



Hope  
Empowerment  
Acceptance  
Love

*Don't Worry,*



*Be Happy*

## **Caring for a loved one with Dementia**

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# What is Dementia?

- A brain disease (syndrome) that results from brain cells dying at a rate faster than normal
- Memory, cognition, behaviour and emotions are affected
- Can happen to anyone
- Degenerative and progressive, so no cure
- Treatment is to alleviate symptoms only
- Have several causes – including Alzheimer's and Vascular



# Stages of Dementia: Early Stage

- Forgetfulness
- Losing track of time
- Becoming lost in familiar places

# Stages of Dementia: Middle Stage

- Becoming forgetful of recent events and people's names
- Becoming lost at home
- Having increasing difficulty with communication
- Needing help with personal care
- Experiencing behavior changes, including wandering and repeated questioning

# Stages of Dementia: Late Stage

- Becoming unaware of time and place
- Having difficulty recognizing relatives and friends
- Having an increasing need for assisted self-care
- Having difficulty walking
- Experiencing behavior changes that may escalate and include aggression

# Effect on Family and Carer

- “Loss” of loved one – things change due the illness – especially at middle and late stages – very forgetful
- communication difficulties
- repeated questioning very testing
- worries about safety – wandering behaviour, forgetting to turn off gas after cooking
- unable to recognise close ones; needing help in ADL’s

# Tip for Caregivers

- **Remember the person is more than the disease.** When someone is diagnosed with dementia, it can be devastating to them and their loved ones. Hold on to who you know they are, before the diagnosis.
- **Do not argue with your loved one.** Arguing with your loved one about a forgotten memory will only upset them and further frustrate you. Be willing to let most things go.
- **When your loved one gets agitated** such as wandering in the house, try to divert his attention (e.g. by offering him a cup of tea).
- **If his behaviour is not likely to cause harm,** don't prevent him from doing it (e.g. muttering to himself).
- **Detect and divert things that may cause undesirable behaviour** (e.g. shoes near the front door which may prompt him to want to leave the house).



# Tip for Caregivers

- **When your loved one shows acute and disturbing changes in behaviour**, find out if he is in discomfort (e.g. too tired or thirsty or changes in bowel habits), if uncertain, bring him to see a doctor because he may have an underlying acute medical condition.
- **The disease is responsible for their personality and mood changes.** It can be so hard to watch a loved one change before your eyes. Remember that they are not changing, but the disease is progressing.
- **Take care of yourself.** When caregivers do not care for themselves they can experience caregiver burnout. Be sure to take a few minutes to yourself every day and join an online or local caregiver support group.
- **Meet your loved one in the now.** Don't try to change your loved one back into the person they once were. Grieve the loss of your loved one and then love them as they are right now.
- **Use every method of communication to reach your loved one through the disease.** Art, music, dance, poetry, drama and reading are all ways to connect with your loved one when verbal expression is no longer an option. Even a simple touch on their arm can help communicate that they are loved.



# Tip for Caregivers

- **Be educated about the disease.** Learning as much as you can about the progression of Alzheimer's can help you understand and empathize with your loved one.
- **Understand your own physical and emotional limitations.** Act accordingly to avoid stress and caregiver burnout.
- **Give them independence when possible.** As tempting as it may be to do everything for your loved one, it is important for them to do as many things as possible by himself or herself, even if you need to start the activity.
- **Develop routines and predictable schedules.** As the disease progresses it is more important than ever to have set routines and scheduled. This can help to eliminate confusion and frustration for your loved one.
- **Don't underestimate the power of good nutrition.** Studies have linked Alzheimer's to lifestyle choices, including poor nutrition. Limiting refined sugars and increasing vegetables can help manage behavioural issues.



# Tip for Caregivers

- **Plan daily time for physical exercise.** It's important to focus on the health of your mind, but also your body during this time. Physical exercise can help, especially if you plan a time for it each day.
- **Rely on family members and other loved ones when needed.** After everything you have done to support your loved one with Alzheimer's, remember that you also need support for yourself as well. Turn to family members and other loved ones when you need them.
- **Take immediate action** to complete living wills and other essential documents.
- **Remember that an Alzheimer's diagnosis is not a death sentence.** Many people with the disease live more than 20 years following a diagnosis. Take advantage of the time you have left with your loved one.
- **Have fun!** Your loved one can still have fun. Trips to the park, zoo, local museums and even everyday chores can be enjoyed by someone with Alzheimer's.

# Tip for Caregivers

- **Be realistic in your expectations for yourself and your loved one.** Set realistic goals and learn to expect the unexpected. Don't set yourself up for failure by setting unrealistic expectations as your loved one struggles with Alzheimer's.
- **Maintain a current list of medications** and dosages of medications. This will ensure you always know when their next dose of medication will be and you will be able to accurately share any medication information with doctors or other caregivers.
- **Remember that your loved one can remember emotions** even after they forget the actual event that caused those emotions. Your words and actions matter!
- **Create an environment that is peaceful and pleasing.** Often make him feel at peace and praise him.
- **Take a deep breath!** Caregiving is a big responsibility but you are doing a great job.



# Resources

- Courses about dementia
- Support Groups
- Befrienders (Dementia Friends)
- Home-based care – counselling
- Respite Care
- Dementia Day Care
- Financial Assistance
- Grassroots Leaders
- Volunteer Organisations