Alzheimer's Disease:
How to Take Care of a Patient at Home & How to Take Care of the Caregiver

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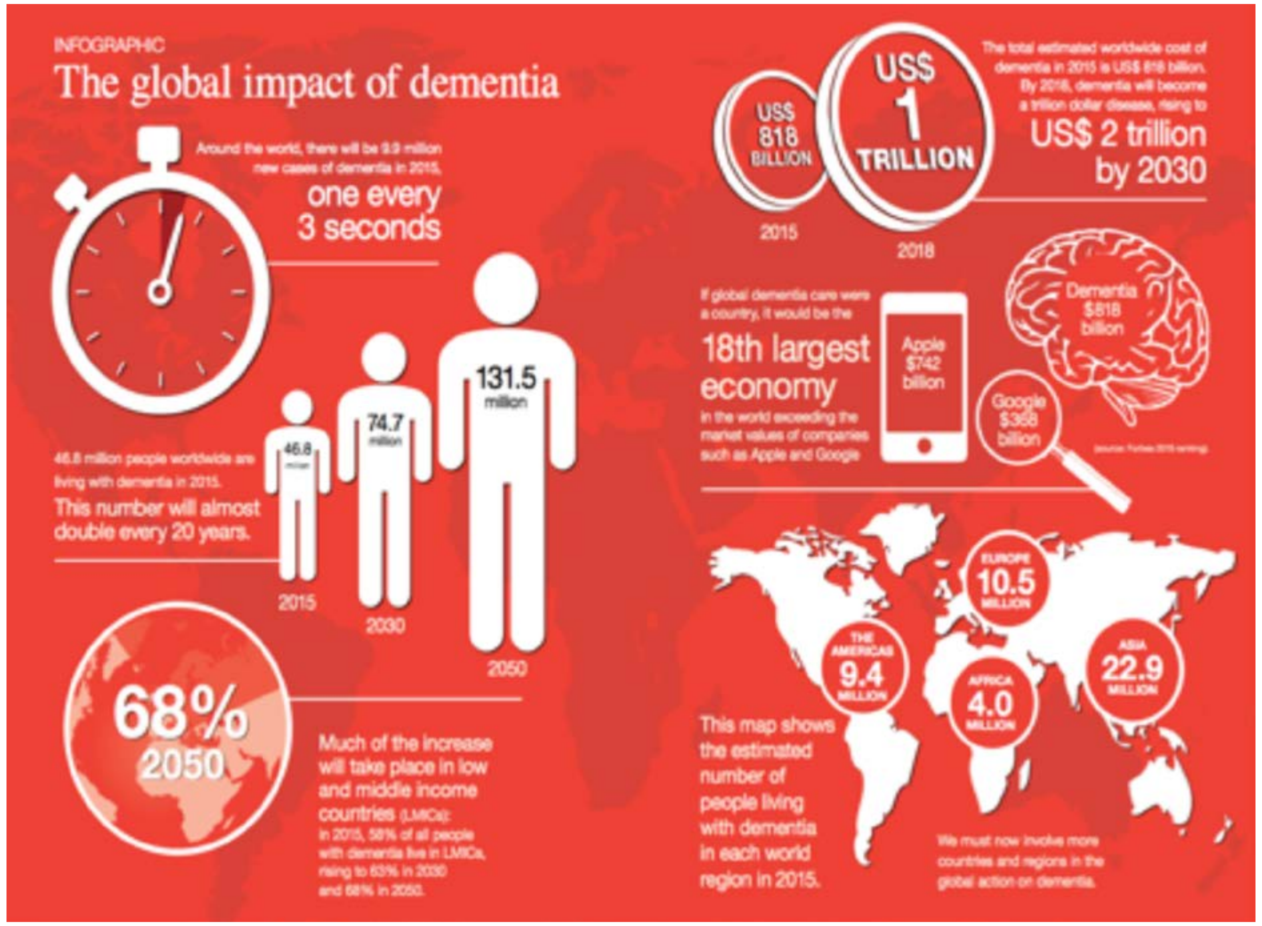
Introduction

There is an unprecedented growth of the global population aged 60 and over, which is expected to expand further, from 12% in 2014 to 21% in 2050.

Most elderly individuals live in low- and middle income countries (Bluestone et al, 2015). With the increased survival of older people, morbidities become more prevalent. Often these morbidities, in particular dementia, are associated with disability. Consequently, the elderly requires assistance and care at different levels: medical, psychosocial and financial (Ryan & Wroblewska, 2013). **Up to 47 million people in the world are living with dementia today, and this number will double every 20 years** (Prince et al, 2015). Most people with dementia reside in low- and middle-income countries (Prince et al, 2015). Most care for the elderly is provided either by formal services or by the family. The former includes nursing home placement and is mainly practiced in high-income countries. Family-based care is predominant in low- and middle-income countries, especially in the Arab region, where it is considered an obligation and a social tradition. Consequently, the level of use of institutionalization is one-fifth of that in high-income countries (Sibai, 2009).

