Getting Through the Fog: Managing Times of Confusion

By Cecily Jenkins, PhD

It is not uncommon for people with early-stage memory loss to describe times when they feel more confused. These experiences can happen unexpectedly and may occur in a variety of situations and settings. It can be hard to predict when the confusion will occur or how long it will last. You may feel frustrated by not being able to accomplish a task, or feel anxious or frightened when you can’t seem to problem-solve effectively. These experiences can be very disruptive and discouraging, but often, episodes of confusion will eventually pass. The fog can lift, and you can return to clearer thinking.

In a recent support group meeting for individuals with memory loss at the UC San Diego Shiley-Marcos Alzheimer's Disease Research Center, a participant shared his experience of disorientation when a dense fog descended on the beach as he was walking alone. With the fog clouding his ability to see beyond a very short distance in any direction, he found himself momentarily confused about which way to go. He described the process he used to reorient himself. First, he stopped walking so he could scan his surroundings and figure out where he stood in relation to the water’s edge. Next, he looked for familiar landmarks behind or up ahead in the landscape. Then, he waited just a little longer until the patch of fog moved on before continuing his walk. By taking the time to stop and study the situation with relative calm, he was able to move along and continue safely on his journey.

This man’s story of successfully finding his way through the fog led to sharing by others about personal experiences with confusion, or 'mental fog'. Group members discussed strategies they have found useful for finding a clearer state of mind when confusion arises, and recommendations they have for reducing confusion in the future. In the following messages, they share their thoughts and strategies with others who might have had similar experiences.

Experience: “I had trouble figuring out how to turn on my computer, even though I’ve done it so many times before. I was pretty sure that if I just sat quietly at the desk it would come to mind in just a little while. And eventually, it did.”

Recommendations: DO take some time

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to think through the steps needed to solve the problem. Sometimes quiet reflection helps bring forth the solution.

DON’T be self-critical or get so worked up with frustration that your thinking becomes even foggier!

**Experience:** “I had difficulty finding my car after having lunch with a friend in a part of town I’m not very familiar with. My friend was parked in a different area and she had already driven away. I did not want to bother her by calling her to come help. Luckily, I eventually recognized an orange crosswalk sign that I remembered seeing on my way to the restaurant, but it was kind of scary until I figured it out.”

**Recommendations:** DO make note of ‘landmarks’ such as a prominent sign or building in the immediate area you want to remember. Make a written note of specific information that will help you find your way back (e.g., nearest street intersection, parking row and number). DO keep a written list of important phone numbers (including family members, friends, and community service organizations such as police and volunteer ride services) with you at all times so you have contact information at hand if you need it.

DON’T let pride or worry about being a bother to someone keep you from reaching out to others whom you trust. Others generally feel good knowing they have helped out.

**Experience:** “I started noticing more confusion in the mornings right when I woke up and then things improved for the rest of the day. I wondered if it might be related to a new medication I was taking so I called the doctor to find out if the medication could cause this symptom.”

**Recommendations:** DO pay attention to the circumstances that may contribute to your confused thinking.

DON’T automatically assume that memory loss or dementia is the underlying cause of your confusion. There are other medical conditions (e.g., diabetes, infection, thyroid disorders, depression, sleep apnea) and some medications that may cause or increase mental confusion. Medical treatment or medication management of any other contributing conditions may help you think more clearly.

These are some examples of experiences with brief mental fog, but you may have your own experiences and your own solutions. Recognize those situations or circumstances when you are at your foggiest and also when you are able to think most clearly. Perhaps the fog clears when you are well rested, or when there is limited noise or distraction. Sometimes routine and structure promote clearer thinking. Make a list of when you feel confused and when you feel at your clearest and do share with others your own strategies for lifting the fog!
Brainstorming

We asked people with Mild Cognitive Impairment or Early Alzheimer’s:

“What do you do when you have a hard time concentrating?”

Here are some of the replies:

“I need to be alone when I am concentrating on what I’m going to wear in the morning. It just takes me awhile to get it together and I really can’t concentrate if I’m rushed.”

“I take a lot of deep breaths and just relax when I can’t concentrate. It doesn’t do any good to get all worked up, so I try to calm myself down.”

“I just focus on reading. I’ll take out a book or magazine and get involved in it and somehow my mind gets clearer.”

“I play a game or do some kind of distraction on the computer when I get stressed and can’t concentrate. It makes me relaxed. Sometimes it makes me fall asleep, so I guess that’s a good escape when I can’t concentrate!”

“Meditation can be helpful. I sit down and have a mantra I try to focus on and repeat and it helps me focus sometimes.”

“I just sit with my little dog. He likes to be in my lap so I can pet him. He doesn’t care if I think clearly!”

“I make sure I get enough sleep. If I’m tired, I can’t concentrate on anything. An afternoon nap is sometimes good for a tired brain and body.”

“Taking notes helps me to concentrate. I keep just one or two big notepads around the house so I can jot something down when I need to.”

