caregivers for people with dementia, research on effective treatment for trauma, and research-backed elements of therapies derived from cognitive theory and other therapies, to ease the particular suffering of the person who serves as a caregiver for a person with dementia.

### *Hypotheses*

1. Precise, comprehensive knowledge of the reality of one's feelings and thoughts serves as data for effective problem-solving.
2. The intensity of the caregiver's inner experience and disconnection, plus the demands of caregiving, may leave a caregiver with a broad, undefined sense of distress.
3. Avoidance of reality can create or exacerbate stressor-related and trauma disorders. For caregivers, avoidance can occur in the form of other-blame and disease-blaming, all beyond the caregiver's control. For potential therapeutic effect, the focus of the questions is on the caregiver.
4. Engaging cognitive functions eases distress and regulates emotions.

5. The existence of the questions assists caregivers more precisely identify the sources of their distress.
6. Engaging with the questions - although some questions may illicit strong feelings and uncomfortable thoughts - requires use of cognitive functions and may ease distress.
7. Awareness, in and of itself, can foster helpful thinking. Self-administering this assessment and tool once or multiple times can result in heightened awareness of self, others, and the world for the caregiver. "Returned to the self," the caregiver's heightened awareness can result in orientation towards reality and, thus, realistic problem-solving.
8. Caregivers can effectively self-administer therapeutic protocols.
9. Early interventions may reduce current distress and prevent development of distress-related psychological symptoms after the person's death.

### *Procedures*

Parts I - III ask the caregiver to become aware of their experience of the impact of the person's condition, words, and actions. Although not all questions will apply, questions are multiple so that caregivers may individually identify elements of their experiences.

In Part IV, caregivers are asked to consider aspects of the logistics of caregiving that trouble them. Other, more comprehensive instruments about the burdens of caregiving exist. These items specifically relate to particular dimensions of being a caregiver for a person with dementia.

In Part V, caregivers consider a set of statements, informed by therapeutic protocols, and devised to be specifically therapeutic for caregivers of people with dementia.

*Self-Assessment and Tool*

I. Behavioral and psychological symptoms of dementia (BPSDs)

As a person who cares for a person with dementia, to what extent does the person's display of the following symptoms trouble you?

Symptom	A lot	Some	Neutral	A little	Not at all
Stating things as facts that aren't true (delusions)					
Stating beliefs that aren't true (delusions)					
Stating views markedly different from ones held prior to illness					
Expressing suspicions and fears about threatening people or conditions not in evidence (paranoia)					
Speaking with people, animals, or beings not in evidence (hallucinations)					
Physically interacting with people, animals, or beings not in evidence (hallucinations)					
Identifying sights and sounds not perceived by others (hallucinations)					
Engaging in movements that, from onlookers' realities, don't make sense (delusions and hallucinations)					
Interacting with the environment in ways that, from onlookers' realities, don't make sense (delusions and hallucinations)					
Saying things and behaving in ways that make the person unrecognizable as themselves					

Inability to express thoughts coherently (word aphasia)					
Inability to respond to a speaker in ways that indicate the speaker is heard and/or understood (invalidation)					
Expressions, movements, uttering sounds, or words indicating pain and/or distress (witnessing suffering)					
Disruptive behaviors (e.g., agitation, aggression, disinhibition)					
Irritability and/or anger outbursts					
Unpredictable moods and mood swings					

## II. Caregiver experience: cognitive realm

To what extent do the following trouble you as the caregiver of a person with dementia?

	A lot	Some	Neutral	A little	Not at all
Loss of connection					
Apparent loss of the person's sensitivity to your feelings and empathy for your situation					
Loss of their ability to contribute to the partnership, to the family, and/or to the larger community					
Ambiguous grief, i.e. both wishing they would die and would not die					
Anticipatory grief, i.e. the frequent presence of sorrow at the forthcoming death and its uncertain timing					

Loss of a person who is still alive					
Loss of a treasured, meaningful, mutual relationship; loss of a sense of belonging					
Loss of - and missing - the person's comfort, consultation, empathy, and understanding					
Loss of a shared past and history					
Loss of identity, i.e. no longer being that person's someone					
Being a witness to their suffering					
Uncertainty about what the person needs and/or what would ease their suffering					
A sense of failure from trying to read the mind of someone whose mind no longer works as it did					
Being a witness to abnormal behavior					
Disorientation from perceiving reality to be one way, then experiencing the person's words and actions not fitting that perception of reality					
Doubting your own perception of reality					
Losing touch with your feelings and thoughts from controlling them in hopes of not upsetting or agitating the other person					
Observing social protocols as if everything is normal and makes sense					
Doubting your understanding of the person, yourself, and the way the world works					
Loss of faith in your self-efficacy, i.e. belief that you can					

make things happen for yourself and others					
Questioning the meaning of existence					
Variability, unpredictability and uncontrollability of stressors, i.e. not knowing what will happen when and how bad it will be					
Push-pull of witnessing presence and absence of familiar personality traits					
Aloneness, isolation, loneliness					
Loss of freedom					
Postponement of dreams and plans					
Experiencing a sense of threat to family's health, stability, and/or standing					
Doubting the universe is a safe and just place					
Prioritizing other-care over self-care					
Fear you will get the illness and suffer the same fate					
Belief that you should be able to handle this, shake this off, get through and over this					

### III. Caregiver experience: realm of emotions

To what extent do the following feelings trouble you as the caregiver of a person with dementia?

