Doing What You Can While You Can

By Hilary Doxford

Editor’s note: Hilary Doxford volunteers for the Alzheimer's Society in England as part of their research network. She was nominated by the Society and joined the European Working Group of People with Dementia in October 2014. She is also a member of the World Dementia Council and was the first person living with dementia to join in January 2015. She lives with her husband, Peter, and their dog, Tilly, in England.

In December 2012, at the age of 53, I was diagnosed with early-onset Alzheimer's disease. Things had started getting hard for me at work. I'd had a pretty intensive one-to-one meeting with somebody I hadn't met before. Then a few weeks later I was at a conference and I could have sworn I had never met that person before. That freaked me out having sat opposite somebody for two hours, having an intense conversation with them and then not recognising them a couple of weeks later.

Also, I found when I was watching television I was losing which person was the goodie and which one was the baddie. I also noticed that with music, I would hear bits of tunes and know I knew the song but I couldn’t continue the tune. So that worried me because I do love music, I do know songs, I do know how tunes go.

My doctor sent me for some tests and a brain scan. As a result, I was diagnosed with early onset Alzheimer's. I wasn't surprised because I had suspicions for years that something wasn't right. I didn't want to hear it but was glad there was a reason for why I had been struggling so much at work. I hadn't told my husband, not because we have secrets because we don't. I just didn't want to worry him if there was nothing wrong.

A lot of people say, “What's the point of having a diagnosis if there's no cure?” and it does make you wonder. But for me I'm glad I got the diagnosis because it's made me buck my ideas up and you know it's about living life to the full whilst you can. So if I actually hadn't had that diagnosis, I'd probably carry on struggling at work, not enjoying work because I'm trying to carry on. At least with the diagnosis you can try to make plans for what you are going to do for however long you have got. I know I am young compared to most people who get the diagnosis, but if somebody gets it young I'd say just carry on doing what you want to do. If you want to carry on working, carry on working. It is a wakeup call about life, so live life to the full and count your blessings. (continued on page 2)
Doing What You Can  
(continued from page 1)

It also helps if you can get involved in something like the Alzheimer Society because you become aware of what's going on, what developments there are. If you've got a particular problem, there will be somebody else who has already gone through it. I've had a lot of help from the Society just by going on their website.

Shortly after I was diagnosed, I was asked for three words to describe how I felt. The first was fear. I was scared. It's not a nice diagnosis to receive. I felt despair. And I felt helpless – didn't know what to do. But you still have that tinge of hope because if you haven’t got hope, what have you got? But I didn’t know where that hope was going to come from, or where I was going to go next. Through the Alzheimer’s Society, I started to participate in many research projects. I love being involved in research. I am well looked after and have a purpose and value. I have interesting discussions and am kept aware of the latest research and results. It keeps my brain active and I have a better understanding of my disease. And just maybe I will be one of the lucky ones who is part of the trial that finds the cure.

So, as far as those three words that described how I was feeling when I was diagnosed, my fear has reduced to concern. I’m no longer scared. My despair is now personal happiness. I’m content with my life, but that doesn’t mean I’m accepting the status quo. We still have to move forward with research. I see what’s happening and it gives me great, great hope.

One aspect of my voluntary work with the European Working Group of People with Dementia concerns me. I come over as ‘normal’ because I am fortunate in that although my IQ had dropped dramatically the last time I was assessed, I was still above average. This allows me to mask the difficulties I now encounter when trying to process information. Does appearing ‘normal’ do more harm than good when trying to gain the support of people who do not understand dementia?

What concerns and disappoints me is the number of people with experience in dementia who at conferences will say that the person with dementia speaking could not, in fact, have dementia. It has happened to many of my friends and myself. Very few people will say it to our faces, but will say it to our friends and family members. If they have the knowledge they proclaim, do they not understand the progression of this disease? The early stages are not always visible. But for every 15 minute presentation we give, we have done many hours of preparation to try and be as good as we can be. To those who question us, if you are trying to give me hope, then thank you, but that is not what I hear. I try not to take it personally, but feel I’m being told I am a fraud and a liar. It is not the person with dementia who ‘confirms’ the diagnosis; we only pass on what we have been told. In my case, two separate neurologists have independently told me I have dementia. I know we can be misdiagnosed, but I do not think anyone can give an informed opinion on the basis of hearing a person with dementia talking in public of their experiences.

