

# PERSPECTIVES

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## A Life Worth Living

Inspired by Participants of the Early-Stage Support Group at the University of California, San Diego, Shiley-Marcos Alzheimer's Disease Research Center

*Editor's note: As the end of a year draws to a close, it can be a time to pause and reflect on some of the things that contribute to a life worth living. Sometimes the daily experiences of Alzheimer's or a related disorder can overshadow all of the rich possibilities inherent in each day. The following messages come from support group participants with Alzheimer's in response to the question:*

***"What makes life worth living?"***

*As you read these responses, think about how you and your loved ones would answer this question and make sure to take these thoughts with you into the New Year!*

**M**y friends make life worth living – especially old friends who still remember! They brighten my life with the history and stories we share.”

“Having good health. I may have Alzheimer's, but at least it doesn't hurt or cause a lot of physical discomfort and the rest of my body is going strong.”

“Flowers and the beauty of nature. There is so much beauty around us. It's worth taking the time to pause and find some beauty in each day.”

“My wife. She's a peach. She is always there to help people when they need help, and now it's me who needs help. I'm so fortunate to have her by my side.”

“All of our caregivers! Where would we be without them? We have to make sure to give thanks for all of the people who help us because it would be hard to make it without them.”



“My grandchildren make life worth living. They're happy and lively and they remind me of the better parts of my own childhood. When we're together, my grandchildren take me by the hand and look out for

me. And when I get a message from them on my computer that says, 'I love you and I miss you' – wow, that makes me feel really good.”

“Popcorn at the movies! If it's a lousy movie, you can still have good popcorn. Sometimes it's the little things in life – and appreciating them – that makes life worth living.”

“Watching a soccer match and having a pint of Guinness during the match. It

*(continued on page 2)*

## A Life Worth Living

(continued from page 1)

makes you really feel alive when you're watching a good game."

"Having something meaningful to do each day or something to be involved in makes life worth living. I like my exercise group because it gets me up and out and no one cares if you have a good memory when you're exercising! I think it's good for my body and my mind to exercise each day. And volunteer work – I can still help out at the church and that makes me feel like I'm worth something."

"My dog. He anticipates different things and tries to communicate with me. I feel complete relaxation when I'm with my dog. I can say whatever I want to him and he's a really good listener. Even if I'm having a down day, he perks me up and life looks brighter."

"Getting out – especially to a place that has a good sale going on. That always makes life worth living. Hey, I like to help the economy!"

"Good food is always a pleasure that we shouldn't take for granted. I can't remember a lot of things, but I can enjoy a great meal of some of my favorite things and feel on top of the world."

"I think this support group makes life worth living. There is nothing like meeting with my friends in this group each week and knowing that I have this community where I can be myself and not worry about making a mistake or having trouble with getting a thought out. It's a highlight of my week and I wouldn't miss it for anything."

"Look, we have a lot to be grateful for. There are a whole lot of people in this world who are far less fortunate than we are. So, we go on living the best we can and give thanks for each day we're given."

## Question And Answer



**Q** I have a real sweet tooth now and my wife says I'm eating a lot more sweets than I ever used to. Is this part of having Alzheimer's?

**A** Many people with Alzheimer's find that they have more of a sweet tooth and may be drawn to cookies, candies, or ice cream. Sometimes the ability to detect flavors can be dulled for people with Alzheimer's, but sweet tastes can still be pleasurable. Or for some, sweets harken back to childhood times and are associated with happy memories around special treats or foods.

An occasional treat is not likely to be harmful unless you are medically advised to reduce or avoid sugar intake. However, excess sweets can dull your appetite for more nourishing food, throw blood sugar levels out of balance, and contribute to significant shifts in mood or energy. So it is wise not to overindulge!

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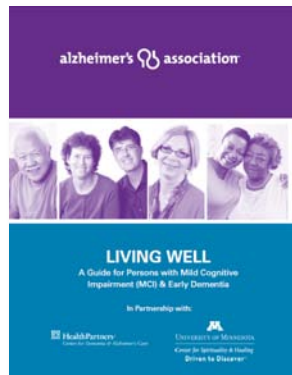
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## HELPFUL RESOURCES

### The Living Well Workbook



The *Living Well Workbook* is a guide for people living with Mild Cognitive Impairment (MCI) or early dementia. A collaboration between the Alzheimer's Association Minnesota-North Dakota Chapter, HealthPartners Center for Dementia and Alzheimer's Care, and the Center for Spirituality and Healing at the University of Minnesota, this guide presents brain wellness strategies and the evidence behind them.

