HELPING DEMENTIA FAMILY CAREGIVERS WITH DECISIONS

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I should be out there making money or helping people more. I’m an onlooker, not a participant. I feel so darn useless, a sense of shame, but nobody really wants to talk to you.

– Cary S. Henderson, PhD

Partial View: An Alzheimer’s Journal
He tries to make Mom a cup of cocoa – the pot boils over. He picks it up from the burner and sets it down on the plastic dish rack. The rack smells. He smells the scorch and moves the pot to another burner.

Plastic has stuck to the bottom of the pot and seeps on to the stove. Now two burners are ruined. The pot, dish rack and stove are a mess. My mother yells at my father. My father retreats upstairs like a shamed dog. My mother stands in the kitchen, shaking and crying...

..There are days when he won’t talk, won’t look at us. He’s afraid to go anywhere, do anything. He understands one thing only. The world has become a treacherous place, full of deceptively innocent objects like pots that can turn on him.

- Kelly Cherry, University of Wisconsin
ANOSOGNOSIA

- Lack of self-awareness, or insight.
- Unaware of one’s own decline or difficulties.
- Person ... is not behaving in a difficult, hurtful or indifferent manner on purpose.
Family care affects all relationships
Family care is rarely fair or equal
Family care disrupts lives
Family care may not be a choice
Family dementia care is different from other care
THE SIX Cs OF DEMENTIA FAMILY CARE

- Common
- Chronic
- Complex
- Costly
- Choices
- Conflict

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WHAT FAMILIES MUST DO

- Define and negotiate complex decisions
- Perform physically intimate tasks
- Manage emotions and communication
- Capitalize on preserved capacities
- Miles to go....
THE FAMILY CARE ROLE: WHAT HAPPENS?

- Organizing for two and adapting work
- Finding, asking for and using help
- Solving problems alone or with resistance
- Making, carrying out and living with the consequences of decisions
- Dealing with imbalances in give-and-take
- Dealing with resentment, disappointed expectations and uncertainty
“While the decisions are difficult, it is not just the decisions themselves which bring pain and confusion. There is the constant fear of how each decision will appear in retrospect, to myself and others, when more information is in...”
CAREGIVER CONCERNS

- Family conflict
- Guilt
- Anger
- What’s next?
- Driving
- Finances
- Home alone?
- Long term care

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I live in the South and down here, guilt is something we pass down through generations like broaches and pound cake recipes.

- Lisa Lopez
Greensboro, NC
Risk factors

- Too many responsibilities
- Unpleasant tasks
- Feeling under-appreciated
- Little support
- No light at the end of the tunnel

“I’m becoming someone scary. I’m not sure what I might do to him.” - A Wife

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“My anger of being a captive of Mother’s AD was so intense that I had to pack a lunch to go to confession.”

- A Daughter
NOT-SO-WELL-BLENDED FAMILIES
THE FAMILY FIXER

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BEWARE: THE SEAGULLS

Long-distance know-it-alls will fly in for “Tea and Criticism” to undo what you have done.
Whose needs?
Autonomy vs. Safety?
How long?
How much?
How to evaluate risk, cost and benefit?
I was taking one day at a time, but then several days got together and ambushed me.
ON TO THE NEXT CRISIS:
EXPECT THE UNEXPECTED
“But honey, I don’t need a doctor. I’m more fit than other women my age at the gym. Haven’t you read about all those medical mistakes? Tests, doctors and pills can kill you.”
The doc asked her to draw a stupid clock, gave her Aricept and said to come back in six months.

The doc advised us to “take her home and love her”

The emergency room doc said she can’t go home alone, but her regular doc has only said she has a little dementia…
She didn’t want me to take over.

- Daughter
“BUT MA – IT’S POURING NOW!”

RAINY DAY SAVINGS BANK

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IT’S THE MEDS!

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WHO ARE YOU TO QUESTION?