“I keep checklists – like when we travel, we have a list of all of the steps we need to do to get ready to leave town and the basic kinds of things we need to pack. Check lists are helpful because I can just focus on one thing at a time on the list and I don’t have to try to keep it all in my head.”

“When I cook, I put out the ingredients for the recipe and then when I have used the ingredient, I put it on a different counter so I can keep track of what I have put into the recipe and what I still have to add. It helps me concentrate to see the ingredients divided up that way because otherwise I may add the same thing twice and that’s not so good when you’re cooking.”

“It’s helpful to get outside and get some fresh air when I can’t concentrate. Sometimes walking or a change of scene just helps me snap out of it and feel more alert.”

“I really have to cut out other distractions when I’m trying to concentrate. Never answer the phone when you’re in the middle of something because you can get so off track and then there is no way back!”

“My wife can tell when I need quiet time alone. I head to my study or the work room in the garage and just hang out by myself until I feel I can concentrate a bit better.”

“One thing at a time and one day at a time. It’s a good motto for living, especially with Alzheimer’s!”
INNOVATIVE USES OF TECHNOLOGY FOR ACTIVITY AND INDEPENDENCE

The last decade has witnessed an explosion of computer and electronic technologies that can be both exciting and exhausting. It may feel overwhelming to keep track of advances or to wonder how it all can apply to living with Alzheimer’s or a related disorder. The following are a few informative and creative opportunities for learning how technology can contribute to your quality of life.

AT Guide: Using Assistive Technology to Maintain Independence

The AT Guide is an on-line self-help guide to enable persons with dementia to maintain independence through the use of strategies that use technology or assistive devices. AT Guide has been developed by organizations in the UK including Trent Dementia Services Development Centre in partnership with the Disabled Living Foundation, Innovations in Dementia, and York St. John University, to help people with dementia and their care partners make informed decisions about the use of assistive technology to support independence.

Persons using the website can select topics of interest that they may have trouble with including (but not limited to) getting dressed and ready to go out; preparing meals; taking medication; keeping busy; or keeping in touch with others. Once a topic is selected, you are asked a series of questions that help to personalize your particular challenges with this topic. Once you have answered the questions, a personalized plan of action is provided with advice and practical steps to help improve your functioning and independence.

These personalized assessments and recommendations are provided entirely free of charge on the website. The AT Guide can be used on one’s own or with the help of a family member, friend, or other care partner. For information see: http://www.asksara.org.uk/

Using Technology to Create Meaningful Activities

The Social Care Institute for Excellence (SCIE) is an independent charity in the UK working with families who need a variety of care services. SCIE’s mission is to gather and analyze knowledge about helpful practices and provide resources and learning materials. The organization maintains a wealth of online information about dementia including a section on using information and communication technologies (ICT) in creating meaningful activities for people with Alzheimer’s or a related disorder. Applications include the use of computers, touchscreen tablets, and other technologies in providing cognitive (mental) stimulation; reminiscence and life story review; ways for staying in touch with friends and family; and creative arts opportunities or entertainment.

Helpful information includes reviews on the benefits and challenges of using ICT and how to introduce technologies to persons with dementia. A complete PDF on using ICT to create meaningful activities can be read or downloaded at the following website: http://www.scie.org.uk/publications/ictfordementia/index.asp.
Music and Memory: The Power of Personalized Music

Researchers have described many benefits for people with Alzheimer’s or a related disorder when they are able to listen to personalized music that is consistent with their music preferences, especially music preferences from their youth. Music & Memory is a non-profit organization that programs used and donated iPods to play personalized playlists. Results reveal that those with even advanced dementia can be awakened, engaged, and have reduced agitation when listening to selections of personalized music.

Founded by Dan Cohen, a social worker and former Department of Education consultant, Music & Memory began in 2008 when Cohen distributed 200 iPods in four New York City long-term care homes and learned that the residents experienced increased socialization and better relationships thanks to listening to personalized music on these devices. The efforts have now spread to more than 50 nursing homes across the US and Canada.

The Music and Memory team trains professional and family caregivers on how to create and provide personalized playlists using iPods and related digital audio systems. The program seeks donations of used devices to fulfill their mission.

For more information and very moving video footage of this inspiring project, see: http://musicandmemory.org/

To donate an iPod or other device, see: https://musicandmemory.org/donate-my-ipod/

ANNUAL PROGRESS REPORT ON ALZHEIMER’S DISEASE NOW AVAILABLE

Every year, the National Institute on Aging (NIA) publishes a comprehensive update on science and research advances in Alzheimer’s and related disorders from the projects and organizations that the Institute funds. This year’s annual publication provides an overview of Alzheimer’s (AD) including the biology and genetics of the disease. Risk factors, methods of detection and diagnosis, and developing treatments are discussed as well as advances in providing care for those affected.

The comprehensive progress report can be read or downloaded on the NIA’s Alzheimer’s Disease Education and Referral (ADEAR) website at: http://www.nia.nih.gov/alzheimers/publication

Reading the report online also affords access to some interesting video clips and interviews that help to further explain reported updates. While you’re on the website, be sure to review the many other helpful publications and resources available through ADEAR. You call also call ADEAR at 1-800-438-4380.
RESEARCH UPDATES

Can Exercise Slow Decline in Mild Cognitive Impairment (MCI)?

