A Typical Day
Living with Mild Cognitive Impairment

Memory loss is a common experience for people living with mild cognitive impairment (MCI) and Alzheimer’s disease. A “Typical Day” is a photography project that allows older adults with MCI to document their lives as a way of communicating about living with memory loss. MCI is a condition in which people have more memory or other thinking problems than normal for their age, but their symptoms do not significantly interfere with their everyday activities. MCI can often, but not always, develop into Alzheimer’s or a related disorder.

Sometimes it can be difficult to describe experiences of memory loss in words. So participants of the Typical Day project recently expressed themselves through images. Tigist Hailu, MPH, Director for Diversity in Research and Education at the Penn Memory Center in Philadelphia, spearheaded the project in an attempt to be inclusive of the diverse voices and experiences of people living with memory loss. Cameras were provided by the Penn Memory Center for the project. Over the course of a week, twelve participants photographed a typical day for them including the people, places, and objects that now make their daily lives easier or more difficult as they live with MCI.

(continued on page 2)
A Typical Day (cont. from page 1)

Their photos help to facilitate conversation about living with memory loss.

Doris recalls receiving her diagnosis of MCI: “I was more relieved than scared because I suspected it. Matter of fact, I think it helps a lot because I’m aware of it now. I monitor myself.” She has a caring network of friends who support one another through companionship, assistance with errands, and shared spirituality. Her photos capture her appreciation for this treasured community.

Dr. Jason Karlawish, Co-Director of the Penn Memory Center, believes that the Typical Day photos and stories provide valuable insight into the quality of life of the person with memory loss. He states, “A day that is busy, engaged and safe is arguably better than one that begins and ends with sitting on a couch before a TV, punctuated only by three meals, a snack, and a nap.” Many of the project participants documented the importance of various activities in their daily lives.

Christopher shares his enjoyment of walking: “I like to walk because it frees my mind...I find walking in the neighborhood is a way of allowing my mind to throw out some of its limitations.”

Joanne feels it is important to keep her mind stimulated. “Reading is good for the memory as far as I’m concerned. It helps...If I read something in the paper and I find it to be important, then I re-read it. I know I’ll probably forget it.”

Gerson acknowledges his reliance on his wife: “I just took a picture of my wife, who is so important to me. She accompanies me wherever I go, and handles the details more so than I can ever do, and I'm really dependent upon her to do that...When she reminds me of something that I don't want to be reminded of, and I think I should know myself, it's difficult for me and it's difficult for her.”
A Typical Day (cont. from page 2)

A photo can also provide a moving tribute to an enjoyable activity that is no longer possible due to memory loss. Thomas says, “I played poker until I couldn’t remember what they had said; like if they say it’s a pass or hold. I wouldn’t be able to remember whether the guy said pass or hold. I had to keep asking people what they said, so I retired.” Thomas attends a weekly MCI support group at the Penn Memory Center where he is able to connect with others to share experiences. “Sometimes you hear solutions to things you haven’t thought of...”, he says. “It’s good to know that other people are battling the same problem.”

Photography and stories, can also change the way others think about Alzheimer’s disease. Tigist Hailu believes that the Typical Day project helps to humanize the research efforts at the Penn Memory Center. The public and possible research participants see that researchers are interested in the whole person and their experiences of living with memory loss. She is also working with the Healthy Brain Research Network so other centers across the country can contribute to the project in order to expand representation of other populations and/or regions. To learn more about this Network, see: https://www.cdc.gov/aging/healthybrain/research-network/

To learn more about Typical Day, view the website at: http://www.mytypicalday.org

Hypothermia
A Cold Weather Hazard

Many people living in the Northern Hemisphere face very cold winters and safety hazards associated with freezing temperatures. Hypothermia occurs when your body loses heat faster than it can produce it, resulting in a dangerously low body temperature (below 95 F or 35 C). Low body temperature doesn’t allow your brain and body to work properly and in some cases, can be life-threatening.

It is especially important that people with dementia take safety precautions in cold weather as they (and older adults in general) are particularly vulnerable to hypothermia. Memory loss can contribute to safety concerns such as getting lost in cold weather, wearing less clothing than necessary, or forgetting to turn up the thermostat in your home. Diabetes, low thyroid, arthritis, Parkinson’s disease, and some medications can also make it difficult to stay warm. Check with your physician to make sure that any of your prescribed or over-the-counter medicines or particular health conditions don’t put you at increased risk for hypothermia.

