

Case Study

Two Professionally Led Choir Programs: Empowering People with Dementia and Their Care Partners

by Helen Kivnick, PhD, LP, LICSW and Debra Sheets, PhD, MSN, RN



Educational Objectives

Identify the benefits of participation in a community-based choir for persons with dementia (PwD) and their care partners.

1. Describe the work of the choirs to show the potential of living well with dementia.
2. Identify the ways in which the choirs address stigma and social isolation.
3. Highlight lessons learned and future directions from this social movement.

Background

In 2019, the estimated number of people with Alzheimer's disease and related dementias (ADRD) was more than six million in North America, with dementia rates projected to nearly double by 2031 because of the large boomer population and increases

in longevity. No medical cure is expected anytime soon. Most of us have had personal experience with dementia and know the significant medical, financial and emotional impacts it has on families. There is an urgency to develop low cost and effective community-based programs that support people with dementia and their care partners.

Stigma represents one of the biggest barriers to living with dignity following diagnosis. Many older adults with dementia fear stigmatization and would not want others to know they have dementia. It is, therefore, all too common for those with dementia to become socially isolated, a condition that poses health risks comparable to being sedentary, smoking 15 cigarettes a day, or being obese (Holt-Lunstad, et al., 2015). It is also a strong predictor of mortality (Holt-Lunstad, et al., 2010).

How can we address the deleterious effects of stigma and social isolation associated with dementia? Arts-based approaches are unique in shifting attention from disease-related declines and losses toward innovation and creative action. Among such interventions, community choirs have garnered increased interest as a result of promising findings from several pilot studies (Bannan & Montgomery-Smith, 2008; Camic, et al, 2011; Unadkat, et al., 2016). For example, Bannan & Montgomery Smith (2008) found that persons with dementia (PwD) involved in group

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singing had increased engagement, better recall, and were able to learn new music. In another pilot study, Camic et al., (2011) found that even as PwD choir participants deteriorated, quality of life for them and their caregiver remained stable.

Singing in a choir is also associated with positive outcomes that include improved mood, increased energy, reduced stress, and higher self-esteem and confidence (Johnson, et al., 2015; Johnson, et al., 2013). Recently completed research on a community choir intervention to promote well-being among diverse older adults (N=390), although none with cognitive impairment, found that participants experienced significant improvements in loneliness and interest in life, compared to controls (Johnson et al., 2020).

Similarly, choral participation for PwD and care partners has been shown to facilitate stronger relationships within dyads (Dingle, et al., 2012; Han & Radel, 2016), to promote positive affect in care partners (Han & Radel, 2016), and to foster improved general health and well-being for the “duets,” that is, PwD and their care partners (Dingle, et al., 2012; Holt-Lunstad et al., 2010).

Raising Our Voices for Those with Dementia

We write as representatives of two non-profit organizations, one in the USA and one in Canada, that offer community-based choirs for people with mild to moderate dementia, also called ADRD, and care partners. *Giving Voice*, based in Minneapolis, MN, directly sponsors five choirs in the Twin Cities, and has provided inspiration, a toolkit, and ongoing support for over 42 additional choirs in the USA and internationally. *Voices in Motion*, based in Victoria, British Columbia, directly sponsors six choirs and has provided support for at least three other choirs in Canada.

Giving Voice was co-founded in 2014 by two women with high-level experience in administration, Alzheimer’s disease, and radio production. In addition to being long-time friends, both women had lost a parent to Alzheimer’s disease; they were eager to create something positive from their personal loss that would benefit PwD, their families, and communities experiencing ADRD stigma. They established *Giving*

Voice in collaboration with the Minneapolis MacPhail Center for Music’s “Music for Life” program.

Voices in Motion (ViM) was inspired by *Giving Voice* and launched in 2018 by an interdisciplinary research team (i.e., music, nursing, psychology, and sociology) at the University of Victoria in British Columbia. Research funding came from the Alzheimer’s Society Research Program (ASRP) and the Pacific Alzheimer’s Research Foundation (PARF). The research involved two community-based *ViM* choirs conducted over 18 months. The *ViM* study investigated the impact of participation in a professionally directed community choir for ADRD on measures of stigma, social connections, and well-being for PwD and their care partners.

Our Choir Programs

Although our choruses are “therapeutic,” we have deliberately not organized them as music therapy or linked them to medical treatment. They are intended as arts-based, high-quality music participation programs that are “healing,” making one whole (Kivnick & Erikson, 1983; Cohen, et al., 2006). Both *Giving Voice* and *Voices in Motion* choruses spring from the conviction that older adults with chronic disabling conditions are also people who retain skills, abilities, competencies, and have the potential to contribute to the lives around them. They remain people who, like all of us, need to be needed, want to be useful, and are capable of experiencing joy. *Giving Voice* and *Voices in Motion* provide these opportunities

Participants in both *Giving Voice* and *Voices in Motion* rehearse weekly, for up to two hours. We do not require a background in music. Each choir consists of 50+ singers, including people with mild to moderate stage ADRD, care partners, and volunteers. Care partners include spouses, siblings, friends, children, and grandchildren. Volunteers include community members with interests and expertise in music, music teaching, gerontology, ADRD, and other related areas. Increasingly, volunteers also include care partners of chorus singers who have died or moved into residential facilities. *ViM* is an intergenerational choir; 20 students from a local high school volunteer in order to get community service credit. Volunteers primarily assist ADRD singers whose care part-

ners sing in other sections. They also help prepare member music resources and organize the social time snacks described below.

These year-round programs include a fall season and spring season (each 12 to 14 weeks). *Giving Voice* offers an eight-week summer season. *ViM* will offer a bi-weekly “Music in the Garden” drop-in choir for choristers across all three choirs for the first time this summer to ensure opportunities to get together and sing. Rehearsals are run by a professional Choral Director/Vocalist who is “equal parts music director and cheerleader.” *Giving Voice* uses a professional accompanist; the *ViM* Director accompanies herself. All participants wear name tags.