So to those who tell us that we haven’t got dementia, I pray you are right. But please remember, our public face does not reflect what goes on behind closed doors or inside our wayward brains. But it is about doing what we can, whilst we can because you don’t know what’s round the corner tomorrow. We live for today and we enjoy it!

“I love being involved in research...I have a purpose and value.”

[Signature]
Understanding Alzheimer’s Genes

Many people affected by Alzheimer’s wonder how they developed it or whether it may run in the family. One’s chance of having Alzheimer’s may be higher when certain genes are passed down from a parent. However, having a parent with Alzheimer’s does not necessarily mean that you will develop the disease. Some more rare forms of Alzheimer’s are linked with certain genes that determine much greater risk, especially in cases of younger onset dementia with a strong family history.

The National Institute on Aging (NIA) publishes many resources that can be very informative for families living with Alzheimer’s or a related dementia. These resources can be found under the Health and Aging tab on their website at: https://www.nia.nih.gov/. One of the most recent resources from NIA is Understanding Alzheimer’s Genes: Know Your Family History. This booklet aims to help families understand the role of genetics in Alzheimer’s disease. This booklet will help you learn:

- what genes are
- how genes relate to Alzheimer’s disease
- what it means if you have a family history of Alzheimer’s
- what you can do if you are at increased risk for Alzheimer’s
- how to obtain more information

Read the booklet online or print it out at: https://goo.gl/gzVND1

Speaking Up About Dementia

For some people, the diagnosis of Alzheimer’s or a related disorder is a private matter and discussion may be limited to family or close friends. Others, however, find benefit to themselves and others by being more open about their diagnosis as a means of reducing isolation, possible stigma, or confusion about memory loss and other symptoms.

Each time you speak out on behalf of yourself or others with Alzheimer’s or a related disorder, you are being an advocate in raising awareness about dementia. Some may choose to take this advocacy a step further to become involved in their communities locally or even nationally to advance the knowledge, education, and scientific progress needed to improve the lives of all those affected.

The Alzheimer Society, British Columbia recently released a very useful and informative 14-page guide for anyone wishing to play a role in bringing attention to dementia issues. Speaking Up About Dementia – A Simple Guide to Raising Your Voice provides a discussion of:

- what advocacy is
- how to speak to others about dementia
- how to engage politicians through letter writing or in-person meetings
- how social and print media can make a difference

Read or download this excellent guide at: https://goo.gl/BG4nEZ
“I Don’t Want to Give Up Cooking”

Editor’s note: In February 2016, Carol Mothershead, a participant of the early-stage support group at Alzheimer’s and Dementia Alliance of Wisconsin in Madison, wrote the following letter to cooking show celebrity Rachael Ray. Sadly, she did not hear back from Ms. Ray, but Perspectives heard Carol’s voice and we have printed her letter below. We now hope that Carol will hear from fellow readers of Perspectives, too!

Please share your cooking tips or easy-to-make recipes with Carol by sending them to her support group facilitator, Danielle Thai, at support@alzwisc.org.

All suggestions and correspondence will be shared with Carol and her support group. If we receive enough suggestions, we will compile them to send out to Perspectives readers. Please try to participate in this effort!

Below is Carol’s letter to Rachael Ray:

Dear Rachael,

I love to cook, and I have Alzheimer’s. Due to my symptoms, I have difficulty following recipes. This can be incredibly frustrating. My hope is that you could come up with some recipes that might make it easier for people like me to follow. I know your recipes are meant to be simple and easy already. However, I think recipes need to be adapted even more for people with Alzheimer’s.

I started baking and cooking when I was just a little kid. My grandmother and her family were from Louisiana, and they know how to cook down there with lots of delicious spicing. I was always a super-baker. Pies were my specialty, and at fundraisers one of my pies might go for fifty or sixty dollars!

Since my diagnosis of Alzheimer’s, I have been struggling with recipes. I struggle with measuring ingredients, remembering what I’ve already put in, and where I am in the recipe. Sometimes I can spend an hour just trying to find the right spice in the cupboard. However, I don’t want to give up cooking yet. I want to be able to do it if I choose to. I want that option for myself and for my husband.