	A lot	Some	Neutral	A little	Not at all
powerlessness					
helplessness					
hopelessness					
despair					

fear, anxiety, dread, panic					
shock and/or horror at the difference between the way things were and the way they are now					
sorrow, grief					
hope and disappointment roller coaster					
betrayed by your belief that one can affect change					
betrayed by your belief in the "just-world hypothesis," i.e. "Good things happen to good people and bad things happen to bad people. Good deeds are rewarded and bad deeds are punished."					
constrained, cornered, trapped, stalled, optionless					
victimized					
overwhelmed					
disoriented					
uninterested, unmotivated, discouraged, immobilized					
unvalued, devalued					
lonely, isolated, alone					
separate; made different by the experience, community membership canceled; no longer belonging; made an outlier					
left out; intentionally, perhaps unconsciously, perceived as too touched by hardship to include; ostracized					
uncertain about the past, present, and future; wondering "What's it all about, Alfie?"					
feeling nothing done is ever good enough					



longing for the past					
regretful					
guilty					
ashamed					
humiliated					
distrustful					
fearful, anxious; a sense of dread; a sense of panic					
sorrowful, full of grief					

#### IV. Caregiver experience: logistics

With regard to the logistics of providing care to a person with dementia, to what extent do the following trouble you?

	A lot	Some	Neutral	A little	Not at all
Making financial, legal, and other decisions on behalf of someone who cannot (creating a loss of integrity and identity through a sense of betraying the person and colluding with the illness as enemy and perpetrator)					
Direct provision of care					
Heart, mind, time, thought, diligence, and vigilance required to coordinate effective, safe care					
Other caregivers' complaints about the person's behavior					
Imposition of religious, political, or other ideologies upon the person					

#### V. Assistance to the caregiver

##### A. Acknowledging realities

To what extent do you find acknowledging the following difficult?

	A lot	Some	Neutral	A little	Not at all
Although I desperately wish otherwise, I understand no effective cure or treatment for dementia exists.					
Dementia symptoms tend to persist and worsen in spite of any and all medicinal, behavioral, and environmental interventions.					
Even if I could arrange for impeccable care given around the clock by a team of expert caregivers in a spa with gourmet food, that would not significantly impact the progressive deterioration of this person's brain and functioning.					
Although I may ardently wish otherwise, this person's health and life outcomes are objectively uncontrollable.					
The contributions of this person are probably done.					
Aspects of the words and actions of the person, in other settings, would be considered "gaslighting" or abusive.					
Many aspects of this situation do not respond to either-or thinking. Many things - sometimes opposites - are often true.					
My giving care to this person depends upon the fundamentals of self-care: adequate sleep,					

nutrition, exercise, and social contact and support.					
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## B. Self-kindness

People who give care to people with dementia face enormous difficulties. Maintaining stability can be a challenge. Attempting to grow or thrive can seem impossible. Holding fast to one's own reality can feel tenuous. Research suggests, however, that people can access their own strengths and inner wisdom to assist themselves through this unprecedented experience. Following is a set of ideas that may be helpful to consider.

With regard to being a person who gives care to a person with dementia, to what extent do you find the statements below to be true for yourself?

	Very	Some	Neutral	A little	Not at all
I am of service to this person.					
Although I find it extremely difficult, providing care for this person aligns with my values.					
Much of my distress is a normal reaction to an abnormal situation.					
That I would have intense feelings in this situation is understandable.					
That I would have troubling thoughts in this situation is understandable.					
Self-appreciation strengthens me. Self-judgment and self-criticism weaken me.					

Although I feel obligated to care for this person, and choosing to not give care to this person would be astronomically difficult, I am not forced to provide care. I choose to provide care.					
In the future, although I will grieve the loss of this person and the opportunities I lost from caregiving, I will have few regrets about giving this person care.					
As a result of my efforts, this person does not have to go through this experience alone.					
I don't need to minimize this. This <i>is</i> hard.					
I can separate who I am from what is happening to me.					
I can separate who I am from what is happening to this person.					
I can create a sense of enough safety and enough stability enough of the time.					
I appreciate how much my heart hurts for this person, for myself, for all people with dementia and their caregivers, and for anyone who has ever suffered.					
Perhaps not all the time, and perhaps only in a small way, I can detect within myself a sense of well-being.					
Although I might ardently wish otherwise, things are as they are.					
I appreciate myself for what I am able to accomplish for myself and for this person.					

Although it is difficult, I can see this situation as unfortunate rather than purposeful or meaningful.					
I see and accept what I can change and what I cannot.					
I see that if I hold still, I will probably feel deep sorrow. This feeling is understandable.					
I can't know what a different future might have held. It might have been better and it might have been worse.					
Although I would not wish this experience on anyone, I have gained some wisdom from it.					
Within the constraints of ethics and the law, I have done my best to grant what I know of this person's wishes for end-of-life care.					
I have done the best I know to do with the resources I have at this time.					

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