Musical repertoire is chosen to facilitate social connection and to stimulate memories and emotions. Repertoire explicitly includes songs from the past, songs in different languages, songs that require movement, and contemporary songs with which participants may be unfamiliar. Each member receives a notebook each season, with the season’s repertoire in both sheet music and lyrics-only format. Members also receive practice CDs for each season, to support practicing between rehearsals. In addition to working on three to five songs, each rehearsal includes 10-15 minutes of directed physical movement to live music, and at least one “Music and Me” presentation, in which a member describes their personal history with music. Good. Bad. Funny. Who knew how much history we all shared? Weekly sessions also include social time where members mingle informally, enjoy snacks and beverages, and, over time, come to know each other across choir sections. In addition to invited performances, each season ends with a public performance followed, the next week, by a debriefing session.

The Choir as Intervention

ViM’s mixed methods research design involved participants from two choirs over an 18 month period. Sample size for the two choirs was 64: 32 care partners (usually spouses or adult children) and 32 PwD. (Data gathered from the high school students is not reported here.) IRB approval was obtained from the University of Victoria, BC, Canada. Over the course of the choir season, participants underwent compre-

hensive assessments every four to six weeks as part of an intensive repeated measure design. PwD and their care partners took identical assessments. Standardized measures were used to gather data during face-to face interviews using an assessment battery that included neuropsychological assessment, cognitive testing, physical assessments, gait mapping, and a quality of life survey. Care partners and PwD also completed a questionnaire to gather self-report data on physical health, medications, activities of daily living (ADL), social networks, caregiver burden, affect, depressive symptoms, quality of life, and more. Finally, choir participants engaged in a semi-structured, in-home interview lasting about one hour.

Research findings indicate that *ViM* is having significant impacts on care partners, PwD, and students; findings are summarized below.

Care partners. Analyses show that levels of care partner distress significantly decline ($p < .05$) over the choir season, and that distress increases again during the choir break over the summer. Levels of distress decline again upon resuming the following choir, supporting a conclusion that the choir is causing this effect. Care partners also experienced a significant cognitive boost with increases in episodic memory, i.e. word recall, ($pp < .05$) and reduced depressive symptoms ($p < .05$).

PwD. Surprisingly, cognition improved significantly ((i.e., Mini-Mental State Exam (MMSE)) ($p < .05$) for choir participants with dementia. We suspect that this is not because the disease process changed but rather it suggests how the stigma of dementia prevents people from functioning at their optimal level. In a welcoming place like the choir, PwD are able to function at their best. Similarly, scores on episodic memory significantly increased, indicating improvement in ability to recall a list of 30 words provided earlier in the assessment. In short, the choir offers a boost in PwD’s cognition by reducing stress. Depressive symptoms were significantly reduced from minimal to no symptoms.

Students. Qualitative findings indicate that the intergenerational component added value to all participants’ experiences of the choir. Focus groups with students found shifts towards more positive views of

aging and of dementia. One student stated: “When you hear people just talking about people suffering from memory loss, you just assume that they’re very old and near death. But I think this choir solidifies the whole concept of human dignity and . . .how these people are still very much here and they’re very present and they still have these personalities that are just incredible. And I think the stigma surrounding something like memory loss is just so, so stupid.” One older singer said: “I just love seeing the kids here. We live in a senior complex with too many old people. All our friends are old, my husband is old. I’m just so . . . sick of old people.” Music was a catalyst for the formation of an intergenerational community that resulted in new friendships and social connections.

Qualitative Research Findings

Both choirs have conducted qualitative research based on open-ended interviews with members and staff, and on ongoing participant-observation during rehearsals and performances. Thematic analyses of chorus benefits by participant group are summarized in Table 1.

Case Study #1: Voices in Motion

Virginia is an 85-year-old widow who has always sung in community choirs. A few years ago, dementia terminated her participation. She could not follow the music and the choir was not able to accommodate her need for support. Carolyn, Virginia’s daughter, moved in with her about 18 months ago when her business failed. About the same time, it became clear that Virginia needed additional support to continue to live in her home as her dementia progressed. However, in the last year, Carolyn has experienced increasing stress as Virginia’s dementia progresses. Virginia has no close friends, for most have died. Both Carolyn and Virginia are increasingly isolated. Social activities centered around trips to the store or going out to eat together. No other family members live nearby. Carolyn has never belonged to a choir before. She didn’t think she could sing and viewed bringing her mom to the choir as one more “task” to do.

During the first season, Carolyn’s resentment at additional strain imposed by attending and participating in the choir rehearsals gradually evaporated. She met other care partners she felt she could “vent to” be-

Table 1. Summary of Choir Participant Benefits by Group

<p><u>PwD</u> Affective (Individual) Joy (singing; good mood) Energy / relaxation Identity other than Alzheimer’s Increased self-esteem, confidence Misc. emotions (laugh/smile; tears; light-in-eyes) Social Health Belonging; Being welcome Shared experience Egalitarian participation; Ownership See/help others New friends; Ordinary friendship Moving / Hugging Transcendent Hope; Purpose Spirituality Healing “Rejoin human community” Choir-Audience Reciprocity Change attitudes Admiration / Respect</p>	<p><u>Care Partners</u> Enjoyment / Heartwarming New friends Relief from Caregiver burden Rediscovery Personal growth</p> <p><u>Couples</u> Changing roles “Breathes oxygen into the relationship” Togetherness/family outside rehearsal</p> <p><u>High School Volunteers</u> (Where applicable) Meaningful contact/communication with older adults Recognition of human dignity in “these people” Enjoyment New friends Helping others</p>
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cause they understood her situation. She enjoyed the respite of being in a different section from her mom and simply focusing on learning her part in the choir. It was wonderful to see her mom smiling and singing across the room with a high school student who was becoming a close friend. Over time Carolyn became even more committed to *ViM* than her mother, as she discovered their relationship deepening as they regularly sing together with the practice CD.

Case Study #2: Giving Voice



75-year-old Rob was diagnosed with Alzheimer's after losing a second job for poor performance. After

retiring, he occupied himself with long-time hobbies that included listening to long-beloved opera recordings, woodworking, and reading. But he gradually stopped being able to concentrate on anything. Rob and his wife Kate had joined an Alzheimer's Association Memory Club, where they learned about the disease and its progression, and shared stories and survival strategies with other couples. Their group provided peer support for one another. They commiserated about being dropped (sometimes not so gently) from groups in which they had participated for decades. Over lunches and dinners, they shared coping strategies and funny stories. But as Alzheimer's progressed among the peer support group, some members stopped being able to socialize, some entered memory care, all became increasingly fragile, and the group disintegrated.