The following resources from the National Institute on Aging provide helpful information on recognizing and preventing hypothermia. Hypothermia: A Cold Weather Hazard is a brief brochure available to read online or download at: https://goo.gl/kJSwNH

Stay Safe in Cold Weather is a comprehensive booklet available at: https://goo.gl/dbeW62
Awakening and Maintaining Your Five Senses
Part Four: TASTE

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

In the last issue of Perspectives, we discussed how a diminished sense of smell is common for people with Alzheimer’s or a related disorder. The senses of smell and taste are closely linked so if your sense of smell is less sensitive, your sense of taste will be affected, too. An example of the link is when you have a stuffy nose or blocked sinus, you may notice that you can’t taste food as well. Sensitivity to taste can also diminish with age, heavy smoking, poor mouth or dental hygiene, and some medications. All of these various factors can contribute to changes in your eating habits.

It is not uncommon for people with dementia to have certain food cravings. As taste buds become less sensitive, you may be drawn to sweets or fatty foods with more intense flavors. Neurologist Ronald Devere of the Taste and Smell Disorders Clinic in Austin, Texas, notes that our enjoyment of food depends on a number of factors including smell, texture, temperature, flavors, and visual appeal. He suggests that foods that are more bulky, sticky, or thick and creamy stay in the mouth longer and can stimulate all of the taste buds for a longer time (as long as one does not have swallowing difficulties).

Consider the following tips for managing any changes in your sense of taste:

• Keep a journal of foods that do and don’t taste good to you so you can track any changes in your food preferences. The texture of food can also be important for stimulating taste, so be aware of textures that are particularly pleasant.
• If you are losing weight, keep nutritious snacks that you enjoy within easy reach. Eating more frequent smaller meals can be more manageable than large meals that may be harder to digest.
• Some people with dementia gain weight because they don’t recognize the sensation of being full, may forget that they have already eaten, or eat out of boredom. Try to maintain some social, mental, and physical activity every day for overall well-being so that food isn’t a primary focus or activity.
• If you have more interest in sweets, include some that provide nutrition such as fruit flavored yoghurt or smoothies, applesauce, granola, or power bars. You can marinate meats or vegetables in sweet and sour sauce or drizzle a bit of honey on cottage cheese, popcorn, or crackers to enhance their appeal.
• Although more salt can be tempting, use herbs, spices, soup broth, mushrooms, Marmite or Vegemite (common in Great Britain and Australia) or a savory cheese like Parmesan to boost flavor.
• If you wear dentures, make sure they fit well. Poor fitting dentures may limit your interest in eating.
• Watch out for rancid foods in your refrigerator. A poor sense of taste (and smell) makes it harder to detect them.
• If you are losing interest in food, try to make eating a social activity so that you eat with others in a calm environment that supports some of the positive traditions around sharing a meal together.
BRAINSTORMING

Our cover article discussing the “Typical Day” project inspired us to ask people living with memory loss the question:

What routines or events do you look forward to every day?

Here are some of their replies:

“Seeing the sun come up!”

“I look forward to my morning routine – coffee in bed, meditating, journaling, prayer. It sets a positive tone for the day.”

Hobbies and Activities

“I live in an Alzheimer's place and I have a job taking care of the horses everyday. I used to ride my bicycle daily for 50 miles. Now I have to wait for someone to go with me because I can't go out on my own.”

“I grow celebrity tomatoes and I have 20 plants. It takes daily care and I really love it. I don't remember what I do everyday-not sure if I have a routine.”

“I watch the news and stay engaged with political events. I also love working on my 1955 De Soto.”

“I help with a remodeling project and visit with my neighbor’s dogs.”

“I like to go out into my yard everyday and enjoy the garden. Once a week I look forward to Tuesday night pizza with my old high school friends at Filippi’s.”

“Keeping up with the news. I read the New York Times every morning.”

“I collect stamps and I make bookmarks.”

“Following the Warriors!” (A professional basketball team based in Oakland, California.)

“Volunteering for the Alzheimer’s Association.”

“Eating chocolate after dinner!”

Exercise

“I go to the gym five days a week and work out. If it wasn’t for working out I wouldn’t be able to survive. Working out every day lifts the fog in my brain.”

“I take the dog out for a walk every day by myself. I try to remember the day of the week and then I get the newspaper to check and see if I am right. Then I read it.”

“Daily exercise. I run, hike, or ride my bike every day at the same time.”

“I walk regularly – it gives me a chance to enjoy nature. I appreciate the beauty of my surroundings. I try to write every day. It's very important. I'm writing my story and it's helped a lot. Getting out in public makes me feel alive.”

“I love my cats and walking on the beach.”

Social and Family Relationships

“Checking my Facebook page.”

“Spending time with my spouse and loved ones.”

“Volunteering for the Alzheimer’s Association.”

“Spending time with good friends!”

“Online dating!”

“I love my routine of walking the dogs, meeting up with neighbors, and playing with the kids in my neighborhood.”

How would you answer the question?

