I don’t think I’ve ever had a sharp memory but it’s even less so now. I would say the pain of not being able to remember is gone now, but also some of the experience of excessive joy that some memories bring. It’s like getting older – you have that a lot. Things aren’t as intense. Everything is muted down – your eyesight, your hearing. We lose the intensity as we get older.

I always loved intensity, so at first when this memory loss started happening, I felt things were sort of blah. But I’ve gotten used to it and it’s a refreshing way to live to not be so affected by things and not to need that intensity. You want to look at it as a blessing, not a lack. One of the lessons of age is to allow things to be the way they are and not always try to change that. You don’t get as agitated by things, and I used to sort of enjoy being agitated by something. It was like a kick in the seat of the pants. It was that feeling that I was really alive.

I was mad at first about my memory loss because I couldn’t remember something – the details of things. I fought against it. I’d say to myself, “Come on – what’s the matter with you!” But now there is less that I have to remember. It would be very frustrating if I did have a lot I had to remember. I have fewer responsibilities now. There is nothing I really have to do. It’s a different way of living. If I had to remember appointments or remind people of things, it would be hard. I can remember to make sure that my cat has cat food and to take the garbage out, but that’s about all I have to do.

I’ve been very fortunate in all of this. Instead of finding experiences to be really negative, I just find them interesting.

If I was the way I am now and didn’t have anyone caring for me, it would really be a struggle. My feeling is that for some people, their pride says I can’t accept help from you. But if you realize you’re denying the other person something by not accepting, it can hurt the other person if you don’t let them help. They may get some

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joy or satisfaction out of helping. But never assume someone is going to enjoy it either. In some ways it’s very fulfilling to help someone else and it can be harder to accept the help. Our ego likes the thought of “I’m fine on my own – I don’t need any help.” But relationships are two part – the giving and the receiving and you want to be able to do both. If you’re just receiving, it makes you feel weak to have to receive all of the time. But it’s important to be gracious in the receiving. It’s been a process. I’m very fortunate that I have enough family who remind me that I am worth something. And my purpose can be to go to the grocery store and smile at people. How important these things are. It’s a way of graciously slipping into life.

I think the knowledge that you really have a new memory every moment is important and I focus on that rather than the old ones. I don’t remember pain that much. I remember beauty, places I’ve been, family, joy. I don’t know how to tell people to have a different attitude if you’ve always been pessimistic and think you have to look at the world that way. I’ve always looked at the world from a positive point of view. It’s more enjoyable that way. If something bad is going to happen, it’s going to happen. I’ve never lived thinking about the future and that hasn’t always been practical, but I like living in the now.

If you can look at your life as a story, then you can find it more interesting and memory loss just becomes part of the story. It doesn’t mean that you aren’t in pain sometimes about the memory loss, but you can step back a bit and just observe it all and try to accept it.

It’s what you do remember that’s interesting. It’s like eating the icing on the top of the cake and not having to worry about the whole cake. You have a choice and you get the sweet tidbits. You could always pick out the bad tidbits. I’m not blind to them; I just focus on the good. The more you focus on the good, the more the good comes. The more grateful you are, the more you have to be grateful for. But that’s my philosophy. It’s whatever works for you.

Editor’s note: Jennifer has four children, eight grandchildren, and six great-grandchildren. She lives with her beloved cat, Charley, on the island of Maui. She enjoys painting (see her Hibiscus painting above), reading, and time with family who live nearby or come to visit from the mainland.
Question and Answer

I used to love going to the movies but I have a hard time keeping track of plots now. I don’t want to give up on watching them or going to theatres, but I don’t like the frustration. Do you have any ideas on how I can continue to enjoy movies?

We asked people with memory loss to offer some suggestions and here are the very helpful replies:

“I watch more National Geographic or travel types of movies or documentaries now because they have interesting scenery and information without a complicated plot to keep track of. I liked ‘March of the Penguins’ and ‘Winged Migration’ because they had amazing bird footage. We also like watching Rick Steve’s travel shows on public television.”

