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## Caring for Caregivers

### At the Movies

Two movies released in 2020 depict the painful reality of dementia. “The Father”, starring Anthony Hopkins, follows an aging man who is experiencing progressive memory loss. He refuses all assistance from his daughter and begins to doubt his own mind and the fabric of his reality.

“Supernova” stars Colin Firth and Stanley Tucci as a same sex couple together for 20 years. They are dealing with the reality of younger-onset dementia affecting Tucci’s character, Tusker, as they travel across England in their camper van visiting old friends.

“Robin’s Wish” is a 2019 documentary about the last years of Robin Williams’ life, his suicide and his post-mortem diagnosis of Lewy Body Dementia. His widow described his dementia as “the terrorist inside my husband’s brain,” affecting his memory and motor skills.

Julianne Moore received an Oscar for her performance in “Still Alice”. The story shows what younger-onset dementia looks like and feels like for the patient and the family. It is a story of caregiving and the dignity of dementia sufferers.

All of these films capture the devastating effects of dementia, especially younger-onset dementia.

### Younger-onset Dementia: In the Prime of Life

People with younger-onset dementia are most commonly diagnosed in their 50’s, but dementia can occur in the 40’s and even as early as in the 30’s. Younger-onset dementia simply means that dementia occurs before the age of 65. Frontotemporal and Alzheimer’s are the most prevalent dementias with younger-onset. People who are diagnosed with younger-onset dementia are still in the midst of their careers, raising families and supporting their elderly parents. Dementias that strike in the prime of life are devastating to the sufferer, their caregiver(s) and their younger families which may include children still living at home.

Age-appropriate services are lacking for people with younger-onset dementia, especially in adult care services. The delay in getting younger-onset dementia diagnosed means jobs and long-term disability can be lost, and out of pocket expenses can soar and destroy financial security.

Frontotemporal Dementia(FTD) damages the area of the brain which controls personality, often manifesting with behavioral changes that can lead to a misdiagnosis of psychiatric illness. For example, a female patient in her 50’s with FTD, developed an obsession with motorcycles and younger men. Another patient pulled food off grocery shelves and ate it. Sufferers may end up in prison or psychiatric care. Families and caregivers suffer with high levels of psychological trauma and divorce rates are high. The children of a parent with FTD can suffer acutely. Imagine your parent is unable to attend your graduation or wedding, or you can’t have friends over because your parent has dementia.

Both younger-onset Alzheimers’s and FTD have a strong genetic component. People with significant family histories may consider genetic testing and counseling.

## Zoom Support Groups

**Elderhaus offers two virtual caregiver support groups weekly. All community members are welcome. Every Monday 1-3 p.m. or Wednesday 9-11 a.m. Please send your email address to [caregivers@elderhaus.org](mailto:caregivers@elderhaus.org) and you will be sent an invitation with a link to join the meetings. Even though we can't meet in person we can still offer support to each other.**

## A Caregiver's Hats

How many hats do caregivers wear? A lot. The caregiver role demands so much time and energy that other roles can be neglected. For example, a woman who cares for her aging parent may find she has little time or energy to devote to her spouse, children or her job. The caregiving role does not stay static, it changes as care needs change or dementia progresses. Caring for a spouse with dementia can become like caring for a child so the role of spouse changes. Caring for a loved one with dementia demands a caregiver play a variety of roles to support their loved one:

- Keeping track of doctor's visits and ensuring medications are being taken
- Managing the patient's finances
- Personal care such as bathing, dressing, preparing meals and feeding etc.
- Finding and using support services such as adult support groups and day service programs
- Managing others who provide patient care
- Doing household duties like cleaning, maintenance and repairs

A caregiver's relationship with their spouse can suffer as their time and attention are focused on the care receiver. Spouses of caregivers may feel their needs take a backseat. It is important for caregivers to set aside time for social activities with their spouse. If the care recipient is living with the caregiver and spouse it is paramount that privacy and boundaries be set with the care recipient. Enlisting help from your spouse can be beneficial. Checking in regularly with your spouse is important.

Because many caregivers are caring for elderly parents and parenting children still living at home, role conflicts in this situation are common. Children need time and attention and family rituals and celebrations shared with the caregiver. A caregiving Mother is sure to experience guilt trying to provide the best care to her children and to the care recipient. Children need to be able to express their feelings and to have some one-on-one time with their parent. Managing these role conflicts is a delicate balancing act.

Artificial intelligence is no match for natural stupidity.

HA!

Nothing in fine print is ever good news.

HA!

A dog has an owner. A cat has a staff.

HA!

**Elderhaus is open on a limited basis. Details are posted on our website [elderhaus.org](http://elderhaus.org) and Facebook page. Support services for caregivers are available virtually. Contacts: Tim or Danita @970-221-0406 or [caregivers@elderhaus.org](mailto:caregivers@elderhaus.org)**