Each chapter includes information about a specific strategy, its benefits, personal experiences of people living with MCI and early dementia, practical action steps, and a place to build an individual "living well" plan. People with early memory loss can take charge of their own health and well-being. This guide offers an opportunity to explore lifestyle changes that could lower the impact of disease symptoms and improve day-to-day living. To download the *Living Well Workbook* (FREE of charge), go to: [www.alz.org/mnnd/](http://www.alz.org/mnnd/). Click onto "Local Resources for People with Dementia" and scroll down to "Early Stage Resources." Click onto the *Living Well Workbook* PDF at the bottom of the page.

To receive a print copy of the *Living Well Workbook*, contact Sara Tucker, Early-Stage Services Manager, at 952.857.0553 or [sara.tucker@alz.org](mailto:sara.tucker@alz.org). There is a small fee for postage and handling.

## New By Us For Us<sup>©</sup> Guide



The *By Us For Us<sup>©</sup> Guides* are published at the University of Waterloo, Ontario, Canada, by the Murray Alzheimer Research and Education Program (MAREP). These guides are written by and for persons with dementia and cover a range of topics. The sixth *By Us For Us<sup>©</sup> Guide*, titled ***Living and Celebrating Life Through Leisure*** has recently been released and discusses the different ways that persons with dementia and their loved ones can continue to enjoy meaningful and enjoyable leisure activities together. Leisure can encompass many kinds of activities including those that provide: opportunities for personal expression, connection with others, or engagement in fun and enjoyment; ways of contributing to one's community; or opportunities for personal growth. The guide also explores some of the challenges individuals with dementia face when they attempt to engage in leisure activities and how to overcome some of those challenges.

This sensitively written and insightful 20-page booklet can be meaningful to anyone involved in the dementia experience. It is available to download (FREE of charge) at: [www.marep.uwaterloo.ca/products/](http://www.marep.uwaterloo.ca/products/). Scroll down to *By Us For Us Guides* to see all of the guides in the series. You can also inquire about the guides by calling: 1-519-888-4567.



## Storytelling Program Improves Quality of Life

By Anne Basting, PhD

We read the bad news about dementia all the time: still no cure for Alzheimer's; the cost of dementia care projected to explode as the Boomers age; the immense stress and burden of day-to-day caregiving. In contrast, the *TimeSlips* Creative Storytelling Project provided some rare good news for people with dementia and their families and caregivers when it launched a new, free, and interactive storytelling website, [Timeslips.org](http://www.timeslips.org) at: <http://www.timeslips.org>

Using photos and word prompts to inspire participants' creativity, *TimeSlips* provides a fun, low-pressure way for people with dementia to spark their imaginations, connect with one another and with caregivers and family members, and express themselves without worrying about embarrassing memory lapses or "wrong answers." Visitors to the new site can sit with a person with dementia and read, create, and share stories inspired by hundreds of images and questions in the site's library of prompts. Or they can work online with family members or friends across the country to write a story together.

Families wrestling with dementia are commonly consumed with the daily challenges of managing care. The new website provides a creative and positive way to take time off from focusing on the disease, and instead spend time growing, learning, and even playing together. *TimeSlips* is a

joyful experience that opens the power of storytelling to everyone by replacing the concern about memory with an opportunity to enjoy the power of imagination. Peer-reviewed research suggests that *TimeSlips* storytelling activities improve communication and increase the pleasure that people with dementia take in their daily lives. In nursing homes settings, it has led to increases in social engagement between staff and residents.

Visitors to the website can use [Timeslips.org](http://www.timeslips.org) free and without training, although people who plan to use *TimeSlips* with groups of people with dementia in care settings are encouraged to get trained. The *TimeSlips* Creative Storytelling Project offers individual and organizational certification in the method.

[Timeslips.org](http://www.timeslips.org) and the companion online training have been endorsed by people with dementia and leaders in the fields of aging services, the arts, education and civic engagement. "The revelation and realization that, 'I can't remember, but I can IMAGINE!' blessed my mind, heart and soul. I hope I remember that until I can't remember!" said recently diagnosed Dave Sheehan, about the new online training.

For more information see: [www.timeslips.org](http://www.timeslips.org).



*TimeSlips* Storyteller and Facilitator share in the joy of imagination.

