

Adjourning Alzheimer's

Caregiving (Day 60)

First, we introduce an often-forgotten therapy in Alzheimer's - **caregiving**. Despite the promise surrounding many potential therapies, quality caregiving remains the most effective, gold-standard therapy for Alzheimer's to this day.

A **caregiver** is someone who supports another person for personal - not professional - reasons. This includes supporting that person's health, but it also includes supporting that person in other ways, such as cooking, shopping, and transportation, to name but a few. Therefore, caregiving constitutes an all-encompassing therapy for a person with Alzheimer's.

Unfortunately, many caregivers are susceptible to **caregiver burden**, a state of stress perceived by the caregiver due to the homecare situation. It is important to note that caregiver burden is subjective; the severity of it depends on the combined physical, psychological, emotional, and financial stress **as experienced by the caregiver** rather than what other people perceive that stress to be. Caregiver burden can result in fatigue, poor sleep, depression, anxiety, social isolation, and a reduced quality of life for the caregiver; in fact, some studies show that up to 50% of caregivers meet the criteria for major depression.



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There are two factors that make a particular caregiver more prone to caregiver burden compared to another. First, caregivers who are **immediate family members** of the person with Alzheimer's experience a greater degree of caregiver burden than more distantly related caregivers. Second, the longer the **period of time spent as a caregiver**, the more prone a person is to caregiver burden.

Those caregivers experiencing caregiver burden generally mention four things in particular to be the **most** burdensome:

(1) **The energy required to be a caregiver** - Given that many caregivers are spouses and therefore the same age as or older than the person with Alzheimer's, they may have health problems of their own. Moreover, caregivers who are the children of the person with Alzheimer's often have many other responsibilities relating to work and family; there's not always enough energy to go around.

(2) **Desire for the supported person to get better** - Adjusting to the inexorable progression of a disorder like Alzheimer's is difficult for many caregivers; often, they just want the Alzheimer's to get better. It is therefore not surprising that most caregivers consider quality of life to be more important than survival time in their loved one with Alzheimer's.

(3) **Insufficient time for one's own interests** - Caregiving is often a full-time job, one with the potential to encompass the entirety of a caregiver's life. There's not always enough time for a caregiver to pursue their own hobbies and interests.

(4) **Sadness over the fate of the supported person** - In the latter stages of Alzheimer's, the person may be different from the person that the caregiver once knew. This can result in intense feelings of loss and sadness.

If caregiver burden is not treated and checked, it can lead to **caregiver burnout**, a state of physical, psychological, and emotional exhaustion that may lead to changes in attitude, **from positive and caring to negative and unconcerned**. This can happen if caregivers either don't get the help they need, or push themselves too hard. Warning signs of caregiver burnout include changes in weight or sleep, increased irritability, decreased participation in hobbies and interests, withdrawal from other family members, and loss of hope. Caregiver burnout must be treated before it occurs.

WARNING SIGNS

Warning signs of full-blown case of caregiver burnout according to WebMD:

- ◆ **Withdrawing from friends and family**
- ◆ **Loss of interest in activities**
- ◆ **Feeling blue, irritable, or hopeless**
- ◆ **Losing or gaining weight**
- ◆ **Changes in sleep patterns**
- ◆ **Immunity – getting sick more often**
- ◆ **Wanting to hurt self or the person cared for**
- ◆ **Increased Alcohol or Drug use**
- ◆ **Feeling Isolated**



Warning signs of caregiver burnout.

Caregiver burden must be identified by the caregiver - and if they do not, by family, friends, and medical professionals - before it has a chance to convert into caregiver burnout. Once identified, there are a number of **interventions targeting caregivers** that can be instituted, all of which have been proven to reduce caregiver burden:

(1) **Arranging “time for self”** - Caregivers ought to allocate a small amount of time several times a week when they can do what they want to do, ideally alone. If the supported person has more advanced Alzheimer’s, a period of respite care is very helpful; respite helps the caregiver “recharge” which will allow them to provide a longer period of caregiving in the long run.

(2) **Joining a support group** - A caregiver support group, with regular meetings, is an excellent way to relieve caregiver burden. It also allows caregivers to swap useful tips and experiences when faced with difficult situations - when in doubt, ask another carer.

(3) **Receiving education and training for challenging behaviours** - A person in the later stages of Alzheimer’s may develop behavioural difficulties such as agitation, aggression, hallucinations, and delusions. Learning about and knowing how to manage these potential behaviours has been shown to alleviate caregiver burden.

(4) **Seeking counselling** - This has been proven to be very helpful in reducing caregiver burden, either through individual counselling, or family counselling.

(5) **Treating mood disorders** - Caregiver depression and anxiety must be treated. This can be done with medications or non-medical therapy - it does not matter how, but if left untreated these two mood disorders will substantially increase caregiver burden.

(6) **Organizing institutional care** - Institutional care is a two-edged sword. On one hand, caregivers often feel relieved that the supported person’s care will be taken over by an institution, but on the other hand, there may be feelings of guilt. Moreover, although caregiver anxiety usually decreases post-institutionalization, caregiver depression often worsens. It may be helpful to surround a person in a care facility with **memorabilia** (things that remind a person of good times, such as life pictures or favourite music); memorabilia have been shown to contribute to positive feelings in the caregiver and reduce medication usage in people with advanced Alzheimer’s residing in care facilities.



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Let's sum up. Quality caregiving remains the **most effective, gold-standard therapy** for Alzheimer's today. However, caregiving is far from easy, and for that reason, caregivers themselves are at risk of caregiver burden, which if untreated can lead to caregiver burnout. Hopefully, the caregiver possesses the insight to identify if they are undergoing excess caregiver burden, but if they do not then it is up to family, friends, and medical professionals to do so. There are a number of interventions targeting caregivers that can help them maintain their own health, which in turn will maintain the current gold standard of therapy for a person with Alzheimer's.

No study of a potential therapy for Alzheimer's can ignore the well-being of the caregiver. Thus, the **Alzheimer's Dietary Study** will not only aim to help each participant stick to their diet, it will also aim to help each study partner or caregiver in making the transition to a modified diet as seamless as possible. We will do our best to answer questions and address problems using a supportive framework consisting of regular emails, weekly online videos, and additional contact as required. Moreover, the caregiver will be a vital part of the assessment at each clinical visit - while we will be assessing the cognition of each participant directly, we will also be assessing their function and quality of life via their study partner or caregiver. I sincerely hope you will join us.

Matt (Neurologist, Waikato Hospital).

References

(1) Sansoni et al. 2013. Caregivers of Alzheimer's patients and factors influencing institutionalization of loved ones: some considerations on existing literature. *Ann Ig* 25, 235-246.

(2) Mohamed et al. 2010. Caregiver Burden in Alzheimer's Disease: Cross Sectional and Longitudinal Patient Correlates. *Am J Geriatr Psychiatry* 18(10), 918-927.