Although Kate was eager to serve as a volunteer, she was adamant that "For us, this chorus has to be something we share. Something for both of us. I'm happy to help a soprano with Alzheimer's, but I refuse to be Rob's caretaker in here." So Kate buddied up with a soprano with Alzheimer's, and volunteers vied for the privilege of helping Rob follow his lyric sheets. Within the first several weeks of rehearsals, Rob established himself as jokester-in-chief. He began telling the Music Director, "In here, I feel like myself again." At each rehearsal, a different member shared their personal singing history. Surprisingly quickly, this gathering of "lovers of singing, with personal Alzheimer's connections" became a com-

munity whose members looked forward to being together each week and part of a chorus where they all belonged. One day Rob asked the Music Director, "Are the men singing a quarter note or an eighth note at Letter 'E'?" Flabbergasted, she replied, "Rob, you use the lyrics. How can you be asking that question?" Rob was nonchalant. "I remembered how to read music." Over with the sopranos, Kate beamed.

These stories illustrate specific benefits of choir participation. In Case #1, we see how both care partner and PwD benefit from new social connections and a shared activity that strengthens their mutual relationship. Case #2 shows how the choir helped restore a PwD's sense of self and supported his optimal performance despite memory loss.

Lessons Learned

A number of lessons can be drawn from both programs. First, the personality of the professional choir director is crucial; she/he must be able to make the choir fun, challenging, and achievable. The choir director is also social facilitator; so she/he must be comfortable helping people to get to know one another through all choir activities. Second, choirs need administrative support to help with recruitment, concert planning, photocopying, collating music notebooks, coordinating volunteers, organizing refreshments, and more. Third, a carefully selected Board of Directors is critical to the long-term sustainability of these choirs and to reflecting participant preferences in decision-making. Fourth, well-chosen partnerships (e.g., high schools, Alzheimer's Associations, caregiver organizations, churches) can enrich and support these choir programs. Fifth, a few passionate people can make programs like ours happen in their own communities. These programs are socially compelling and their positive impact on health and well-being, as well as overall community vitality, is supported by a growing body of research, not only for PwD but also for all participants and audience members. Moreover, an energetic network of dementia choir programs is helping this social movement and its new programs to grow. In broader psychosocial terms, we are seeing choir programs like these promoting the vital involvement that Erikson and colleagues (Erikson et al., 1986; Kivnick & Wells, 2014) have defined as meaningful, reciprocal

engagement between self and outside environment; these scholars have identified vital involvement as the fundamental dynamic for creating and maintaining psychosocial health.

Primer

Giving Voice has created a Toolkit (downloaded from <https://givingvoicechorus.org/>) that addresses the elements and FAQs of planning and running a high-quality chorus for PwD and care partners.

Giving Voice also sponsors a National Collective Leadership Gathering in Rochester, MN, in July. For two days, continent-wide staff, administrators, board members, and researchers of existing choruses and those still in planning share experiences and information, tell stories, brainstorm problems, report research, participate in exercises, and otherwise celebrate the potential of people with dementia.

Voices in Motion is currently developing an online “Train the Trainer” program to supplement an initial weeklong in-person training program on how to develop a community choir for PwD. The training program will launch in 2021.

Conclusion

Participants in all of our choirs are consistently impressed with the psychosocial benefits of involvement, whether as PwD, care partners, staff, volunteers, audience members, or guest composers. PwDs emphasize the importance of individual experiences of personhood, identity, competence, joy, purpose, hope, and friendship; they increasingly find themselves without such experiences as their disease progresses. To these benefits, care partners add welcome relief from burden, pride in their partner, regained intimacy, new relationships, and personal growth.

As important as these internal, personal experiences are, all participants express overwhelming feelings at being part of a wonderful group. Major health risks associated with loneliness and social isolation are increasingly recognized by practitioners and researchers of ADRD, in particular, and of aging, in general. Chorus participation counters pernicious disconnectedness with the belonging, cooperation, sharing,

and ownership that are natural parts of meaningful, regular social engagement. A newly arrived choir member recently told his choir, “I’ve only been here for these first two rehearsals. But this is a *real* choir. It belongs to all of you, you all belong to it, and you all belong to each other. That comes through so powerfully in the way you all sing together.”

Equally important is the dismantling of society-wide negative attitudes and stigma around ADRD. Audience members routinely find themselves wondering who among the singers onstage has dementia and who does not. Wrote one concert attendee, “[You] inspire all not only to have a better understanding of dementia, but also to advocate for those who are walking through this journey.” A volunteer contributed to a concert debriefing session, “A little boy was wriggling in his mother’s lap in the front row of the audience. I saw him point at the man who was comedically introducing the next song, and ask her ‘Is that Grandpa? He never does anything but sit with his eyes closed!’”

Study Questions

1. Explain two key benefits of participation in the dementia choir program on the health and well-being of: 1) a PwD and 2) their care partners.
2. Identify two ways in which these choirs can address dementia stigma and social isolation.
3. How can student participation in choirs contribute to a change in society-wide attitudes about dementia and aging?

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Drs. Kivnick and Sheets are equal co-authors of this piece.

From the Director, Virginia Center on Aging

Edward F. Ansello, Ph.D.

Finding Light in the Darkness: The Role of Humor

“There are only two or three human stories,” said writer Willa Cather, “and they go on repeating themselves as fiercely as if they had never happened before.” Confronting darkness of varying hues is one of these human stories. How one responds to it creates the repeated variations of this human tale.

We are in a period of darkness around most of the world. The novel coronavirus COVID-19 is striking fear in hearts. It is the latest darkness so many of us are confronting. We are told to maintain “social distancing,” to hunker down, and to stock up on supplies.

I’m of an age where all this reminds me a bit of the bomb shelter mentality of the early Cold War. Then, the dark threat was nuclear warfare with the Soviets. Today, it’s a deadly virus. During the Cold War some answered the threat with withdrawal; some transferred their fear, transforming it into something alien but palpable, hence the splurge of science fiction movies with creatures who personalized the unseen threat of nuclear destruction or the spread of communism. Others responded with humor. One of the most popular movies of the time was *Dr. Strangelove*, which treated America’s enemies with absurd, off the wall, humanizing levity. The film’s full title is *Dr. Strangelove, Or How I Learned to Love the Bomb and Stop Worrying*.