Editor’s note: We are grateful to early-stage memory loss support group participants from the Shiley-Marcos Alzheimer’s Disease Research Center in San Diego and the Alzheimer’s Association, Northern California support group sites for their answers to the question.
READING ABOUT RESEARCH: THINGS TO KEEP IN MIND

Editor’s note: We are grateful to the Alzheimer Society of B.C. for permission to reprint the following article.

It seems like we hear about a new study that reports exciting progress in dementia research almost every week. We hear about these “breakthroughs” on the internet, in newspapers, and magazines. However, the reports on these studies may not tell the whole story. So how do you know what to believe?

It is important to be critical when you read or hear about new research. There are several things to keep in mind when thinking about how reliable a study may be. Here we share information to help you understand and interpret the results of research studies:

WHAT IS THE SOURCE? Anyone with an opinion can write an article on a web page, but credible research is published in scientific magazines or peer-reviewed journals (publications reviewed by professionals working in the same field). A good source could be a government web page or scientific magazine. A less credible source could be a magazine or website written by someone with no relevant qualifications.

WHO DID THE RESEARCH? Legitimate research articles always state the name of the researchers, their credentials, the organization where they work, when the research was done and where the research study was originally published. A reliable study would likely come from researchers who are associated with a respected organization or educational institution and have experience in the area they are writing about. For example, a trustworthy researcher could be a professor from a university who specializes in brain research. A less credible person could be a celebrity who does not have medical or research training.

IS IT AN ANIMAL OR HUMAN STUDY? There are various steps involved in developing an effective treatment for a disease. For example, when developing a drug, laboratory tests are first carried out with a variety of small animals, such as mice, to determine the effects of the drug. However, testing something using animals does not mean that the same results will be found when the same test is conducted with humans. The media may widely report on a study that is promising, but only in the early stages of testing on animals. If the study has not moved to testing in humans, these results may be exciting, but years of more studies are required before this could be determined effective or ineffective as a possible treatment.

HOW MANY PEOPLE ARE IN THE STUDY? The higher the number of participants in a clinical study, the more likely the results will represent the larger population being studied. For example, a study done with only 10 people who have a diagnosis of Alzheimer’s cannot claim to represent all people living with the disease. It may, however, suggest a potential direction for future research.

WHO FUNDED THE STUDY? If the organization that funds the study has something to gain or lose from the results (like having a product or medication approved or rejected), there is more risk for bias. Researchers or companies may be tempted to omit negative results or even exaggerate findings. For example, a

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supplement company may endorse a product as a “miracle cure” even though their claim is based on a faulty study or no study at all. Often, if it sounds too good to be true, it probably is. Note that a reputable journal requires authors to declare any conflicts of interest.

ARE THERE OTHER STUDIES THAT SUPPORT THE RESULTS? One experiment is rarely enough. Many studies are needed on one topic to know we can trust the results. When enough studies have been done, researchers can combine all of these results to look for patterns and draw conclusions.

Benefits of Mediterranean Diet

A study of over 400 seniors in Scotland who did not have dementia found that those who more closely followed a Mediterranean diet rich in fruit, vegetables, whole grains, beans, and olive oil, and with limited red meat, sugar, or saturated fat had greater brain volume over time. Normal aging can reduce brain volume, but this type of healthy eating may provide some longer-term protection. The study did not suggest that a Mediterranean diet could prevent or treat dementia. However, much evidence has pointed to the likely benefits of this heart-healthy diet on the brain by improving cholesterol and blood sugar levels and overall blood vessel health. Although the evidence speaks to prevention, if you have dementia, adhering to the principles of this diet may help to prevent further damage to the brain from vascular or cardiac disease.

LEWY BODY DEMENTIA: 
THE STATE OF THE SCIENCE

There are many forms of dementia. Although Alzheimer’s disease accounts for a majority of cases, some experts estimate that Lewy Body Dementia is the second most common form of dementia. Lewy Body Dementia is an umbrella term for two diagnoses: “Dementia with Lewy bodies” (DLB) and “Parkinson’s Disease Dementia” (PDD). The Lewy Body Dementia Association’s report, *Lewy Body Dementia: The State of the Science*, focuses on DLB. This form of dementia impairs thinking, movement, behavior, sleep, and certain autonomic processes in the body, such as those controlling heart rate, blood pressure, bladder, and gut. *Lewy Body Dementia: The State of the Science* provides an easy-to-read overview of key major findings to date in LBD research. The report also highlights opportunities to drive research progress forward.

For those who are interested in reading an abbreviated and condensed version of the report, there is also a two-page summary available that highlights key research opportunities identified in the comprehensive more report. Both reports are available to read or download at:

https://www.lbda.org/StateoftheScience
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