



***Love, Loss & Resilience:
A Caregiver Perspective on the Impact of a Young-Onset Dementia Diagnosis***



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Love story...



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Signs & Symptoms: My Husband

Changes in behavior and personality lead to difficulties in daily functioning, relationships and communication

“Just wear your tie!”

“Is Mike mad at me?”

117 hours is not enough

The challenge of “rice” and “avocado”

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8 Misdiagnoses

Mike saw **two** primary care physicians, **three** counselors, **two** psychiatrists, and **one** neurologist in a span of 6 months.

He stayed **overnight** at the hospital and spent **a week** in a secure psychiatric unit.

He had many tests.

Diagnosis: Behavioral Variant Frontotemporal Dementia

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Signs & Symptoms: My Dad

Lost at Home

Forgetfulness

Trouble at Work

13 Week Learning Curve

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Consequences of Care



The move to full time caregiving meant leaving work entirely, with no predetermined return date




Unable to make payments, I lost our home to foreclosure, spent our retirement savings and benefitted from public support to make ends meet



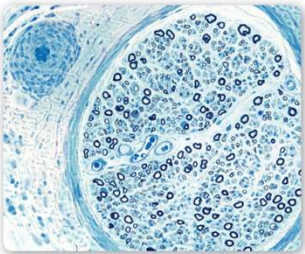
Leaving work and losing my home meant losing connections and relationships I had built over the past 5 years

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The social and economic burden of frontotemporal degeneration, p 2049

Randomized study of IV prochlorperazine plus diphenhydramine vs IV hydromorphone for migraine, p 2075

Infliximab for the treatment of CNS sarcoidosis. A multi-institutional series, p 2092

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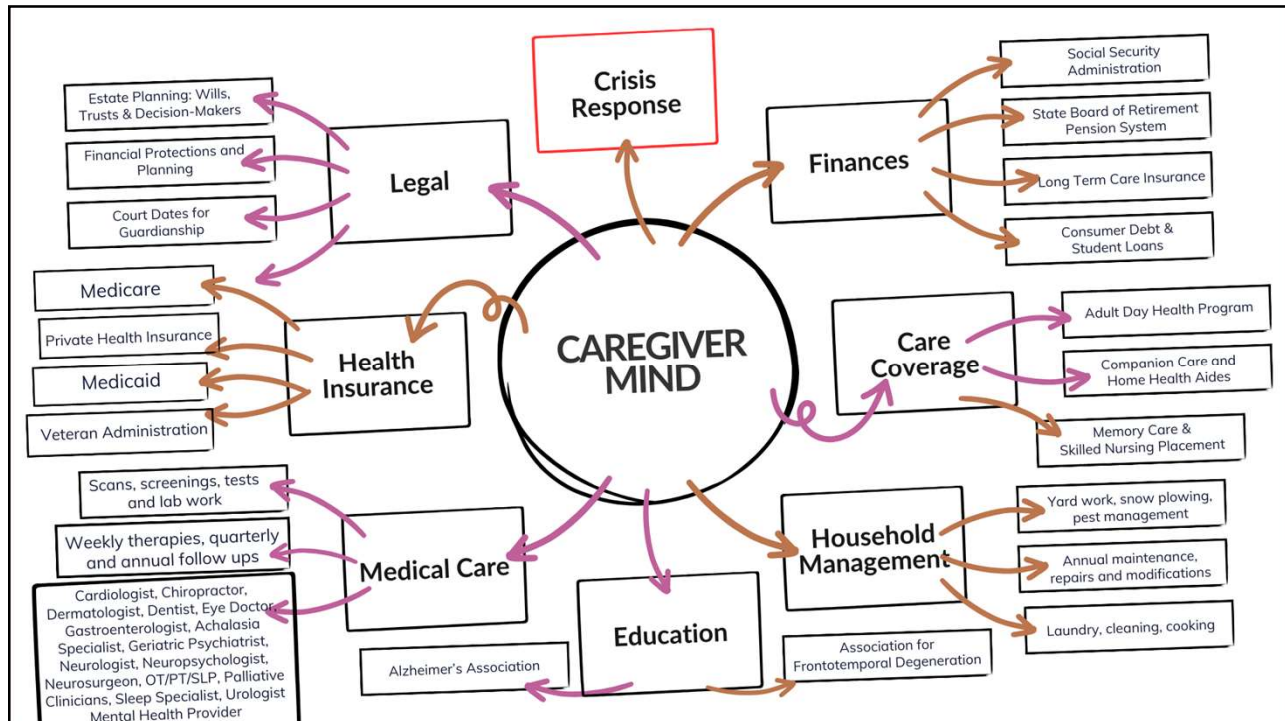
New Report Highlights Increasing Cost of Family Caregiving in the U.S.