Much research supports the beneficial impact of aerobic exercise on both heart and brain functioning. This clinical trial seeks to find out if supervised aerobic exercise can influence decline in thinking abilities, slow brain shrinkage, and reduce brain changes in people with MCI. Researchers hope to reduce the risk of MCI progressing to AD. This trial will recruit inactive volunteers with MCI to participate in a year-long program in which one group will do high-intensity aerobic exercise and the other stretching. The study will begin recruiting in summer and we will keep readers informed of study sites.

Can Deep Brain Stimulation Treat Alzheimer’s Disease?

Researchers in the “ADvance Study” are investigating a new approach to treating Alzheimer's disease (AD). This study (clinical trial) involves a process commonly used to treat Parkinson’s disease known as “deep brain stimulation” or DBS. Electrical impulses are delivered to the brain, through a device that acts somewhat like a brain pacemaker. In this Alzheimer's clinical trial, a device that is surgically implanted in the brain will deliver electrical impulses to the fornix, a region of the brain that is important for memory. Researchers hope they can slow the decline of memory loss through this method. This small study will enroll 20 people at 4 sites in the US and one site in Toronto, Canada. For more information, please visit the clinical trial website at: http://www.advancestudy4ad.com/

What Does 2013 Hold in Store for Other Clinical Trials?

We await the results from a promising Phase 3 clinical trial of Intravenous Immune Globulin (IVIG) in persons with mild-to-moderate AD. This compound targets the amyloid protein deposits associated with AD. The study is no longer enrolling, but an overview can be read at: http://www.adcs.org/studies/igiv.aspx

We look forward to additional findings from the Alzheimer's Disease Neuroimaging Initiative (ADNI) that is focusing on identifying the earliest changes seen in the AD brain so that treatments can be targeted to prevention or postponement of AD onset. See: http://www.adni-info.org/

Additional clinical trials in AD are ongoing, with several new compounds being prepared for launch in mid 2013. One of these includes the intranasal insulin study, which has had positive early results. Fluctuations in insulin levels may contribute to thinking and brain changes associated with AD. Insulin nasal spray may help to regulate blood sugar and will be researched for its possible benefits to people with AD.

We look forward to keeping you updated on what is happening in the world of dementia research in the upcoming year, and are optimistic that there will be promising developments in 2013.
Gather at the Gallery: Creating Art and Community for People with Dementia and Their Families

By Lisa Meschino, PhD

Research suggests that people with dementia appear to experience an improved sense of well being after looking at works of art or listening to music. Gather at the Gallery is a unique visual art program for people with dementia and their families living in the Canadian city of Kitchener-Waterloo. The program is led by Cara Dowhaniuk, program coordinator at the Alzheimer Society of Kitchener-Waterloo, and myself, postdoctoral researcher with Dr. Sherry Dupuis at the Murray Alzheimer Research and Education Program (MAREP) of the University of Waterloo.

Inspired by the Museum of Modern Art’s Meet Me at MoMA program in New York City, Gather at the Gallery provides an opportunity for people with dementia and their families to visit local museums and galleries for guided art tours. Participants also make art, such as pottery, collage, and glass fusion, with local professional artists. In addition, Gather at the Gallery is a research project funded by the Alzheimer Society of Canada Research Program. Through interviews and observation, I collected participants’ reflections on their experiences in the first year of the program and its impact on their quality of life.

Gather at the Gallery brings together a diverse group of husbands and wives, mothers and daughters, even friends and neighbours, all of varying ages, stages of dementia, and experience with art. Making art with others who share the experience of memory loss creates a safe, social environment for people to express themselves and form friendships. For one participant with young-onset dementia, connecting to others through art took away the feeling of ‘why me’ and changed the way he felt about the disease. He said, “I was impressed by the fact that all the other people are dealing with their situations quite well...So I feel a lot more into it [the art]”. The art educators who facilitate the tours and hands-on activities also engaged with the group on a more personal level. One educator commented, “...at the end I felt that I’d made friends with some of the couples...that doesn’t often happen when you do a tour.”

Our participants are proud of their creations. Some reconnect with a past passion for art. The husband of one woman with dementia spoke of his joy at witnessing his wife, who had always enjoyed painting, flourish once again in the Gather program. She had become quieter and more isolated after diagnosis, but now joked with the instructors and other participants with renewed enthusiasm for art.

Awakened to their creativity, our participants welcome opportunities to consider new ideas and relish the challenge posed by more nonrepresentational artwork. One of our oldest participants with dementia called it “a good mental outing.”

Program organizers, participants, friends and family celebrated the success of the first year of the program with a public exhibition of participants’ artwork at the Button Factory in Waterloo. The art exhibit, along with participants’ stories, raised greater awareness of how engaging in art supports continued abilities and enhances relationships of all involved.

For more information contact Lisa Meschino: lisamarie.meschino@gmail.com
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