Cultivating a sense of humor has been, and can be, a lifeline in times of darkness. It doesn’t dismiss the darkness but helps us to respond.

Our contemporary coronavirus crisis is only one of many darkneses that we will face in our lives. Some of us have dealt or are dealing with cancer, debilitating illnesses, loneliness, substance abuse, death of loved ones, chronic caregiving or other serious challenges. Again, it’s one of the enduring human stories.

Being able to escape and be distracted is supportive. There are many theories of the value and meaning of humor and laughter. Plato and Aristotle saw them

negatively, equating them with scorn of others.

Similarly, the Puritans discouraged them, favoring firm, sober living. More recently, philosophers and non-philosophers alike have come to see humor and laughter as a type of safety valve releasing built up tension, producing relief.

We’ve previously discussed some of the benefits of “Laughter and Well-Being as We Age” in our Summer 2017 editorial where we noted that laughter, even simulated or forced laughter, what some researchers call self-initiated laughter, produced measurable, healthful results, such as reduced anxiety and increased positive affect or mood.

Other research on the benefits of humor and laughter extends the findings, showing benefits in a surprisingly wide array of contexts. For instance, Eshg and team (2017) showed the effect of humor therapy in lowering blood pressure of patients undergoing hemodialysis; Feingold and colleagues (2011) found that patients with COPD with a sense of humor reported less depression; and Ryu and co-authors (2015) described how laughter therapy increased immune responses in postpartum women. Still other studies have shared findings indicating that humor and laughing can serve as a muscle relaxant, help boost one’s immune system, dilate the inner lining of blood vessels, and expand the lung’s alveoli, allowing greater oxygen exchange.

Mark Twain called humor “mankind’s greatest blessing.” It can be a helpful aid in times of darkness, though admittedly difficult to find in adverse times. In crisis, one can be riveted to the crisis itself. Perhaps we should force ourselves to think outside the particular crisis box we find ourselves within.

So, if we are, or someone we care for is, dealing with darkness, COVID-19 or otherwise, consider these lifelines.

If you are of Social Security age, you will likely

recognize and remember the following suggested outlets for experiencing humor and laughter. If you are a mid-life caregiver, there may be some sources new to you that you can enjoy, as well as some others more recent with which you are already familiar. The following are usually available on the Internet and some can be borrowed as CDs or e-materials from the local library.

For older adults and for those younger who are caring for them, there are many resources that bring alive the humor of the 1940s, 1950s, and 1960s.

Old Time Radio (www.otr.net). As it says on its website: “The OTR Network Library is a free resource for Old Time Radio (OTR) fans. We have over 12,000 OTR shows available for instant listening.” There’s also Old Radio World (www.olderadioworld.com). Both give free access to thousands of hours of radio broadcasts, including hundreds with real audiences laughing and enjoying inevitably clean humor. Programs include episodes from Abbott and Costello, The Jack Benny Show, The Adventures of Ozzie and Harriet, The Bing Crosby Show, The Bob Hope Show, George Burns and Gracie Allen, and much more.

Steve Allen, author, comic, music composer, and host of his own television show was a communications genius in his era and appeared in various media from the 1950s to the 1990s. Search online for his “Man in the Street” interviews, which feature a recurring cast of comedians Louis Nye, Don Knotts, and Tom Poston; you’ll find a vinyl record released in 1959 and some episodes on YouTube. All are G-rated for family viewing.

The Marx Brothers have been called pioneers, for they launched the prototype for comic film-making, with extraordinarily clever repartee, inventive plays on words, and fast paced visual antics. Here’s Groucho Marx: “One morning I shot an elephant in my pajamas. How he got in my pajamas, I will never know.” And another: “Outside of a dog, a book is man’s best friend. Inside of a dog, it’s too dark to read.”

For outrageous conniving, look up Sgt. Bilko, played by Phil Silvers; it’s also listed as The Phil Silvers

Show. Over the 142 half-hour episodes, and multiple Emmy awards for best comedy series, he plays the scheming conman with a memorable cast in his Army motor pool, including Pvt. Doberman, Cpl. Barbella, and Cpl. Henshaw, all under the command of the clueless Col. Hall.

For Baby Boomers who are in darkness or are caring for others in such situations, we can add the British group Monty Python, who had years of somewhat Marx Brothers-like inventive humor in their television series and several movies. They may not be everyone’s cup of tea but are certainly a prime example of absurd comedy. Their episodes, movies, and “best quotes” are readily available on the Internet.

Then, of course, there’s Mel Brooks, one of Hollywood’s most creative comedic geniuses. Even segments of *Young Frankenstein*, *The Producers*, *Blazing Saddles*, *Spaceballs*, or *Robin Hood: Men in Tights* can lighten the darkness.

We should also mention stand-up comedians who put real thought into their humor, such as Bob Newhart, whose imagined two-way telephone conversations with others displayed hilarious predicaments and depth of irony; look up the King Kong story or Sir Walter Raleigh’s call to Queen Elizabeth. Also, Jerry Seinfeld who made a successful television series out of “stories about nothing.” And the cerebral Stephen Wright who observed, “Sponges grow in the ocean. That just kills me. I wonder how much deeper the ocean would be if that didn’t happen.”

The human story of confrontations with darkness can be lightened with the aid of humor and laughter. We are not trivializing real crises in our lives but encourage looking for support available around us. And, after all, the Latin root of the word “levity” is *levitas*, meaning lightness.

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From the Commissioner, Virginia Department for Aging and Rehabilitative Services

Savannah Butler, DARS Prevention Program Coordinator

Nine Year Experience with Chronic Disease Self-Management Education

Older adults and people with disabilities are disproportionately affected by chronic illness. According to the Centers for Disease Control and Prevention (CDC), about 80% of older adults live with at least one chronic health condition. People with disabilities experience an average of nine days of restricted activity every month due to health challenges, more than four times the rate of their counterparts without a disability.