“I prefer to rent movies and play them at home because then we can stop them part way through if I’m lost or need to be reminded of the plot or a character. My wife is amazingly patient with the occasional pauses and it helps me stay on track.”

“I like musicals because I can always enjoy the singing and dancing even if I can’t keep track of who is doing it! You don’t find that many contemporary musicals, but there are some great oldies you can rent. ‘Mama Mia’ is newer, but I love watching ‘Oklahoma’ or ‘South Pacific.’ Some of those classics never get too old.”

“You can go on the TV to the Turner Classic Movie channel. There are some great old movies and I think the plots were simpler back then. I also remember those actors and actresses from the past, so it’s easier to follow them. And it doesn’t hurt that I’ve seen so many of these movies a lot of times. Eventually I remember them pretty well! ”

“If you can find a movie that focuses on just one or two main characters, it’s a lot easier. I really liked ‘The King’s Speech’ because it was one man’s story of overcoming a disability. There are lots of other good biography movies. Some movies have too many characters who all start looking alike and get mixed up with one another until it’s a confusing mess.”

“Before we go to a movie, my husband and I try to discuss the write up about it and review the general plot. That way I am a little prepared for the general themes. Then we also talk about the movie afterwards to refresh my memory.”

“If you go to a movie theatre, take a flashlight! It’s dark inside and easy to trip. That can sure wreck your enjoyment of the movie!”

“I used to like a good detective movie or a shoot-em-up, but now I find they are often just too stressful. I know my brain has slowed down a bit and it’s exhausting to try to keep up with car chase scenes or people yelling a lot. So, I try to stick to more uplifting kinds of feel-good movies. Even if I don’t remember the details, I leave the movie theatre feeling happier, so that’s worth the price of admission.”

“Don’t try to do too many things at once when you’re watching a movie. If you’re watching one at home and trying to eat dinner at the same time, and the phone rings, and the dog starts barking, it’s too much. Just focus on one thing at a time. That’s my motto for managing memory loss in general.”
The Benefits of Meditation
Understanding the Practice of “Mindfulness”

Over the past two decades, there has been rapidly growing media, medical, and scholarly attention given to the science and practice of “mindfulness.” Jon Kabat-Zinn, PhD, a professor and founding Executive Director of the Center for Mindfulness at the University of Massachusetts Medical School, is widely recognized for his work in the field and defines mindfulness as “paying attention in a particular way, on purpose, in the present moment and nonjudgmentally.” His program called “mindfulness-based stress reduction” (MBSR) has been researched extensively and can help people cope with stress, anxiety, pain, and other physical and emotional challenges. MBSR is now offered to patients and the general public at a growing number of medical centers, hospitals, and other health-related organizations. Some of these institutions have developed whole departments focused on teaching and researching mindfulness practice. For example, see the University of California, San Diego’s Center for Mindfulness at: http://mindfulness.ucsd.edu

So what role can mindfulness have in the lives of people with Alzheimer’s or a related disorder and their care partners? Research suggests that chronic stress can place a person at increased risk for Mild Cognitive Impairment (MCI) or Alzheimer’s disease (AD). Also, many people diagnosed with these conditions report that the challenges of memory loss and other changes in thinking often make it difficult to keep up with the many things that compete for our attention. This can contribute to stress. For example, we try to eat breakfast while reading the morning paper and talking to our spouse with the television on in the background. Although people with memory loss are often counseled to focus on one thing at a time in order to accomplish tasks or manage memory challenges, this is not always easy. Our attention becomes easily divided or distracted in too many ways.

One objective of mindfulness is to focus the mind more effectively with full attention. This important skill can be improved over time through regularly practicing a type of meditation that focuses on the cycle of breathing. When distracting thoughts or concerns arise, one just observes them non-judgmentally and then focuses the mind back to the inhaling and exhaling of the breath. Though difficult at first, practice can lead to improvement, and to a better understanding of how the mind functions.