If you have some recipes that are tasty, nutritious, and extremely simple, that would be wonderful for cooks like me, as well as for family members who are caregivers. I think recipes with only a few ingredients that don’t require specific measurements would be most helpful. At a support group I belong to, we came up with cooking tips for people with Alzheimer’s and the social worker who facilitates the group wrote a handout with our suggestions (see page 5).

I am writing this letter with the help of Danielle Thai who facilitates the early-stage support programs I attend through the Alzheimer’s & Dementia Alliance of Wisconsin. These programs bring together people like me who have early dementia who are still very active and who have many interests. We don’t give up our interest in living life to the fullest just because we have Alzheimer’s. My husband and I still take ballroom dancing lessons and participate in dance exhibitions. We don’t want to give up anything until we absolutely have to!

Thank you for considering our request for recipes adapted for people with Alzheimer’s who like to cook.

Most sincerely,
Carol Mothershead
(with Danielle Thai, CISW)
Alzheimer’s & Dementia Alliance of Wisconsin
517 North Segoe Road, Suite 301
Madison WI 53705
Tips for Simplifying Your Cooking

Editor’s Note: The following ideas are from Alzheimer’s & Dementia Alliance of Wisconsin early-stage support group members or from staff who work with, and always learn from, them.

Don’t let memory loss keep you from cooking tasty, healthy foods for you and your family. Below are some tips to simplify your cooking. Pick and choose what is most helpful for you or come up with your own ideas to simplify.

Find simpler recipes or adapt your favorite recipes to meet your needs

• Pick recipes with fewer ingredients and fewer steps.
• Use more pre-packaged food such as canned beans, frozen vegetables, etc. You can even purchase pre-chopped produce.
• Use recipes that don’t require exact measurements (e.g. “to taste”).
• Use a crockpot or slow cooker to make everything in one pot.

Get your kitchen organized

• Keep regularly used kitchen supplies together somewhere easy to reach and see.
• Label cabinets and drawers with words or pictures so you know where things go.
• Consider getting rid of duplicate utensils and appliances (such as multiple measuring spoons or cups) to reduce clutter and make it easier to find what you need.
• Clearly label canisters and other containers (such as flour, sugar, salt).

Prep ahead

• Read recipes from beginning to end before cooking so you know what you need.
• Have everything that you need set out before you begin.
• Ingredients: Make sure that you have all the ingredients (including spices) before you begin cooking and set them on the counter.
• Tools: Bowls, pots, pans, cutting boards, stirring spoons, knives, measuring cups or spoons, etc.
• Some people find it helpful to measure the correct amount of each ingredient into separate bowls ahead of time. That way you can double check that you have all the ingredients correctly measured before they are mixed together. Writing the name of each ingredient on a sticky note can help you remember what is in each bowl.

Use memory aids

• Make a copy of your recipe. As you do each step, put a checkmark beside it so that you know you have completed it.
• As you finish measuring each ingredient, you can remind yourself that you’ve already used it by:
  - Putting the item away immediately after measuring
  - Checking that ingredient off of your recipe list
• Set a timer to time all cooking and baking times.
• Find what works best for you and feel free to get creative. One member of our early-stage support group puts the lid on each spice jar and turns the jar upside down immediately after adding it to the recipe to remind her that she’s finished with it.

Consider working together with a friend or family member to prepare meals or have someone else prepare some of your meals for you

• Some families and friends prepare meals to freeze for later. Others take turns cooking and sharing meals together.
• There are a variety of services that deliver prepared food directly to your home, everything from pre-packaged frozen dinners to chefs who prepare a week’s worth of meals fresh in your home. Go online and search “home delivered meals.”
Awakening and Maintaining Your Five Senses

Part Three: SMELL

Over the course of five issues of Perspectives, we are exploring dementia and each of the five senses. In our previous two issues we discussed sight and hearing. In this issue, we explore the sense of smell.

It is not uncommon for people with dementia to have a diminished sense of smell. Although a reduced sensitivity to smell can occur with normal aging, long-term smoking, head trauma, a history of chronic sinus or respiratory problems, or many other reasons, research suggests that a significant decline in the ability to smell or identify odors on certain tests of smell may be one of the earliest symptoms of Alzheimer's. This may be due, in part, to the anatomy, or structure, of the brain.