In 2010, the Department for Aging and Rehabilitative Services (DARS) received the first of three grants from the federal Administration for Community Living (ACL) to provide the evidence-based Chronic Disease Self-Management Program (CDSMP) developed by Stanford University. The program provides older adults and adults with disabilities with education and tools to manage their chronic conditions, including diabetes, hypertension, heart disease, chronic pain, arthritis, and depression.

CDSMP is a six week workshop, consisting of 2.5 hour weekly sessions, during which participants learn about a variety of topics, such as healthy eating, the importance of exercise, appropriate use of medications, and effective ways to talk with healthcare professionals. Classes are highly interactive, and participants help each other through brainstorming and problem-solving as they develop weekly achievable action plans. Participants are considered “completers” if they attend four or more of the six weekly sessions.

There is strong evidence across many studies that CDSMP participants experience several beneficial health outcomes, including greater energy, increased participation in physical activity, improved health status, reduced pain symptoms, and improved psychological well-being. Participants also report enhanced communication and partnerships with physicians and greater confidence that they can take actions to

affect their own health. Long-term, CDSMP has been shown to reduce healthcare costs by decreasing the number of emergency room visits, the number of hospital admissions, and hospital length of stay.

Other evidence-based workshops are now available and make up a suite of Chronic Disease Self-Management Education (CDSME) programs that include the Diabetes Self-Management Program (DSMP); Chronic Pain Self-Management Program; Tomando Control de su Salud, a Spanish version of CDSMP; and more. These programs are currently licensed by the SMRC (Self-Management Resource Center), formerly the Stanford Patient Education Research Center.

In August 2016, DARS received its third grant award from the ACL under the *Empowering Older Adults and Adults with Disabilities through Chronic Disease Self-Management Education Programs* to expand CDSME statewide. During the grant period, which ended in July 2019, Virginia’s Area Agencies on Aging (AAAs) delivered a total of 495 workshops in 82 counties and cities and reached 4,708 completers. This accomplishment was 190% above the original completer target goal of 2,469. During the grant project, DARS formed a partnership with Health Quality Innovators (HQI), formerly VHQC or Virginia’s Quality Improvement Organization, to help deliver its Everybody with Diabetes Counts (EDC) initiative. The purpose of the EDC initiative was to:

- Improve health equity by improving health literacy and quality of care among people with diabetes and pre-diabetes, including Medicare beneficiaries and individuals dually eligible for both Medicare and Medicaid.
- Target Medicare beneficiaries from medically underserved racial/ethnic minority and/or rural populations.
- Engage beneficiaries and providers to decrease the

disparity in diabetes testing by improving eye exams, foot exams, blood pressure control, weight control, and testing for HbA1c and lipids.

- Improve actual clinical outcomes of the above measures.
- Facilitate sustainable diabetes education resources by engaging public/private/agency/organization partnerships at the community, state and national level.

Through the delivery of DSMP and CDSMP, both the Commonwealth of Virginia and the state of Maryland, in partnership with HQI, were able to empower over 7,200 people with diabetes and pre-diabetes to improve their health. This initiative helped to prevent 54,214 avoidable hospital admissions and 15,454 avoidable hospital readmissions, saving over \$745 million. Because of this impact, DARS won the first place HQI award for the “2019 Health Quality Innovator of the Year for Collaboration.”

Since the beginning of CDSME in 2010, Virginia’s AAAs have administered 1,385 workshops, with 17,470 participants enrolled and 13,414 completers. Currently, Virginia has a completion rate of 77%, which is higher than the national average of 73%. Over the years, the program has also been offered to special target populations, including individuals with early stage dementia and their caregivers, and to offenders in correctional centers. The impact of CDSME workshops on participants’ overall health and wellbeing is best summed up by these individuals’ experiences:

“I am writing this letter to express my appreciation and gratitude for your care, time and efforts to offer such an informative class, especially to incarcerated individuals like myself. The class gave knowledge that I could use in more ways than just chronic conditions. I use the knowledge for personal growth as well. I feel that this class has made me a better person.”

“I wasn’t sure I belonged in the CDSMP workshop but was coming to support my wife. Through the course of the workshop, I realized that I also had some chronic conditions. I hadn’t thought they were bad enough to count as chronic diseases but began to recognize the importance of managing them early before they get worse. I also learned new ways to

encourage my wife.”

Although the grant project has ended, DARS has entered into a partnership with the Virginia Department of Health to assist with its Arthritis Prevention grant from the CDC by providing CDSMP through the AAAs. With this partnership at the state level, and the local community partnerships formed by the AAAs, Virginia is finding ways to sustain CDSME and build capacity for these vital programs.

DARS 2020 Meeting Calendar

The DARS advisory boards meet quarterly and are open to the public. All meetings will be held from 10:00 a.m. - 2:00 p.m. at the Virginia Division for Aging Office, 1610 Forest Avenue, Suite 100, Henrico. For information, call (804) 662-9333 or visit vda.virginia.gov/boardsandcouncils.htm.

Commonwealth Council on Aging

June 17, September 16, December 9

Alzheimer’s Disease and Related Disorders Commission

June 9, September 8, December 8

Virginia Public Guardian and Conservator Advisory Board

June 11, September 3, November 19

Visit Our Websites

VCoA: vcoa.chp.vcu.edu

DARS: www.vadars.org

The Virginia Center on Aging's 34th Annual Legislative Breakfast

VCoA hosted its 34th annual breakfast on January 22, 2020, at St. Paul's Episcopal Church in Richmond. We welcomed members of the General Assembly, their staffs, the Executive Branch, state departments, Councils, and colleagues in agencies and organizations across Virginia.

VCoA hosts this annual breakfast to inform the General Assembly, which created it in 1978, of progress in meeting our three fundamental mandates: interdisciplinary studies, research, and information and resource sharing. We take this opportunity each January to review our activities in the calendar year just concluded. As has been the case for so long, partnerships with many others enabled us to achieve success in helping older Virginians and their families. VCoA trained, consulted, researched, or collaborated in every region of the Commonwealth in calendar year 2019. We were honored to have Attorney General Herring welcome attendees.

You can see our Legislative Breakfast Power Point presentation by visiting <https://bit.ly/3cE06rt>.