Recent research reveals that mindfulness meditation practices may provide some benefits to people with Mild Cognitive Impairment (MCI), early Alzheimer’s disease (AD), and their care partners. Rebecca Erwin Wells, MD and colleagues conducted a small, randomized study of people with MCI and found that those who were trained in MBSR and practiced the mediation/yoga combination for at least two hours a week had less shrinkage in the hippocampus (an area of the brain responsible for memory) and increased connections across other regions of the brain that are affected by MCI or AD. This study needs to be replicated with larger numbers of participants, but does suggest

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exciting ways in which mindfulness meditation might have a positive influence on brain structure and connectivity.

A new study on the topic of meditation was recently published by Ken Paller and his colleagues at Northwestern University and Northwestern’s Cognitive Neurology and Alzheimer’s Disease Center in Chicago. They tested an 8-session class in mindfulness training for individuals with early-stage dementia and their care partners. Meditation was beneficial for both groups by easing feelings of depression and improving sleep and quality of life. Participants learned to focus on the present and find enjoyment and acceptance in the moment instead of worrying about the future.

Although the participants with dementia in this study had mild-to-moderate memory loss, they were able to use preserved thinking abilities during the mindfulness training exercises and experienced positive benefits. This is the first study to show that the care partner and the person with dementia both benefit from participating in mindfulness training together.

“Mindfulness involves attentive awareness with acceptance for events in the present moment. You don’t have to be drawn into wishing things were different. Mindfulness training in this way takes advantage of people’s abilities rather than focusing on their difficulties.” --- Ken Paller, PhD

For more information on this program and research study, contact Ken Paller at kap@northwestern.edu. For an example of one of the classes from the training, you can watch a full-length YouTube video at: http://youtu.be/D1MutebKiik

The practice of mindfulness is also being introduced to family and professional caregivers as they learn to provide compassionate care to persons at all stages of Alzheimer’s or a related disorder. Marguerite Manteau-Rao, LCSW is founder of the Presence Care Project, a mindfulness-based dementia care training program for caregivers that has also included persons with dementia. Her website features an informative section of articles under the “publications” tab and podcasts of a few sample meditations: http://www.presencecareproject.com/ She notes that mindfulness allows us to step outside of our usual way of thinking and respond more effectively and compassionately to whatever is happening in the present moment. She offers the following as one simple practice to do every day to ease stress and develop a calmer mind:

- **Find a quiet place and a chair to sit in.**
- **Close your eyes and focus your attention on your breathing.**
- **Every time your attention wanders from focusing on inhaling and exhaling, just bring your attention back to the act of breathing.**
- **Try to do this for a few minutes at a time and then gradually increase the meditation time as you become more familiar with it.**

If you have never practiced before, it can be helpful to begin with a guided tape. You can listen to brief podcasts with Marguerite Manda-Rau through her website as noted above (click onto the “podcasts” tab) or search on YouTube under “Meditation” for many options.

If you have had experiences with mindfulness or other meditation practices that you would like to share with Perspectives readers, email a note to Lisa Snyder at: lsnyder@ucsd.edu. We always like to hear from you!
The National Institute of Health (NIH) and the National Institute on Aging (NIA) are significant funding sources for research in Alzheimer’s and related dementias. The NIA maintains an excellent educational resource center through Alzheimer’s Disease Education and Referral (ADEAR). View their comprehensive and highly informative website at: http://www.nia.nih.gov/alzheimers.

ADEAR’s most recent publication, *Participating in Alzheimer’s Research: For Yourself and Future Generations* provides a helpful overview on how clinical trials are developed, important considerations and steps in participation, ensuring privacy and safety, and ways to find clinical trials near you.