Latest data attaches \$600B value to the estimated 36 billion hours of unpaid care that family caregivers provided in 2021

The Quiet Cost of Family Caregiving

Many employees reduce their hours or stop working to help ailing family members. But it may be years before they fully return to the work force, studies indicate.

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One Diagnosis: Two Patients

Symptoms of caregiver stress:

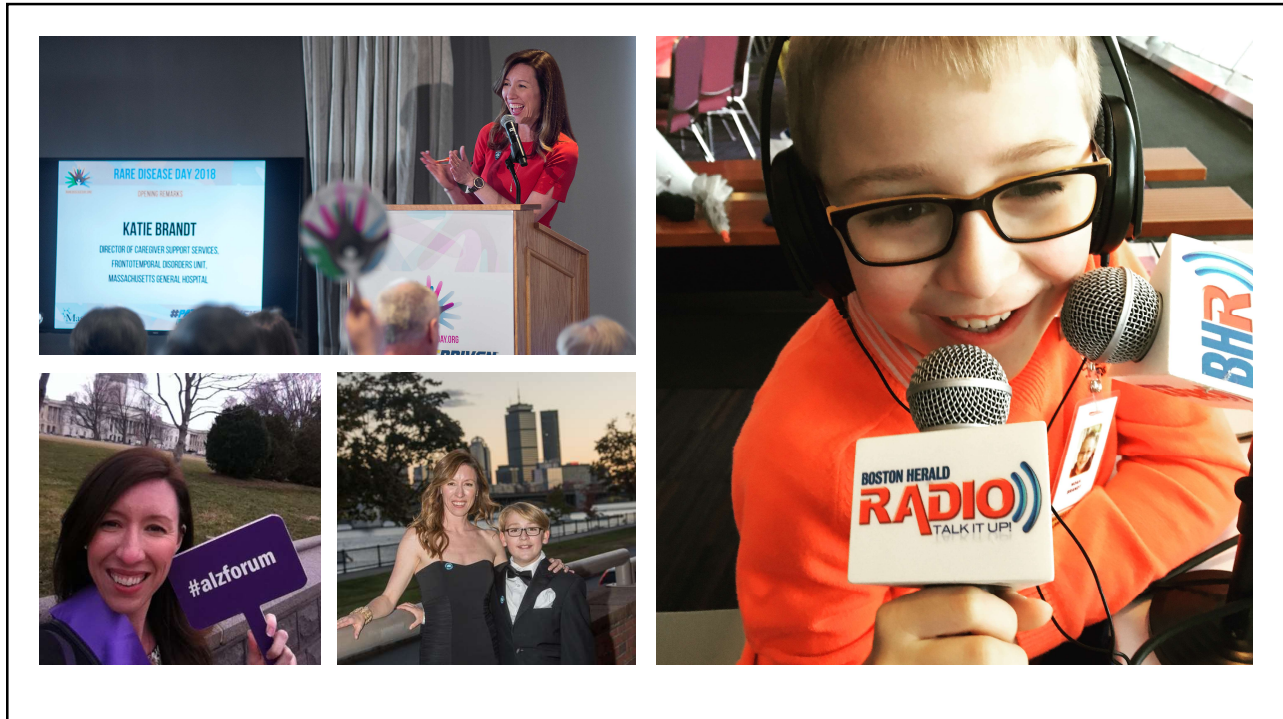
Symptom may include changes in appetite, weight or both; feeling blue, hopeless, irritable, or helpless; **withdrawal from friends and family**; changes in sleep patterns; getting sick more often; feelings of wanting to hurt yourself or the person for whom you are caring; loss of interest in activities previously enjoyed; emotional and physical exhaustion; and irritability.

- ↑ Depression
- ↑ Anxiety
- ↑ Substance Abuse
- ↑ Heart Disease
- ↑ Chronic Diseases
- ↑ Mortality

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Just because dementia has come into your life doesn't mean that joy has to go out.

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In Loving Memory of Michael Brandt



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