It is not uncommon to hear from persons with dementia that memory loss or the challenges of expressing oneself in conversation can lead to communication difficulties. It can be hard to have a voice in day-to-day matters or to openly express thoughts as they arise. But a novel project in the United Kingdom (UK) is helping people with dementia make their messages heard.

On Our Radar is an organization that helps people or communities around the world who may not otherwise be heard to share their stories. In January 2015, On Our Radar started Dementia Diaries in partnership with the UK-based Dementia Engagement and Empowerment Project (DEEP). Dementia Diaries aims to help record the daily experiences of people living with dementia by providing individuals with a small hand-held portable device for reporting their thoughts and reflections. Participants simply press a button to record their message and the recording automatically forwards to the On Our Radar team who log the reflections. Thus far, over 700 clips have been recorded from 27 people with dementia, some of which have been featured on prominent radio and television stations in the UK. Themes discussed by Dementia Diaries participants include issues of care and support; public perceptions; family and friends; living well with dementia; daily challenges; and public policies and services.

Retired teacher, Keith Oliver, reports his thoughts about metaphors for Alzheimer’s: “I think it can be useful to give people insight into my world of living with dementia. One metaphor I used is about the fog, which on bad days it’s like living in a fog and on good days – there are more good days than bad – the sun shines and life is much clearer. The other metaphor is about the hole punch which is where the memory and something you’re trying to do, it’s as if someone has got a hole punch and punched holes in what you’re trying to do or look at or remember. Sometimes there are a few holes, sometimes there are lots, sometimes it’s almost entirely obscured by holes.

The third one, which people like to use, is the Swan. Often people think you’re doing well. You’re coping well because they only see what’s on the surface like a Swan–serene and majestic on the surface and (continued on page 2)
Dementia Diaries
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below the surface, paddling madly. The fourth metaphor, one which has occurred to me recently, is about mining – coal mining...This is because living with dementia is sometimes like digging a new mine and posting pit props to support safe movement in the mine. The props are like a support I receive which allow me to be safe and confident. Remove the props and the mine cracks. Very much like my ability to live as well as possible.”

Jo Bennett recorded memories of being diagnosed and how she is learning to cope: “I just wanted to give a bit of real talk about when I was first diagnosed with dementia. It was a big shock because I had only gone to the doctors because my son-in-law kept saying he thought I had dementia. And to keep him happy, I went over. When I was diagnosed, we found it hard to accept. Everyone accepts the diagnosis in different ways, but as soon as I opened my eyes until I fell asleep, it was all I could think about for nearly two years. It didn’t matter how many people or times they said you’ll get used to it. I thought, ‘no, I won’t.’ But gradually, I began to realize that I wasn’t thinking about it all the time, and there had become some space in my head for other things again. I think it’s best to keep doing as much as possible, to keep active. Don’t sit at home and vegetate. Keep your brain as active as possible with things like Sudoku, crosswords, walking, joining a group, talking.

My daughter said that the most helpful thing she found was having a close friend to talk to. At the beginning, she was afraid to talk to me about dementia, but we’ve had a breakthrough and I talk to her more about it now. Not only about how it’s affecting me and her, but my husband, as well. So don’t keep things to yourself and bottling them up. Join groups, get help, get up and about, and share things.”

Paul Hitchmough, is a retired taxi-cab company owner and musician who was diagnosed with Alzheimer’s in February 2014. In one recording he states, “Since I got diagnosed, I feel maybe 20-25% more on the edge to write music and do songs. It’s very much a deed at the front of my mind all the time.” His song, “The Same Man”, features friends from his local dementia support group on back up vocals. “I have been really touched by the response to my single so far...I also really hope that my lyrics will resonate with people and that people will be moved by the message behind the song, which is that despite my condition, I am still the same man.” Listen to Paul’s very moving song: https://vimeo.com/135975247

Paul is using his song for fundraising for the Alzheimer’s Society. See the website: https://www.justgiving.com/Paul-Hitchmough

Chris Forse and his wife, Carol, have formed helpful teamwork around making sure Chris can still record his messages in Dementia Diaries. In one recording, he discusses how he has overcome communication challenges with her assistance: “I’ve not made any reports lately. I’ve been finding it a bit difficult. I knew what I wanted to say. Then I’d go upstairs to send a report but often then I’d put it off, finding reasons to do it later or at another time because I was finding I just couldn’t always string the words (continued on page 3)
Dementia Diaries  
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Anne MacDonald provides a rich summary of the value of Dementia Diaries in one of her recordings: "Great to hear so many voices sharing, living with dementia. We have opened our hearts to the world. Please listen and learn from us. With personal factual information we can reduce fear built up by media headlines and sensational reporting. My voice could help someone else realize they still have a good quality of life. We all need hope and understanding. Our voices need to be heard for those coming after us."

Listen to recordings of all of the Dementia Diaries participants at On Our Radar’s website: http://www.onourradar.org/dementia/

For more information about Dementia Diaries, contact Paul Myles at On Our Radar: paul@onourradar.org. For information about DEEP, see http://dementiavoices.org.uk/.

