

What Dementia Care Costs Me

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BACKGROUND Found poetry provides a more accessible method for participants to receive study findings.

METHOD This found poem was created from the words from focus group participants who are persons living with dementia and their care partners.

RESULTS By using participants' rich descriptions of their experiences, we can gain a more emotive and nuanced understanding of their lived experiences.



Image creation facilitated by AI

What happens to the caregiver,
the person living with dementia,
no longer able to work or
function,
it's a big worry.

We can't afford to hire somebody.
To leave her, I'd have to have
somebody come in,
extra added expense
Makes more sense for me to do it.

The cost of over-the-counter
products
sure do add up:
Accessible toilet seat, ibuprofen,
lidocaine patches.

I can relate, I can tell some stories
How its affected my family.
Going through a maze,
keep hitting dead ends.

First step was losing a career.
We've lost insurance and 401Ks,
access to long-term care;
Future planning goes away.
It's getting harder as time goes
with dementia
needing to provide for yourself,
survive and start working again.

Wish there was some kind of
program
pay whatever amount – to take
care of your loved one.
The VA pay a family member to be
the caregiver,
an outside resource most don't
have.

Medications are exorbitant
not all insurances pay.
One pill costs \$5,000 a month–
couldn't pay that if I had to.

Barely making it month to month,
paycheck to paycheck
savings is gone.
You cut back, save your money.

I'm privileged
In a field where we have more
flexibility.
I was able to decline a job, more
prestigious,
so I can be closer to Mom.

We're blessed to have retirement
and Medicare.
Some people live on Social
Security.
Some have a health flexible savings
account
other people don't.

Never had to keep a budget,
don't know how to spread that
money out,
don't know how to make the
difficult decisions.
Stress about worrying how to
afford things

It's not just about money.
The worst thing of quality of life,
can't do the stuff we used to.
Had to change our lifestyle
drastically.

I wish there was a resource
more financially helpful
all those resources--
not helpful.