

To better understand the struggles faced by family caregivers, C-TAC undertook a digital ethnography of over 6,700 conversations from websites where family caregivers discuss caring for a loved one. The analysis provided a vivid depiction of the state of family caregivers in the United States and the need to do more to support these individuals and their families. This project was supported by funding from the Cigna Foundation

Overall, the **draining nature of the work** is a top issue for family caregivers who often feel their work **lacks meaning**. 69% of caregivers reported a net negative experience with caregiving. They also struggled with a **lack of knowledge** about the disease they're caring for, what to expect in the process, and how to cope with the demands of caregiving. Finally, their **financial burdens** are significant. We are creating a whole generation of caregivers who sacrifice their jobs and personal relationships, lack financial security, and are left with little after their loved ones pass away. While these challenges are not necessarily new, this research adds vividness and personal dimensions to the problem.

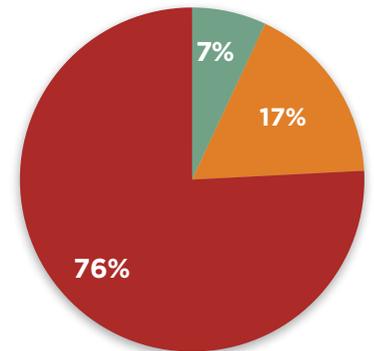
ISSUES FACED BY FAMILY CAREGIVERS

STATE OF MIND

Biggest Impact is seen on caregivers' **state of mind**:

- Mental fatigue, loneliness, and anger arise from caregivers' **resentment at lack of support**
- Feel sad, anxious, and helpless when they see their **loved ones suffer**
- Grief (29%), mental fatigue (29%), and anxiety (20%) are the primary emotions that impact caregivers' state of mind

"His family refuse to be involved with his care, I feel so alone and helpless."



■ Negative ■ Mixed ■ Positive

SOCIAL LIVES

The **social lives and personal relationships** of caregivers are hampered:

41% express resentment towards families

32% feel isolated

26% report social life suffers

10% Report feeling neglected

- Very difficult to **balance other relationships**
- **Inability to leave** patient isolates them from the rest of the world

"I have no social life and when friends call I have to pass."

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HEALTH

- 97% of caregivers report a decline in health
- Caregiving is a **high stress task** that takes a toll on both emotional and physical health of the caregiver
- **High emotional spending** leads to depression (24%) and insomnia (19%)

21% report physical fatigue

19% report insomnia

17% report aggravated medical conditions

"I also have a condition that requires having to pay extra attention to my physical well-being. It's easier said than done. I find myself pulled in too many directions."

FINANCES

- Aggravated conditions result in **higher medical bills**
- 48% of caregivers are unable to work and report a negative impact on their **financial health**

94% of family caregivers report a deterioration of financial health

51% of caregivers report compromised career

33% of caregivers report deprioritizing work

"Fast forward 8 years: I'm exhausted, broke, still not getting any help, but need an income, so I take on part time work wherever I can find it. It's not easy at all to find work in your late 50's."

SUPPORT

- Caregivers find respite by **sharing their experiences online** with other caregivers
- 24% of caregivers **don't get adequate support** from their families

"I'm on burn out from caregiving for hubby for cancer. Suggested I go online to discuss it. He's had three surgery this year alone, and starting to fail a little. Hard to watch. Been married 48 years."

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