In the Arab region, only a handful of studies have been conducted on carers of the elderly (Leichtentritt et al, 2004; Khalaila & Litwin, 2011).

Studies on the impact upon the person doing the caring are scarce. None has examined the effect of dementia on the carer's well-being (Seoud et al, 2007; Chemali et al, 2008). Nevertheless, there has been a call for action emphasizing the importance of recognizing the essential role of the family in low- and middle-income countries and how best to support them in that task (Sibai, 2009). Lebanon's proportion of people aged 60 years or over is projected to reach 26% in 2050 (Mirkin, 2010). Only 1.4% of the elderly live in nursing homes, and 70% are females (Chemali et al, 2008). As in other countries in the Arab region, cultural and religious values emphasise the central role of family care. A recent study showed that a typical Lebanese family carer is a married daughter (average age 46 years), who is usually unemployed (67%) and is providing care to a 76-year-old widowed woman who lacks medical insurance (Seoud et al, 2007). Reports in the literature show that the impact on the carer of looking after an elderly relative with cognitive impairment, behavioural problems or dementia leads to high rates of depressive disorders, anxiety, feelings of burden and poor physical health (Papastavrou et al, 2007; Brodaty & Donkin, 2009; Tremont, 2011).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The global impact of dementia

Around the world, there will be 9.9 million new cases of dementia in 2015, one every 3 seconds

46.8 million people worldwide are living with dementia in 2015. This number will almost double every 20 years.

Much of the increase will take place in low and middle income countries (LMICs): in 2015, 58% of all people with dementia live in LMICs, rising to 63% in 2030 and 68% in 2050.

The total estimated worldwide cost of dementia in 2015 is US$ 818 billion. By 2018, dementia will become a trillion dollar disease, rising to US$ 2 trillion by 2030

If global dementia care were a country, it would be the 18th largest economy in the world exceeding the market values of companies such as Apple and Google

(source: Forbes 2015 ranking)

This map shows the estimated number of people living with dementia in each world region in 2015.

We must now involve more countries and regions in the global action on dementia.

Caregiving at Home

Sometimes, you may feel that you don't know how to care for the person with Alzheimer's disease (AD). You're not alone. Each day may bring different challenges. Learning about AD can help you understand and cope with these challenges. AD consists of three main stages: mild (sometimes called early-stage), moderate, and severe (sometimes called late- stage).

In mild AD, the first stage, people often have some memory loss and small changes in their personality. They may forget recent events or the names of familiar people or things. They may no longer be able to solve simple math problems. People with mild AD also slowly lose the ability to plan and organize.

In moderate AD, memory loss and confusion become more obvious. People have more trouble organizing, planning, and following instructions. They may also need help getting dressed and may start having problems with incontinence. They may have trouble recognizing family members and friends. They may not know where they are or what day or year it is. They also may lack judgment and begin to wander, so people with moderate AD should not be left alone.

Severe AD is the last stage of Alzheimer's and ends in the death of the person. In this stage, people often need help with all their daily needs. They may not be able to walk or sit up without help. They may not be able to talk and often cannot recognize family members. They may have trouble swallowing and refuse to eat.

Taking care of an AD patient at home may have its challenges such as changes in communication skills, changes in personality and behavior, sleep problems and agitation and aggression.

Change in communications skills: Communication is hard for people with AD because they have trouble remembering things. They may struggle to find words or forget what they want to say. The caregiver may feel impatient and wish they could just say what they want, but they can't. The first step is to understand that the disease causes changes in these skills. The second step is to some tips that may make communication easier. Make eye contact to get his or her attention, and call the person by name. The caregiver should be aware of his tone and how loud his voice is; how he looks at the person, and his "body language." Also, a two-way conversation is encouraged for as long as possible. This helps the person with AD feel better about himself or herself. In addition, the caregiver to show a warm, loving manner; to hold the person's hand while talking; to be open to the person's concerns, even if he or she is hard to understand and to let him or her make some decisions and stay involved.