Dementia Diaries reveals the power of providing opportunities for persons with dementia to have a voice. In the USA, people with dementia have been sharing their stories in a different way through StoryCorps, a project that is committed to recording the diverse voices and experiences of citizens throughout the country. In 2006, StoryCorps launched the Memory Loss Initiative to support and encourage people with memory loss to share their stories. The person with memory loss is interviewed by a family member, friend, or supporting professional at a Story Core booth or partnering site across the country, and stories are archived at the Museum of American Folkart in Washington, DC. Some stories are broadcast on National Public Radio or archived on the StoryCorp website. To date, this wonderful initiative has partnered with 180 organizations to collect more than 1,800 interviews from people with memory loss.

StoryCorps’s Memory Loss Initiative now offers a unique, downloadable toolkit called “Commemorate”, designed to help families or organizations record, share, and preserve the stories of persons with memory loss. Offering Commemorate conversations to people living with memory loss can enhance the bonds, whether between people at home, in social day programs, or long-term care settings. These interviews provide an opportunity for families or staff to preserve the legacy of a person with memory loss.

To learn more about StoryCorps Memory Loss Initiative, listen to interviews, or download the Commemorate toolkit, see: http://storycorps.org/memory-loss/.
World Alzheimer’s Month

September 2015

Join the campaign

According to Alzheimer’s Disease International, every 4 seconds, someone in the world develops Alzheimer’s or a related dementia. September is World Alzheimer’s Month, an international campaign to raise awareness about Alzheimer’s and to challenge stigma and misinformation surrounding dementia. World Alzheimer’s Day occurs within this month on September 21st.

The theme for this year’s World Alzheimer’s Month campaign is “Remember Me.” This theme can be broadly interpreted, and both the Dementia Diaries and the Story Corps projects provide inspiring examples of how we can facilitate remembering for the person with memory loss, while creating recorded legacies so a person’s thoughts and reflections can be remembered for future generations to come.

How might you acknowledge the “Remember Me” theme in your family or community? See the World Alzheimer’s Month website, or contact your local Alzheimer’s organizations to see if there are planned events in your community.

http://worldalzmonth.org/eng/home

Thoughts on Life Lessons

The “Remember Me” theme of World Alzheimer’s month can inspire us to think about life lessons and how we might want to be remembered. Participants in the weekly early-stage dementia support group at the University of California, San Diego Shiley-Marcos Alzheimer’s Disease Research Center were asked: What have you learned about life that you might want to pass along?

Here are some of the answers:

“To share. Share your time, share your money, share yourself, and share your memories. My mom taught me that.”

“Tell the next generation the important things that happened in your life, then ask them the same question so they can also reflect on it with you.”

“I set aside money for my kids with the stipulation that the money is only to be used for them to get together once a year and share time with each other.”

“Be cautious, careful, and try new stuff.”

“Try to do something you wouldn’t normally do - open your mind.”

“Treat people the way you want to be treated.”

“Try to instill a good work ethic - work hard.”

“Keep a gratitude list and do it by decades - the first 10 years, 20, 30 etc. Adopt the attitude of gratitude and it will change the way you look at things.”

“Remember, tomorrow is another day.”

“Family togetherness is the most important thing - more important than all the success and money in the world. Treasure your time together.”

“Have a sense of humor!”
In an exciting development, the Centers for Medicare and Medicaid Services has approved a four-year $100 million study to better understand whether getting an amyloid PET scan can affect the diagnosis, management, and care of individuals whose cognitive symptoms (changes in thinking) cannot be diagnosed with current techniques. An amyloid PET scan can detect amyloid, one of the proteins responsible for Alzheimer’s (AD) in the brain, but having a positive scan does not mean that one has or will develop AD. However, a negative scan in which there is no amyloid seen in the brain, rules out AD. The Amyloid PET scan can be very useful in a diagnostic work up for AD when the symptoms are complex or unusual, but currently Medicare and other insurances do not pay for these scans.

In this study, Medicare will pay the costs of one scan and participants will learn their results. There will be up to 18,500 patients enrolled at over 200 sites around the USA. Participants in the IDEAS study must be age 65 or older and receiving Medicare. Perhaps the greatest impact of the IDEAS study will be on patients with Mild Cognitive Impairment (MCI) in which the person has memory loss, but it is not clear as to the cause. Amyloid PET imaging can clarify the diagnosis and could influence future treatment plans.