Top Left: VCoA's Jeffrey Ruggles and Advisory Committee Chair Bob Schneider

Top Center: Justine Young, Piedmont Senior Resources, Area Agency on Aging, and Donna Smith, Eastern Shore Area Agency on Aging/Community Action Agency

Top Right: Ron Boyd, Local Office on Aging, Inc., with Chris Stone and Debbie Spencer of the District Three Governmental Cooperative

Middle Left: Emily Ihara, George Mason University, and VCoA's Bert Waters

Middle Center: Attorney General Mark Herring addresses the audience

Middle Right: Rev. Pernell Johnson, First Baptist Church Midlothian, Rachel Ramirez, and John Lemza, all of the Lifelong Learning Institute in Chesterfield

Bottom: Delegate Betsy Carr and Delegate Chris Head in conversation with VCoA's Ruth Anne Young, Jeffrey Ruggles, and Ed Ansello



Row 1 Left: Bert Waters, VCoA; Dolores Clement, VCU; and Thelma Watson, Senior Connections, The Capital Area Agency on Aging

Row 1 Center: Erica Wood, Northern Virginia Aging Network and Adrienne Johnson, VirginiaNavigator

Row 1 Right: Marcia DuBois, Virginia Department for Aging and Rehabilitative Services, and Martina James Nalley, Virginia Association of Area Agencies on Aging

Row 2 Left: Jenni Mathews, VCoA, and Veronica Cosby, Virginia Department of Health

Row 2 Center: Delegate Betsy Carr and VCoA's Ed Ansello

Row 2 Right: Harvey Chambers, Anthem HealthKeepers Plus, in discussion with Ed Ansello and Erica Wood

Row 3 Left: VCoA's Catherine Dodson, Senator Emmett Hanger, and his wife Sharon

Row 3 Center: Christy Jensen, Riverside Center for Excellence in Aging & Lifelong Health, and Bill Massey, Peninsula Agency on Aging, Inc.

Row 3 Right: Sherry Peterson and Patricia Slattum

Row 4: The Legislative Breakfast provides great opportunity for networking.

Row 5: Dr. Peter Boling, VCU Health, speaks with Senator Emmett Hanger

Row 6: Representatives from the Petersburg Sheriff's Department listen to the presentations.

Preying on Our Nation's Seniors

by Rachel Snead, Esq.

(This article originally appeared in the March 17, 2020 issue of the Hook Law Center newsletter and is reprinted by permission. Hook Law Center publishes many helpful resources for older adults. See: https://www.hooklawcenter.com/publications/?utm_source=newsletter)

Financial Fraud is the fastest growing form of elder abuse in the nation. Elder fraud, which is also known as elder financial exploitation or elder financial abuse, is the abuse of financial control or misappropriation of financial resources, resulting in harm to an elderly victim, usually in a relationship where the perpetrator is in a position of trust.

Elder financial abuse is tough to combat, in part because it often goes unreported. Many elderly victims are often too confused, fearful, embarrassed or even unaware that a crime has occurred, to report it. A recent Comparitech study found that while more than 200,000 elder fraud scams are reported to US authorities each year, resulting in an estimated \$1.17 billion in damages, this is likely only a drop in the bucket compared to the true number of elder fraud victims.

Based on other findings reported by Consumers Digest, it is estimated that the real number of annual elder fraud cases in the US is closer to 5 million, but law enforcement or government officials only learn about 1 in 25 cases due to underreporting. The National Council on Aging estimates that the annual cost of elder financial abuse is more accurately up to \$36.5 billion annually. These recent findings show that seniors are being disproportionately targeted as victims for fraud at a shockingly high rate. So why are seniors being targeted?

Common problems. Seniors share common concerns such as Social Security, health care coverage, retirement funds, medications, etc. These very real and significant concerns are shared by the senior population and widely known of by the general public making them an easy target to exploit.

Isolation. Many seniors are isolated from their friends and family members. Seniors have a more difficult time using technology to communicate with others and struggle to travel as they start to lose mobility. Scammers prey on these individuals, knowing that they have no one to discuss things with.

Diminished Capacity. Unfortunately, as we age it is not uncommon to experience some level of diminished capacity. With diminished capacity comes difficulty making sound decisions and recognizing when we are being taken advantage of.

The silver lining to all of this is that elder financial abuse is getting the attention it deserves and is being recognized as a real threat to our nation's seniors' financial and overall well-being. In an effort to combat elder fraud, Attorney General Barr recently announced the launch of a National Elder Fraud Hotline, which will provide services to seniors who may be victims of financial fraud. The Hotline will be staffed by experienced case managers who can provide personalized support to callers. These case managers will assist callers with reporting the suspected fraud to relevant agencies and by providing resources and referrals to other appropriate services as needed.

Reporting is the first step to understanding the magnitude of this problem and being able to address it effectively. If you think that you or someone you know may be a victim of elder fraud, call the Hotline's toll free number at 833-FRAUD-11 (833-372-8311).

Other Resources

NAPSA <https://www.napsa-now.org/get-informed/exploitation-resources/>

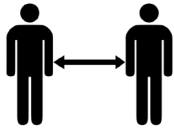
National Center on Elder Abuse www.ncea.acl.gov

VCoA maintains a program to combat abuse in later life. Staff members Ruth Anne Young and Courtney O'Hara provide training programs funded by the Virginia Department of Criminal Justice Services for law enforcement, victim services, prosecutors, APS, and others to foster prevention of and effective multidisciplinary responses to maltreatment of older adults. For information: <https://vcoa.chp.vcu.edu/programs/elderabuse.html>.

10 Mental Health Tips for Coronavirus Social Distancing

by Dr. Giuseppe (Bepi) Raviola, Director of Mental Health, Partners In Health

(The following was posted by Partners In Health on March 16, 2020, where Dr. Raviola “put together a list of key practices to maintain good mental and emotional health for those asked to stay at home in efforts to prevent further spread of the novel coronavirus, or COVID-19.” It is reprinted by permission.)



As we enter this new and unprecedented phase of the pandemic, we are inundated with guidelines about how to keep ourselves and our families healthy and virus-free.

Yet a key item on the list, social distancing, poses unprecedented challenges to our mental and emotional well-being, and requires consideration. The risk may be especially high for our children, who are suddenly cut off from school and friends.