“Today, at least 70,000 volunteers are urgently needed to participate in more than 150 active clinical trials and studies in the United States that are testing ways to treat, prevent, or cure Alzheimer’s disease. All kinds of people, including healthy volunteers, are needed.”

You can read this publication online at: http://www.nia.nih.gov/alzheimers/publication/participating-alzheimers-research/introduction

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**A New Clinical Trial for People with Mild-to-Moderate Alzheimer’s**

**N**OBLE (also called T-817MA) is a study to evaluate a drug that targets amyloid beta, a protein that causes damage to brain cells in people with Alzheimer’s. Participants will receive the study drug or a placebo. Participants who are already taking Aricept or Namenda, will likely continue to take their medication along with the study drug or placebo. The investigational drug may work by protecting brain cells, which could result in improved memory.

The study will enroll 450 people at over 40 research sites across the US. Total participation time is about 14 months. To learn more about this study, participant qualifications, and whether there is a site near you, see clinicaltrials.gov and enter T-817MA in the search box: http://clinicaltrials.gov/

**Insight Into Emotional Memory**

**E**dmarie Guzmán-Vélez and colleagues at the University of Iowa reported findings from a small study that illustrates how people with Alzheimer’s can retain an emotional memory of an event longer than they remember actual details of the event. The researchers showed study participants 20 minutes of sad and then 20 minutes of happy movie clips. Before and after watching the clips, participants answered questions about their feelings. After watching the movie clips, they had higher levels of sadness or happiness for up to 30 minutes even if they did not remember any details of what they had watched. These findings support the fact that people with Alzheimer’s can forget an experience that caused a strong feeling, but still retain the feeling for many hours, days, or longer. It is wise to be alert to both positive and negative emotional experiences and not assume a feeling will disappear just because the memory of the associated event is forgotten.
HELPFUL RESOURCES from CANADA and the UK
More Informative Guides from Murray Alzheimer’s Research and Education Program (MAREP)

Murray Alzheimer’s Research and Education Program (MAREP) is based at the University of Waterloo in Ontario, Canada. MAREP is committed to research and education in Alzheimer’s and to improving the quality of life for people living with a dementia. Over the years, MAREP has produced a number of excellent hands-on guides called the “By Us For Us” guides. This series of informative booklets is written by persons with dementia and/or their care partners. The newest in the series of booklets is “Living Safely.” It offers many tips and strategies concerning safety issues in and out of the home including driving, financial and physical safety, the use of technology, health and medication, and the safety of persons with dementia when home alone or living alone.

The “Food & Mealtime” guide includes the experiences of persons with dementia and family care partners. Food and the social connections associated with it are essential activities in daily life. This guide covers issues such as grocery shopping, preparing meals, safety in the kitchen, and going out to eat in a restaurant.

All guides in this series can be purchased or read online at:

Useful Tools for Professionals Working in Early-Stage Dementia

The Dementia Engagement and Empowerment Project (DEEP) brings together over 35 different groups comprised of people with dementia from across the UK. These groups work in their local communities to increase awareness about dementia and to change common misperceptions about living with Alzheimer’s or a related disorder. DEEP provides ways in which regional groups can share their experiences and learn from one another. Individuals and/or groups serve as consultants on local and national projects related to dementia advocacy, support, and services, and may serve as speakers at conferences or other forums.

DEEP has published a number of guides aimed at supporting people with dementia and helping organizations better serve this population. All of the guides have direct input from people with dementia and some are created solely by them. Many of the guides are directed to professionals and can be helpful resources for people with early-stage Alzheimer’s to share with Alzheimer’s or dementia-related organizations in their communities. Titles include: Creating Websites for People with Dementia; Dementia-Friendly Tips for Employers; Choosing a Dementia Friendly Meeting Place; Collecting the Views of People with Dementia; and Involving People with Dementia in Conferences and Events.

You can learn more about DEEP and read these guides on the organization’s website at: http://dementiavoices.org.uk/ Click onto “DEEP Guides” under the “See Also” tab.
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