We have all experienced links with smell and memory. During the holiday season the smell of a turkey in the oven or the fresh pine scent of a Christmas tree can set off memories or emotions from one’s recent or distance past. When we look at brain anatomy, we find that incoming smells are first processed by the olfactory bulb. This structure starts inside the nose and runs along the bottom of the brain. The olfactory bulb connects with many areas of the brain including the amygdala, a region involved with experiencing emotion, and the hippocampus, a region that plays a significant role in making and storing memories. Scientists know that the hippocampus is one of the first regions of the brain affected by Alzheimer’s and accounts for the loss of short-term memory that is an early symptom. Hence changes in the olfactory bulb and loss of ability to recognize odors or detect smells may reflect very early changes in the nearby hippocampus even before any problems with memory loss are detectable. Researchers are now exploring whether smell tests may play an important role in detecting or diagnosing Mild Cognitive Impairment or the earliest stages of Alzheimer’s when possible treatments may be most helpful.

Not everyone with Alzheimer's has dramatic loss of smell, but it can pose challenges for those who do. Consider the following tips for managing any changes in ability to smell:

- Treat any allergies or sinus problems that could reduce your sense of smell.
- If you live alone, pay attention to dates on food containers. Don’t keep leftovers in the refrigerator for too long, as it could be difficult to smell spoiled food.
- Make sure working smoke detectors are installed throughout your home.
- Since loss of smell can affect taste, food may become less interesting or appealing. Take note of any significant or unintended weight loss.
- Be careful not to season food with excess salt. Too much salt intake can increase blood pressure and risk of stroke. Experiment with using other herbs and spices that may stimulate the taste buds.
- Sometimes loss of smell can become a bit personal. Pay attention to hygiene with routine bathing and laundering of clothes and linens.
- If you have loss of smell, don’t let it discourage you from appreciating your other senses. Even if you can’t smell the flowers, you can still hold and touch the bouquet or see it arranged nicely in a vase on your table!
RESEARCH UPDATES
New Clinical Trials

The MINDSET study is evaluating an investigational treatment (known as RVT-101) for people with mild-to-moderate Alzheimer’s that is taken together with Aricept. In a previous study the combination of RVT-101 and Aricept was observed to benefit study participants’ thinking abilities and some abilities to do daily activities. During this six-month study, participants have a 50% chance of receiving the investigational drug. All participants who complete the six-month study will then have the opportunity to enroll in a 12-month extension study in which all study participants will receive the medication. This study will enroll in sites across the United States and Canada. For more information, see:
http://alzheimersglobalstudy.com/en-us/about

The purpose of these international studies is to evaluate the efficacy and safety of Aducanumab (BIIB037) in persons with Mild Cognitive Impairment or early Alzheimer’s disease in over a dozen countries around the world. Aducanumab is being studied to determine whether it can remove amyloid plaques (abnormal protein clumps in the brain) and slow the progression of symptoms. Participants will be randomly assigned to receive a low or high dose of the study drug or a placebo. After an 18-month period, participants can enroll in a study extension during which all participants will be given the drug. Participants will receive monthly infusions of the study drug.

For more information on enrollment, see:
https://www.aducanumabclinicaltrials.com/
For a list of locations, see clinicaltrials.gov at: https://goo.gl/l2qz4k.

The Simple Things in Life
By Wendy Mitchell

The early morning mist
A bird in the sky
A leaf on the ground
Laughter all around

Simple acts of gratitude
A ‘Thank you’ and a ‘Please’
Don’t cost in terms of finance
Only the time it takes to speak

Simple acts of kindness
A hug or smiley face
Cost nothing more than time itself
Living life at a slower pace

When time is unknown
And days become more precious
Life takes on a new meaning

It’s time to forget life’s stresses.

Sat in my chair watching autumn turn into winter....one of life’s simple pleasures.

Wendy Mitchell was diagnosed with early-onset Alzheimer’s in July 2014. Some of her writings were featured in Perspectives, Vol. 20, No.4. This poem is reprinted with her permission. You can read her blog at:
https://whichmeamitoday.wordpress.com/blog/
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