How do we as individuals and parents cope without driving ourselves and each other crazy?

It’s a question that mental health professionals such as myself are being asked multiple times a day and that urgently needs addressing. This introduction and list was written with the help of people with whom I work, trying to gain steady emotional footing in this strange new scenario we together are in:

Top 10 Practices

- 1) Social distancing does not mean emotional distancing; use technology to connect widely;
- 2) Clear routines and schedule, seven days a week, at home; don’t go overboard;
- 3) Exercise and physical activity, daily if possible;
- 4) Learning and intellectual engagement: books, reading, limited internet;
- 5) Positive family time, working to counter negativity;
- 6) Alone time, outside if possible, but inside too; but remember, don’t isolate;

- 7) Focused meditation and relaxation;
- 8) Remember the things that you really enjoy doing, that you can do in this situation, and find a way to do them;
- 9) Limit exposure to TV and internet news; choose small windows and then find ways to cleanse yourself of it;
- 10) Bathe daily, if possible, to reinforce the feeling of cleanliness.

Remember

- Things will get better eventually, and back to normal; the world is not collapsing (don’t go “catastrophic”).
- Most people are good, and people are going to persevere and help each other
- You’re tough; you’ve overcome challenges before; this is a new one.
- This is a particularly strange and unprecedented situation; humor helps once in a while.
- If (you are) having obsessive or compulsive thoughts related to the virus, or the broader uncertainty, wash your hands once, and then remind yourself that anxiety is normal in this scenario. But the mind also can also play tricks on us. Try to breathe and move the internal discussion on.
- Live in the moment, think about today, less about the next three days, even less about next week; limit thinking about the next few months or years, for now.

Partners In Health (PIH) is affiliated with faculty and colleagues at Harvard Medical School, the Harvard School of Public Health, and Brigham and Women’s Hospital. As PIH notes, “This collaboration among a nonprofit organization, a medical school, a school of public health, and a teaching hospital is a new and fruitful model for leveraging the resources of the world’s leading academic institutions to inspire, enlist, and train others to address the pressing health inequalities of our times.”

Taking Blood Pressure Medications at Bedtime May Be Best



Recently, a large, well-managed research study strongly suggests that when we take our blood pressure medications may be important.

Taking blood pressure medications at bedtime rather than in the morning appears to be more effective in reducing risks of illness or death due to cardiovascular disease.

The study, reported online in the October 22, 2019 issue of the *European Heart Journal* reflects the work of The Hygia Project, a network of 40 primary care centers in northern Spain. Some 292 doctors involved in the project received training in ambulatory blood pressure monitoring, where participating patients wore a special cuff that recorded blood pressure at regular intervals throughout the day and night as they walked, worked, ate, and slept. The “Hygia Chronotherapy Trial” opted to monitor blood pressure for 48 hours, rather than the usual 24 hours, adding further weight to the findings. Professor Ramón C. Hermida, Director of the Bioengineering and Chronobiology Labs at the University of Vigo, Spain, led the team.

Participants in the research were 19,084 adults, ages 18 and over (10,614 men and 8,470 women), all of Caucasian Spanish origin. They each had been diagnosed with hypertension and were recruited to the trial, which for individuals lasted a median of six years during the project period 2008-2018. The patients were randomly assigned to one of two groups: those who took their blood pressure medication in the morning and those who took it at bedtime. Participants had to stick to a routine of daytime activity and night-time sleep.

Doctors took the blood pressure of these participating patients when they joined the study and at each subsequent clinic visit. Each visit was followed by ambulatory blood pressure monitoring over a 48-hour period at least once a year. This produced information on average blood pressures over the 48 hours, including how much blood pressure decreased or

‘dipped’ while the patients were asleep. Blood pressure follows a daily rhythm, rising during the day and falling at night when we are asleep.

Patients with high blood pressure are at risk for cardiovascular problems. During the median of 6.3 years follow-up, 1752 patients died from heart or blood vessel problems, or experienced myocardial infarction (heart attack), stroke, heart failure or coronary revascularization to unblock narrowed arteries.

What did the researchers find from the ambulatory blood pressure monitoring?

Patients who took their medication at bedtime had significantly lower average blood pressure both at night and during the day, and their blood pressure beneficially dipped more at night, as compared to patients who took their medication on waking. A progressive decrease in night-time systolic blood pressure (first of the two numbers in BP readings) during the follow-up period was the most significant predictor of a reduced risk of cardiovascular disease.

The researchers found that those who took their blood pressure medication at bedtime had nearly half the risk (45% reduction) of dying from or suffering myocardial infarction, stroke, heart failure or requiring a procedure to unblock narrowed arteries, compared to patients who took their medication on waking.

The researchers wanted to control for other explanations of their findings, so they adjusted their analyses to take account of factors that could affect the results, such as age, sex, type 2 diabetes, kidney disease, smoking, and cholesterol levels. What they found:

- the risk of death from heart or blood vessel problems was reduced by 66%;
- the risk of myocardial infarction by 44%;
- the risk of coronary revascularization by 40%;
- the risk of heart failure by 42%; and,
- the risk of stroke by 49%.

Overnight blood pressure control is important in lowering these risk factors. As we grow older, we may develop a blood pressure pattern called “non-dipping.” Non-dipping blood pressure tends to remain

high overnight. People ages 55 and older with high blood pressure are more prone to non-dipping.

Non-dipping blood pressure is a problem because it is a major risk factor for several conditions, including heart attack, stroke, and kidney disease. Taking blood pressure medications at bedtime tended to give patients better nighttime blood pressure. If one takes blood pressure medications in the morning, they may wear off before the next dose is due, and blood pressure may be elevated for several hours while sleeping. One may also wake with high blood pressure. Taking medication at bedtime may help prevent this.

Of course, there are always cautions, even with these strong findings. Taking medications with water at bedtime may exacerbate night time urination. And, because we become more individualized as we grow older, there's really no "one size fits all" generalization here. Any medication regimen should be personalized for you based on a discussion with your prescriber.

Still, these research findings are dramatic.

What Is Prediabetes?