I’ve had a clean driving record since before you were born.
RESISTANCE TO COMMUNITY HELP

- Stigma
- Cost
- Denial/Poor judgment
- Too many changes at once
- Loss of control
- Privacy issues
Who knew it would be five years?
The devil is in the details. You can start with the loftiest notions and find yourself ground down by endless details. Who will get Grandpa out of bed? Who will shave and get him dressed...?”
But she fired all the help!
Family Care at Home is Not Synonymous With Caring or Even “Least-Restrictive Environment.”
# Celebrity Community Care

Your Mother Is Eligible If:

<table>
<thead>
<tr>
<th>Requirements</th>
<th>Eligibility Requirements</th>
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<tbody>
<tr>
<td>Short-Term Acute Care Needs</td>
<td>NO History Of:</td>
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<tr>
<td>Homebound</td>
<td>Psychiatric Illness</td>
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<tr>
<td>Compliant</td>
<td>Radical Politics</td>
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<td>Recent Hospitalization</td>
<td>Incontinence</td>
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<td>Bedbound</td>
<td>Combativeness</td>
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<tr>
<td>Over 65 Years Old</td>
<td>Infectious Disease</td>
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<td>Grateful Family Present At All Times</td>
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At work I tried to keep pace with my job while fielding my mother’s incessant phone calls, chasing down doctors, phoning in prescriptions, hiring aids, arguing with my brother, fighting back tears, and dashing out for emergencies.

- Jane Gross, daughter and author, 2011
WHY ISN’T THIS MORE LIKE *TUESDAYS WITH MORRIE*?
HOSPITALIZATION HAPPENS

Drive-Through Discharges Brought To You By “Resource Managers”

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Hospitalization is a choice
• Bag packed, bring a friend and stay
• Family manages and monitors meds
• Primary care and specialist follow-up

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BUT SHE DOESN’T BELONG IN A NURSING HOME...
When I saw him coming toward me in wet socks and somebody else’s shoes, I thought, “Is this what it has come to? I work so hard to protect him and feel betrayed by those I entrusted him to. This is symbolic of the failure of their contract to care for this man who was so important to us....
...when I visit my mother...for a while, I go completely crazy...she is perfectly content to sit and stare. It makes us her children uncomfortable. We want her to be doing something, thinking something, reading something, participating. Her silence is the ultimate lack of confirmation...to lose such an important listener in life is like losing my shadow...

- R. Lindberg, No More Words, 2001
Information

Doers: Wish list, concrete help, accompany

Listeners: Absolution, forgiveness, sensitivity

Reminders: You didn’t cause, you can’t cure, you can’t control

Respite: Fresh perspective and appraisal
HELPFUL FAMILY INTERVENTIONS

- Treat depression/anxiety
- Social connections
- Set realistic expectations
- Support groups
- Respite
- Set personal health goals
People tell me to take care of myself – yeah, right!

People always ask about my husband. Don’t I count anymore?

I’m always waiting for the other shoe to drop.

I’m losing ‘me’ and ‘us’

I can’t not take it personally – why can’t he remember the good stuff?

I’m overwhelmed, beyond exhausted and I can’t see the finish line.

What’s the use? He won’t change.
WHAT DO I DO WHEN...?

- She says she’s going home
- She won’t let me help, but she won’t bathe
- She uses racial/ethnic slurs and curses with helpers
- He asks where I’m hiding his real wife
Mom thinks I’m stealing her jewelry.

He’s getting dressed for work at 2 a.m.

She’s giving money to strangers.

I can’t get my husband to stop driving.
WHAT HELPS?
SAFETY BASICS

- Financial and internet protections
- Medication management, OTCs, toxins
- Safe Return/Medic Alert/Silver Alerts/GPS trackers
- Guns, power tools, kitchen safety
- Monitoring: Low and high tech
WHAT HELPS?
IS SHE OKAY LIVING ALONE?

- Telephone? Mail? Doorbell?
- Med management?
- Day/night?
- Internet shopping?
- Travel outside home?
- Bathroom/continence?
- Falls/injuries?
- Weight loss/food storage
- Available discreet surveillance?

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FAMILY GUIDANCE

- Set priorities
- Find and use different help as things change
- Choose your battles
- Adapt expectations
- Change perspective
"IF YOU CAN'T LIVE UP TO YOUR EXPECTATIONS, LOWER THEM."

Presented by nextavenue
Nobody wants to change relationships

Anticipate role changes

Expect changes in responsibilities

Accepting the “new normal” doesn’t mean liking it
These are circumstances you did not create and which are beyond your control.

Do your best under the circumstances but that does not mean doing it all yourself.

No care plan is forever.
WHAT HELPS WITH GUILT & SEAGULLS?

- Accept negative feelings, expect resentment
- Forgive yourself when efforts go awry
- Work on the quality of time together
- Establish time & energy priorities – what’s most important to you now?
- Set limits, say “no” and mean it
- Act from love or commitment
When someone makes me mad, I take a deep breath, count to ten, and by three I've thought of a really vicious comeback.
I did what seemed best at the time.

