Société Alzheimer Society

Taking a Break: Why it's Essential

Why it is important to take a break and strategies on how to arrange it

The demands on your physical and emotional resources will be high if you are a full-time caregiver for a person with dementia. You are a nurse, cook, cleaner, chauffeur, counselor and comforter. If you are fortunate, you have a strong relationship with doctors, nurses, social workers, case managers, home helpers, neighbours and family. You become the person's defender, navigator and advocate, insisting that the needs you can't meet must be met by others. You are a caregiver because you have an intimate relationship with the person you are looking after. Usually the bond is love, but not always. The bond may be one of obligation, religion or simply the lack of anyone else to do it. Caregiving responsibilities start off slowly, early in the disease, but can escalate to 24 hours a day, seven days a week, often for years, as the disease progresses.

It is not difficult to realize that caregivers who are providing day-to-day care for a person with dementia are at a high risk for exhaustion, stress and burnout. Research tells us that if you don't look after yourself you are at risk for physical and emotional health problems. It is essential that your caregiving is balanced with taking care of yourself. You need to take breaks from caregiving responsibilities and they need to be scheduled into your weekly caregiving plan.

Taking breaks or arranging respite care, can relieve stress, restore energy, and promote balance in your life. Many caregivers find that a regular break means that they can recharge and avoid burn out. It also gives a person with dementia an opportunity to socialise and meet other people and for them to get used to other people providing support and care.

A break can give you:

- Time to do things that you need to get done such as going to the bank or grocery shopping
- Time for yourself such as going to the theater, reading a book, getting your hair done, going for a walk, or attending an Alzheimer Society support group.
- A chance to get away for a holiday for a weekend, a week, a day, or a few hours.

A vital component of taking a break is the knowledge that the person with dementia is safe and happy while you are away. Many caregivers will not truly relax and focus on their own well-being if they feel they may be neglecting their responsibilities. If you know that the life of the person you are caring for is being enriched by positive experiences, which you alone cannot provide, then taking a break will become easier for you to accept.

Resources and options available to help you take a break

Informal resources include:

- Make a list of interested people that will become your "Circle of Care" including family members, neighbours, and friends. Schedule them into the week with specific times and activities.
- Consider asking family and friends to assist you with some specific caregiving tasks. If they offer help, don't refuse. Make a list of things that need to be done and then ask them what they would like to do. Ask them to sit with the person who has dementia while you take a break for yourself
- Volunteer companionship for the person with dementia. If you don't have family members or friends to give you a hand, you may be able to find

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a volunteer through your local place of worship, community centre or your local Alzheimer Society.

Formal resources* include:

- Community support programs that provide help with laundry, shopping, preparing meals, home maintenance and paid companionship.
- Personal care or home health aide services to provide assistance with personal care such as bathing, dressing, toileting and exercising.
- Adult Day Respite Programs offer a place where the person with dementia can be with others in a safe environment. Planned activities are scheduled throughout the day such as music and art programs. Transportation and meals are often provided.
- Skilled care services to help with medication and other medical services such as occupational therapy.
- Residential facilities may offer a stay overnight, for a few days or a few weeks. Overnight care allows caregivers to take an extended break or vacation while the person with dementia stays in a supervised, safe environment. The cost for these services varies.
- * Contact your local Alzheimer Society for information on how to access these services.

Turning a "no" into a "yes"

Occasionally difficulties can arise, particularly when using formal resources for the first time. Some caregivers find that the person with dementia does not wish to have someone in their home that they "do not know" or the person with dementia may be reluctant to leave their home to attend an Adult Day Respite Program, for example. These problems are not unusual and should not stop you from taking a break.

There are many ways to manage these difficulties so that you and the person you are caring for can make the most of respite care.

- Many families and caregivers have found it useful to start using both informal and formal resources as early as possible so that everyone can get used to sharing dementia care. It is often best to start with small breaks and build up to longer ones.
- You will know best how far in advance to tell the person with dementia about the break. Reassure them if they are anxious and make sure that they know that you are positive about the break, even if you're feeling a little anxious yourself.
- When the time comes, talk about the break in the context of a 'little holiday' and be positive in your explanation. Stay calm and give information in a clear and simple manner.
- Remember that it is not selfish to want or need a rest.

For further tips and strategies, refer to the Fact Sheet: "Preparing for in-home help and support" http://www.alzheimer.ca/en/pei/First-Link/Resources/Caregiver-Fact-Sheets

Why caregivers are reluctant to take a break

Despite the uniqueness of every situation, caregivers have the common experience of constantly putting someone else's needs ahead of their own. The needs of the person being cared for always seem to come first. Many caregivers deny that they need to take a break or that they need help from others. The reality is that no one can provide care alone for a person with dementia. For further information, take a look at the video: *No Thanks, We're Fine: Supporting Families Living with Dementia* at:

www.youtube.com/watch?v=1SPEWhue4Do

Take a break! You will be a better caregiver when you return!

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Resources:

- Respite Fact Sheet: <u>http://www.alzheimers.org.uk/site/scripts</u> /documents info.php?documentID=140
- Respite as an Outcome: www.ccc-ccan.ca
- The ABC Approach to Behaviours Fact Sheet: http://synapse.org.au/get-the-facts/abc-approach-to-behaviour-fact-sheet.aspx

Further information on this topic

Visit the following websites:

- http://www.alzheimer.ca
- http://www.alzheimer.ca/en/pei

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