About a third of adult Americans (ages 18 and above) and about a half of older adults are thought to have prediabetes, which reflects a condition called insulin resistance. Prediabetes is when blood glucose (blood sugar) levels are higher than normal but not high enough to be classified as diabetes. There are no clear symptoms of prediabetes. Most prediabetics are unaware of their condition.

Diabetes is a term for a group of diseases, with type 2 diabetes being the most common that affect how our bodies use glucose. Glucose, the simplest of carbohydrates, is vital for health, the body's energy source as it were, and our cells need it.

Our body processes glucose, made by our liver and contained in foods that we eat, by means of insulin, one of the hormones that our pancreas produces. Diabetes can occur when the pancreas doesn't manufacture insulin sufficiently. In this situation, we need

outside help through insulin injections to process and regulate glucose. If the body doesn't produce enough insulin, it can result in the release of free fatty acids from stored fat, which can lead to a condition called ketoacidosis. Ketones, waste products created when the liver breaks down fat, can be toxic in quantities.

Another cause of diabetes is insulin resistance, where the liver doesn't recognize insulin already in the body and continues to make inappropriate amounts of glucose.

Prediabetes is a condition caused by insulin resistance. Left unchecked, prediabetes usually leads to type 2 diabetes. Losing weight (about 7% of body weight), changing diet, and more exercise or physical activity are effective ways of countering prediabetes.

Diagnostic blood tests that help identify prediabetes and diabetes include:

Hemoglobin A1C, which measures the average percentage of our hemoglobin (a protein in red blood cells that carries oxygen) that is coated with glucose. Prediabetes is 5.7% to 6.4%. Type 2 diabetes is 6.5% or higher.

Fasting blood glucose/Fasting plasma glucose (FPG), which measures blood glucose after a fast of eight hours or overnight. Prediabetes results are 100 to 125 mg/dl (milligrams per deciliter) in the blood. Type 2 diabetes is 126 mg/dl and higher.

Oral glucose tolerance, which measures blood glucose after eight hours of fasting followed by drinking a sugary, sweet liquid. Prediabetes is 140 to 199 mg/dl. Type 2 diabetes is 200 mg/dl and higher.

The American Diabetes Association (<https://www.diabetes.org/a1c/diagnosis>) has suggestions for nutrition, online and group community events, fitness, resources, advocacy and more. The federal Centers for Disease Control and Prevention (CDC) is sponsoring the National Diabetes Prevention Program, a diet and exercise program that has been very successful in preventing prediabetes from turning into diabetes. Visit www.DoIHavePrediabetes.org to find a Recognized Lifestyle Change Program near you that is approved by the CDC.

Calendar of Events

Special note: This calendar is up-to-date as of April 2, 2020. Events are subject to change or cancellation due to COVID-19. Please check websites for the most current information.

July 11-15, 2020

National Association of Area Agencies on Aging 45th Annual Conference and Tradeshow. Oregon Convention Center, Portland, OR. For information, visit www.n4aconference.org.

July 20, 2020

Webinar: Changing Practices in Long-Term Care One Stage at a Time. Presented by Cornell University's Edward R. Roybal Center (TRIPLL) and University of Florida's Pain Research and Intervention Center of Excellence (PRICE). Free. For information, visit www.tripll.org.

July 30-August 2, 2020

139th Annual Convention of the Virginia Pharmacists Association. Virginia Beach. For information, visit www.virginiapharmacists.org.

August 9-12, 2020

Pioneer Network: Pioneering a New Culture of Aging Conference. Wyndham Grand Pittsburgh Downtown, Pittsburgh, PA. For information, visit www.pioneernetwork.net.

August 26-28, 2020

Solving the Puzzle: Joining Together to Protect Elder Virginians. Annual Conference of the Virginia Coalition for the Prevention of Elder Abuse. Kingsmill Resort and Conference Center, Williamsburg. For information, visit www.vcpea.org.

August 31-September 3, 2020

Home and Community-Based Services Conference. Hosted by ADvancing States (formerly the National Association of State Units on Aging). Marriott Wardman Park, Washington, DC. For information, visit www.hcbsconference.org.

October 4-7, 2020

71st American Health Care Association/National Center for Assisted Living Convention and Expo. Austin, TX. For information, visit www.ahcancal.org.

October 5-6, 2020

2020 Virginia Governor's Conference on Aging: Connect. Collaborate. Contribute: Communities for the Future. Richmond Marriott Downtown, Richmond. For information, visit www.vgcoa.com.

October 6, 2020

Art of Aging Expo. Resource, information fair, and health screening. Free and open to the public. Germanna Community College, Culpeper. For information, visit www.agingtogether.org.

October 8-10, 2020

Serving Seniors, Veterans, and Those with Disabilities through Diverse Adult Day Programs. 2020 Conference of the National Adult Day Services Association. Omni William Penn Hotel, Pittsburgh, PA. For information, visit www.nadsa.org/conference.

October 14, 2020

Advance Care Planning Training Series: Understanding Breathing Decisions. Presented by Honoring Choices Virginia. For information, visit www.honoringchoices-va.org.

November 10, 2020

Annual Conference and Trade Show of The Virginia Association for Home Care and Hospice. The Fredericksburg Hospitality House and Conference Center, Fredericksburg. For information, visit www.vahc.org.

Age in Action

Volume 35 Number 2: Spring 2020

Edward F. Ansello, PhD, Director, VCoA
Kathryn Hayfield, Commissioner, DARS
Kimberly Ivey, MS, Editor

Age in Action is published quarterly (January, April, July, October). Submissions and comments are invited, and may be published in a future issue. Send submissions to ksivey@vcu.edu.

**Summer 2020 Issue Deadline for Submissions:
June 15, 2020**



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2020 Virginia Governor's Conference on Aging: *Connect. Collaborate. Contribute: Communities for the Future*

Hosted by the Department for Aging and Rehabilitative Services and the
Virginia Association of Area Agencies on Aging

October 5-6, 2020

Richmond Marriott Downtown, Richmond

The conference will include three focus areas to create engagement and action across the Commonwealth:

- Culture Change in Long Term Services and Support
- Safety and Financial Security: Older Adults in the New Virginia Economy
- Livable Communities: Developing Innovative Solutions for Addressing Barriers to Sharing Collaborative Strategies



Registration will open in August. For information, visit www.vgcoa.com.

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