Photo courtesy of Wing Young Huie

*TimeSlips* founder and director Anne Basting is the Director of the UWM Center on Age & Community and Associate Professor of Theatre in the Peck School of the Arts. She is the author of ***Forget Memory: Creating Better Lives for People with Dementia*** (2009, Johns Hopkins University Press), and, writer and producer of *The Penelope Project* ([www.penelopeproject.wordpress.com](http://www.penelopeproject.wordpress.com)) with Sojourn Theatre and Luther Manor.

## RESEARCH UPDATES

It is common to hear distinctions made between “traditional” medicine and “alternative or complementary” medicine. Some people express concern that scientists involved in more academic or traditional medical research may not be open-minded to “natural” supplements or other therapeutics. In fact, many “natural” substances have been, or are currently, under investigation for potential treatment of Mild Cognitive Impairment (MCI) or Alzheimer’s disease. Recently, coconut oil and cinnamon have been receiving greater attention for their potentially therapeutic benefits.

### Cinnamon



Cinnamon is widely used by humans as a spice and as a traditional medicine. It is, perhaps, one of the world’s oldest herbal medicines, having been mentioned in the Bible and in Chinese texts as long as 4,000 years ago. A research team in Israel (headed by Michael Ovadia from Tel Aviv University), has isolated one of the ingredients in cinnamon, CEppt, and used it in a series of tests conducted on laboratory rodents with genetically-induced Alzheimer’s. The rodents received either the cinnamon extract or placebo for four months. The extract improved the rodents’ performance on learning and memory tasks. It also reduced the amount of amyloid plaque formed in the brain and delayed disease development. Further trials will need to be conducted in humans to evaluate both safety and efficacy. To gain the identified Alzheimer’s-related benefits described in this rodent study, a person would have to consume at least 10 grams of cinnamon every day - a **toxic** amount of cinnamon that is not recommended.

### Coconut Oil



Coconut oil has medium chain fatty acids, which are a good source of energy or *glucose*. Glucose is the brain’s primary energy source and there is evidence that people with Alzheimer’s have reduced levels of glucose in their brains. However, Coconut Oil has not been shown to have any direct beneficial impact on Alzheimer’s. The long and short chain omega-3 and 6 lipids are the most studied supplements for Alzheimer’s, with DHA receiving the most attention. At present, however, studies of DHA have not revealed any ability of this supplement to treat symptoms or slow progression of Alzheimer’s. There are ongoing studies looking at its effects in the earliest stages of MCI, before dementia has set in.

### Jellyfish



Jellyfish protein is *Apoaequorin*. The main manufacturer is Quincy, and they ran one study. The Madison Memory Study included 218 men and women ages 40 to 95 who were experiencing some memory loss and examined the effect of a 90-day supply of apoaequorin dietary supplement on cognitive functioning and other quality of life measures. Changes on specific assessments of cognitive function were measured at various time points during the study. The results of the study were promising, but the study did not include people with Alzheimer’s and the findings were not published in any peer-reviewed medical journal. At present there is no evidence that jellyfish can have any beneficial impact on treating Alzheimer’s.

*We are thankful to Mike Rafii, MD, PhD for his contributions to these research updates.*

## Maintaining Hope and a Sense of Humor

**H**ope and humor are not the first words that come to mind when you think of Alzheimer's, but they are two of the most important ones. The ability to laugh and find promise in the future is an enduring gift to be re-opened and savored over and over again.

### The Gift of Humor

Many people with Alzheimer's and their loved ones discuss the benefits of finding humor in everyday life. Laughter can reduce stress. The act of laughing releases endorphins (a naturally occurring brain chemical) that foster a sense of well-being and relaxation. These endorphins are also released during exercise. A good belly laugh is a form of gentle exercise as it engages your chest, abdominal, and facial muscles and temporarily increases both your heart rate and blood pressure. When the laughter subsides, your heart rate and blood pressure can actually drop lower than they were before you were laughing, resulting in a more peaceful feeling.