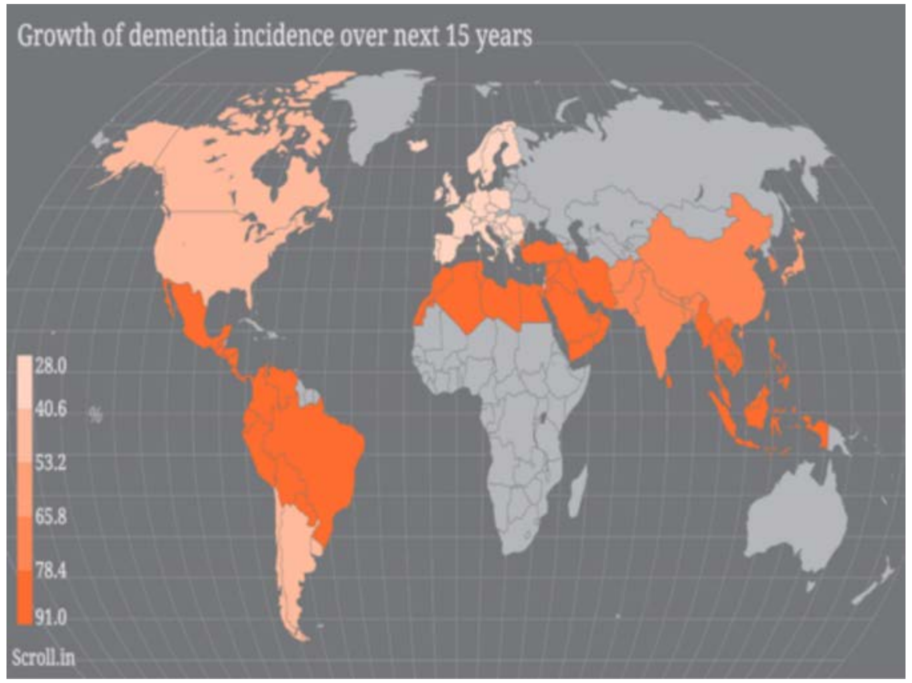
To speak effectively with a patient with AD, offer simple, step-by-step instructions; repeat instructions and allow more time for a response and ask the caregiver not to interrupt. Also, it should not be talked about the person as if he or she isn't there. And it is recommended not to talk to the person using "baby talk" or a "baby voice." Finally, use other methods besides speaking to help the person, such as gentle touching to guide him or her.

Common changes in personality: getting upset, worried, and angry more easily; acting depressed or not interested in things; hiding things or believing other people are hiding things; delusions or hallucinations. Also, wandering away from home, pacing a lot of the time, showing unusual sexual behavior, hitting people and misunderstanding what he or she sees or hears may happen.

To cope with changes in personality, the caregiver must keep things simple such as ask or say one thing at a time. Also, have a daily routine, so the person knows when certain things will happen. In addition, reassure the person that he or she is safe and the caregiver is there to help. Finally, the caregiver should focus on his or her feelings rather than words; for example, say, "You seem worried."

Agitation and aggression: Agitation means that a person is restless and worried. He or she doesn't seem to be able to settle down. Agitated people may pace a lot, not be able to sleep, or act aggressively toward others. They may verbally lash out or try to hit or hurt someone. When this happens, try to find the cause, there is usually a reason. Some reason include: pain, depression, stress, too little rest or sleep, constipation, soiled underwear or diaper; sudden change in a well-known place, routine, or person; feeling lonely and not having enough contact with other people, and interaction of medicines.

To deal with agitation and aggression, look for the early signs. The cause must be dealt with before the problem behaviors start. Doing nothing can make things worse. At times, the caregiver's worries may be affecting the person with AD. Here is it advisable for the caregiver to slow down and try to relax. Also it will be helpful to find a way to take a break from caregiving.



In parallel, allow the person to keep as much control in his or her life as possible; try to distract the person with a favorite snack, object, or activity. Also, keep well-loved objects and photographs around the house. This can make the person feel more secure. Other techniques that may help include reducing noise, clutter, or the number of people in the room. Also using gentle touching, soothing music, reading, or walks are effective ways to reduce aggression and agitation.

Sleep problems: evenings are hard for many people with AD. Some may become restless or irritable around dinnertime. This restlessness is called "sundowning." It may even be hard to get the person to go to bed and stay there.

Some recommendations include: helping the person get exercise each day, limit naps, and make sure the person gets enough rest at night. Also, plan activities that use more energy early in the day. For example, try bathing in the morning or having the largest family meal in the middle of the day. In addition, set a quiet, peaceful mood in the evening to help the person relax. Keep the lights low, try to reduce the noise levels, and play soothing music if he or she enjoys it. Try to have the person go to bed at the same time each night. A bedtime routine, such as reading out loud, also may help. And obviously limit caffeine intake.