There are no perfect answers and no perfect families.

If I had selected another course, I might now have doubts about that as well.

Things would have been worse if I had done nothing.

Others in similar situations have come to similar conclusions.

TEACH FAMILIES TO
RESIST SECOND-GUESSING
The Working Daughter Manifesto

This IS your life. It may not be what you planned, but it’s what you have. Find a way to embrace it and live it TODAY.

Look for what’s GOOD every single day.
There is ALWAYS something good.

Laughter is the best medicine - for the caregiver.
Asking for and accepting help is a sign of strength. Learn to do it with GRACE.

THE ONLY WAY THROUGH IS THROUGH. THERE IS NO GOING under, over, or around. GO NOW!

Perfect is overrated. Caregiving is a JUDGEMENT-FREE zone.

You have the RIGHT to have a LIFE. Your life, your health and your happiness matter as much as anyone else’s.

Life is tough but you are tougher.
Let your cape fly WARRIOR.

On the other side of hell is wisdom, perspective and HOPE.

you are a force for GOOD.
The work you do may be unpaid, undervalued and often invisible, but it is the most IMPORTANT work of all.

TOGETHER we are stronger. No one should do this alone.

www.workingdaughter.com

THE WORKING DAUGHTER MANIFESTO

workingdaughter.com
Liz O’Donnell

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WHAT HELPS?
EVIDENCE-BASED STRESS RELIEVERS

- Yoga
- Tai chi
- Meditation
- Prayer
- Mindfulness
- Relaxation techniques
IS THERE AN APP FOR THAT?

Free with trial
- Headspace
- Calm

Free
- Insight Timer
- Stop, Breathe
  & Think

The Book of Joy
BUFFET OF EVIDENCE-BASED OPTIONS FOR DEMENTIA CAREGIVERS

1. Identify one positive event daily
2. Tell someone or share on social media
3. Write in a gratitude journal
4. Reflect on personal strength and how used recently
5. Set small daily goal and note progress
6. Use positive reappraisal or reframing
7. Perform an act of kindness every day
8. Concentrate on the present moment - Mindfulness

J. Moskovitz, Health Psychology, 2019
IN A SUPPORT GROUP YOU CAN...

- Share difficult feelings such as anger, fatigue, regret and frustration
- Express disappointment in professionals, providers and family
- Recognize that you are not a failure
- Find areas of growth and humor
- Receive immediate, practical help
You mean I’m not the only mean daughter?

I never suspected that there were so many “right” ways to get Dad out of the driver’s seat.

Only these people know why I can’t do this myself.

Where else can I say how I feel and have “fellow travelers” understand?

Welcome to the club no one wants to join.
WHAT HELPS?
RESPITE

- Most preferred, least available, least affordable
- Respite is an outcome, not a service
- Timing, frequency, flexibility, dependability, affordability and quality affect use and outcomes
- By the time respite is needed, there is a need for many other community supports
- Try it, you will like it, and you will want more.

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We had aides coming for a while but, I don’t know, it just got too stressful with them comin’ in because you never know what time they were comin’ and who was comin’ or what they were gonna do. Most of the time they didn’t do what they were supposed to do, so I said I would go back to doin’ the best I can myself. They don’t have any actual training for the job...And some of them would get rude. When we got a good (aide) they either quit or they took them out and gave us somebody else. There was no sense in having them and putting the stress on us.
... another way of taking care of yourself is doing your day job well — making work a place where you feel capable, useful, satisfied, and engrossed — at a time when feelings of incompetence and futility dominate the other half of your life.

- Jane Gross
WHAT HELPS WHEN A FAMILY MEMBER LIVES IN RESIDENTIAL CARE?

- Communicate your relative’s story and participate in assessment and care planning.
- Have family members visit at different times of day and week (comfortable for the resident) and use guest book for communication.
- Join with other family members for shared visits and/or form a family council.


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REMMINDERS FOR DEMENTIA FAMILIES

- Grief comes with this process of loss. It is hard to see suffering.
- There is no single right or wrong place to care or care plan.
- This is the rainy day for which you saved.
- Respite options protect your health and his future care.
Avoid promises that include the words “always, never or forever”

Find ways to help each other to feel purposeful, appreciated and loved

Find forgiveness, expressive and altruistic outlets

Take time to celebrate small victories when things go well