Laughter among family members and friends can brighten dark moments and promote more relaxed and encouraging feelings. Members of a support group for people with Alzheimer's in the San Francisco Bay Area in California advise their family members: *"Have a sense of humor! It helps us to lighten up about things we may have trouble with."* The ability to laugh at one's circumstances can provide welcome relief. Al says, *"Sometimes I feel like a big kid. Every day is a new day with new discoveries because I can't remember anything I've already discovered! I laugh about it and that keeps me young at heart."*

Humor can often form a bond between people and lift everyone's spirits. It can also help to put others at ease. One man with Alzheimer's states, *"I know how uncomfortable I would feel if I knew one of my friends had Alzheimer's...I decided to defuse the situation. If they ask me how I am feeling, I say 'Great! I haven't lost my keys all day!'"*

People with Alzheimer's often share a robust sense of humor with one another. During a support group meeting one woman starts to say, *"I think I may have already shared this story..."* but is interrupted by another participant who says with a raucous laugh, *"Hey, tell us again! Do you really think we've remembered whatever you might have told us?"*



Although humor can be therapeutic, support group members also advise their family members and others to be sensitive about its use. They suggest that humor is not helpful if it is making fun of someone in a hurtful manner; if it leaves someone feeling left out; or when it's hard to understand. They caution that the use of humor could stifle other more serious feelings that need to be expressed.

### Maintaining Hope

You may wonder where to find hope in the experience of Alzheimer's, but it lives in more places than you might imagine. In his public address to the Alzheimer's Association of South Australia, Philip Alderton says, *"We may not be able to change the end result, but our journey there could well be determined by our actions and mental attitude. My feelings are that there is always hope. Wherever there is life, there is hope, however slender that may appear at times."*

*(continued on page 7)*



## Maintaining Hope and Humor

*(continued from page 6)*

Although any disability can be discouraging, it is important to stay involved in life – to maintain activity that will keep you stimulated and challenged. John states, *“Keeping active, getting around, and doing things gives me hope because if I don’t keep doing things, I mope.”* A positive attitude is also essential. Another man says, *“Looking on the positive side of things gives me hope. The negative doesn’t do any good.”*

Thaddeus Raushi defies prevailing beliefs about Alzheimer’s and offers a powerful message of hope. He writes, *“I’d like to suggest that there are Alzheimer’s survivors. For me, surviving is both attitude and action. It means that even while knowing that I have this disease, I can still go on with life always doing the best I can with what I have.”*

Hope is also nurtured through the encouragement you receive from others who understand your challenges. Participants in Alzheimer’s support groups frequently speak about the value of coaching one another along during the tough times. One participant says, *“People coming together, and having everyone hoping together and thinking this way as a group helps a lot.”* One woman speaks to another invaluable source of support, *“I get hope from my grandkids and my family.”*

If you have limited family relationships, it can be comforting to establish a sense of extended community—even one or two significant people who will see you through the ups and downs, and with whom you can share your hopes and your fears. True communication and understanding between people is a powerful ingredient in a recipe for hope.

Advances in science can also provide hope and participation in research can be an effective way of contributing to the cause.

Victor states: *“There is much work being done with research...I would like to take part in the cure... Leave something of yourself for the world so that you can participate in its future.”*

### Can Something Good Come From Alzheimer’s?

Finding and acknowledging positive outcomes from challenging or unwanted situations can greatly improve quality of life for you and your loved ones. Perhaps something encouraging has happened in your relationships with others, in adjustments you have made in your daily routines, or in insights you have gained into yourself. E.L. Gorman writes, *“Yes, having Alzheimer’s has changed my life; it has made me appreciate life more. I no longer take things for granted. I realize that time is precious and not to be wasted on negative emotions like anger, revenge, and hatred. I have learned the power of forgiveness.”*

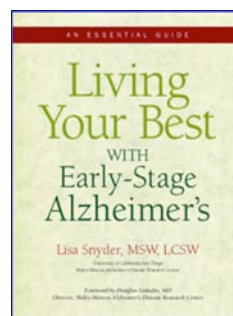
Your life will continue to reveal many opportunities to experience the sustaining benefits of both hope and humor. Keep an eye and ear out for the possibilities, and never miss out on a chance to laugh, give thanks, and feel the promise in each day.

### Questions for Discussion

Do you and your loved ones share a sense of humor? Is it helpful? Is it ever hurtful?

What gives you a feeling of hope?

Has anything good come out of Alzheimer’s for you or your loved ones?



This article is revised and condensed from “Maintaining Hope and A Sense of Humor” in Chapter 22 of **Living Your Best with Early Stage Alzheimer’s** by Lisa Snyder, 2010, Sunrise River Press.

<http://www.amazon.com/Living-Your-Best-Early-Stage-Alzheimers/dp/1934716030>

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