IDEAS will likely begin enrollment in January 2016. For more information see: https://clinicaltrials.gov/ct2/show/NCT02420756

Alzheimer’s Prevention Initiative

Many people with a family history of Alzheimer’s are hoping to find ways to reduce their risk of developing AD. The Alzheimer’s Prevention Initiative (API) is an international collaborative formed to launch a new era of Alzheimer’s prevention research. Led by the Banner Alzheimer’s Institute in Phoenix, Arizona, API conducts prevention trials in cognitively healthy people at increased genetic risk for AD. API will continue to establish the brain imaging, biological, and cognitive measurements needed to test promising prevention therapies and has created the Alzheimer’s Prevention Registry to support enrollment in future prevention trials. For more information, go to http://www.endALZnow.org

Connect

The CONNECT clinical trial will study whether an experimental drug, AZD0530 (saracatinib), will slow progression of early-stage Alzheimer’s disease. This drug is attempting to disrupt the way in which the protein, beta amyloid, forms damaging “plaque” deposits in the brain. Study researchers will use PET imaging to evaluate whether the drug is effective in slowing decline, and will also evaluate the drug’s safety and tolerability in study participants. This clinical trial will enroll 152 participants nationwide and in British Columbia. For more information on enrollment eligibility or study sites see: http://www.adcs.org/studies/Connect.aspx
A Cup of Coffee and a Connection - The Memory Café Movement

By Beth Soltzberg

Great ideas tend to spread. In 1997, Dr. Bère Miesen opened the first Alzheimer’s Café in Holland. In 2008, Dr. Jytte Lokvig brought the first café to the United States in Santa Fe, New Mexico. Now there are close to two hundred “Alzheimer’s” or “Memory” cafés across the USA, and this number is growing quickly.

A café is a relaxed social gathering for people living with Alzheimer’s or a related disorder and their care partners. Cafés meet in a wide variety of settings, including coffee shops, museums, social service agencies, councils on aging, and houses of worship. Some cafés include educational or creative arts programming, or outings. All memory cafés offer an opportunity to get out and socialize in a setting where others will understand and respect what it’s like to live with Alzheimer’s or a related disorder.

How do cafés differ from support groups?

Support groups provide an opportunity to tackle challenges and difficult emotions in the company of others who are on the same journey. Unlike support groups, cafés do not focus on disease or disability. Many people benefit from both kinds of programs - a time to address problems, and a time to “leave the disease at the door,” as Dr. Lokvig says.

Cafés also differ from support groups in that most do not ask guests for a diagnosis; they are open to those who have not been diagnosed or are uncomfortable with their diagnosis. Finally, cafés offer something fun for care partners to do with their loved one or friend who has Alzheimer’s or a related disorder.

Here in Massachusetts, memory cafés have been recognized by our state respite coalition as a form of respite. Often we think of respite as getting a break away from the care relationship. Time apart to do other things is important. However, spouses, parents and children, friends, and others who are in a care relationship also need a chance to enjoy each other’s company. Many café guests have told us that the café helps to “re-charge” their feelings of connection. It is lovely to see café guests holding hands or with arms around each other. One of our volunteers noted that café guests look like they’re going out on a date. Don’t we all need to go on a date at times?

What do people do at a memory or Alzheimer’s café?

At our JF&CS Memory Café near Boston, time is split between unstructured socializing and a creative art activity facilitated by a guest artist. We have enjoyed writing and reciting poetry, creating a paper quilt, storytelling, dancing, singing, and learning about the history of notable artworks. The creative arts take advantage of brain functions that are often affected last and least by Alzheimer’s or related disorders. For care partners, as well as people living with dementia, the arts tend to remind us of our shared humanity, and

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Memory Cafés
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create a sense of connection among people who may have felt quite isolated when they first arrived. Our facilitators are professional artists, so while there are no wrong answers, they challenge guests to explore and grow.

Each café is different, but many offer music or other art forms or activities such as visits from therapy dogs, or light exercise. Debora Tingley and Patricia Ris in San Francisco run memory cafés that focus on outings. At other cafés, guests prefer not to have structured activities, but to just sit and talk.

I’ll let café guests speak for themselves by sharing some quotes from guests at the JF&CS Memory Café, which has run monthly in Waltham, Massachusetts since March 2014:

“I’ve never been to a meeting like it! A very creative format. Wonderful!”
- Jacob, a man living with Alzheimer’s

“This is the first positive activity I have had in months.”
- Darlene, the wife of a man with Alzheimer’s

“It was so good for me to see Dad having a good time and me being able to relax for a while!!! Thanks for all the pampering, too, I needed that!!!!”
- Carla, the daughter of a man with vascular dementia and Alzheimer’s

How do I find an Alzheimer’s or memory café?

In some regions, cafés are organized into networks, and this makes it easier for guests to find them. Dr. Lokvig, in New Mexico, of the National Alliance of Alzheimer’s Cafes and Lori La Bey of Alzheimer’s Speaks in Minnesota have put together national directories of cafés. If there is no memory café in your region, perhaps you can be the catalyst to start one! Running a café requires an ongoing time commitment, so while some are run by volunteers, most have at least an affiliation with a community agency or other service provider. Talking to the social worker at your council on aging or local Alzheimer’s Association chapter can be a good place to start.

There are wonderful toolkits available to help those who want to start a café. Good resources are the websites: www.alzheimerscafe.com and http://memorycafe催化剂组织.org/
The “Resources” tab includes links to café locators, and also to café toolkits.

Hope to see you at a café!

Editor’s note: Beth Soltzberg coordinates the JF&CS Memory Café in Waltham, Massachusetts and the memory café Percolator network, which supports other Greater Boston organizations in starting and sustaining cafés. To learn more about cafés in the Boston area or to talk about developing your own in your neighborhood, contact Beth at bsoltzberg@jfcsboston.org or 781-693-5628.