Family Burden of Care in Lebanon

We conducted a cross-sectional study of people aged 65 years and over in Lebanon to determine the prevalence of dementia and factors associated with its development.
Dementia and depression were assessed by the 10/66 Dementia Research Group (DRG) diagnostic assessment and the Geriatric Mental State (GMS) (Phung et al, 2014). The burden of care was assessed using the Zarit Burden Interview (ZBI), which measures the strain associated with the care of individuals with dementia (Zarit et al, 1985). As measured by the ZBI, strain was greatest among carers who provided hands-on care. ZBI scores were higher if the elderly relative had dementia or depression, and among carers who were: females, immediate family members, unmarried, unemployed, co-residing with the elderly person, as compared with their respective counterparts.
In fact, more than 50% of caregivers have shown high anxiety and depression scores. Patients with longer duration of dementia, greater severity of dementia, and lower education levels significantly differ in anxiety and depression mean scores. (Int'l. J. Psychiatry in Medicine, Vol. 41 (1) 57-69, 2011)

How to deal with caregiver burden and family conflict:
When a loved one is diagnosed with Alzheimer's disease, the effects on the family can be overwhelming. The reality that someone you care for has Alzheimer's can trigger a range of emotions — including anger, fear, frustration and sadness. Conflicts are common as family members struggle to deal with the changes. To minimize conflict, the family should address the issues together.

A caregiver may find himself taking on a new role in his relationship as his partner's memory declines. The person with Alzheimer's disease may no longer be able to perform certain tasks, such as balancing the checkbook, doing the taxes, handling financial and legal matters and doing certain household chores. The caregiver should be prepared for these changes. He must locate financial and legal documents, such as life insurance policies, property deeds and retirement accounts, soon after the loved one is diagnosed. Also they can turn to family, friends, professionals or community resources for assistance, as needed.

Some tips:

Listen to each family member with respect.
Coping with a progressive illness, such as Alzheimer's, can be stressful — and not everyone reacts in the same way. Family members may have different opinions. Some relatives may deny what is happening; a relative living abroad may be resented for living far away; or there may be disagreement about financial and care decisions, especially at the end-of-life. These issues are complex and require ongoing discussions. Everyone must have an opportunity to share their opinion and avoid blaming or attacking each other, as this will only cause more hurt.\

Discuss caregiving responsibilities.
Talk through caregiving roles and responsibilities. Make a list of tasks and include how much time, money and effort may be involved to complete them. Divide tasks according to the family member's preferences and abilities. Some family members may be hands-on caregivers, responding immediately to issues and organizing resources. Others may be more comfortable with being told to complete specific tasks.

Continue to talk.
Keep the lines of communication open. Schedule regular meetings or conference calls to keep everyone involved up-to-date. Discuss how things are working, reassess the needs of the person with Alzheimer's, and decide if any

changes in responsibilities are needed. Plan for anticipated changes as the disease progresses.

Cope with changes and loss together.
As Alzheimer's progresses and cognitive abilities change, it is normal to experience feelings of loss. Caregivers and family members may want to seek support from others who are dealing with similar situations. Support groups are available at Alzheimer Association Lebanon (see later).

Seek outside help.
If tensions and disagreements are ongoing, you may want to seek help from a trusted third party, such as a spiritual leader, mediator or counselor. Sometimes, an outside perspective can help everyone take a step back and work through the difficult issues.

Alzheimer Association Lebanon:

Since its foundation in January 2004, Alzheimer's Association Lebanon (AAL) has brought hope to families and those they care for. For too long, the disease was a taboo subject, families were stigmatized and those affected were deprived of dignity and modern care.
Working closely with top experts in the medical profession, the Association has focused on changing the environment for those affected by the disease: the families and institutions which care for them; and society at large. Guidance and advocacy are the two pillars of AAL's action.

For families, the slow descent into dementia of a loved one is a shattering experience. During the past decades, methods were developed abroad which both help families to deal effectively with the disease, without anxiety and shame, and maintain the dignity of the affected relative.

AAL has made this knowledge available to Lebanese families, touching hundreds of families. It does so through one-to-one counseling, support group meetings, a help line, monthly workshops, and a website.

Support groups for caregivers take place on a monthly basis where caregivers can meet and share their experience and receive guidance from professionals conducting the support group. This activity has been taking place for years now and caregivers wait for it impatiently.

Workshops occur every other month where a subject related to Alzheimer's disease is presented by a professional in the matter. These workshops are open to caregivers and the public at large.

Training of caregivers: recently AAL stated a new program where professionals are sent to people's homes suffering from AD to train caregivers on how to deal with the illness and to evaluate the safety of the house. This program is currently offered free of charge but limited to Beirut. The training's main objective is to decrease the burden of caregiving.

Helpline: any person can reach the association 24h/day on +961 76 030083
Website: the website is a source of information about the disease and helpful tips. It can be viewed at alzlebanon.org

Social Media: AAL has a very active page on facebook where daily tips and information is shared. The page can be followed at facebook.com/Alzheimers Association Lebanon