Life Interrupted: Living with Young-Onset Memory Loss and the Need for Connections

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Presented by Dawn Adler, RT
Dana Rubin–Winkelman, MSW, CAPSW
Session Description

When individuals are affected with memory loss during the middle years of their lives, there are numerous and unique circumstances to deal with.

This session will:

1. Increase awareness of the very different needs and concomitant stressors that active younger individuals face.
2. Share the piloted R+R: ReCharge and Renew Club which provides a needed model for the State of Wisconsin.
3. Offer real-life stories of how specifically designed programs provide the needed connections to each other and your organization.
Points to Ponder…..

Mid-Life is supposed to be a time of new hopes and aspirations, as individuals and families look forward to new-found freedom. Then, suddenly, the rhythm of life is interrupted with a devastating diagnosis.

"You Have Young-Onset Alzheimer’s Disease."

If you do not personally know someone with young-onset memory loss, be assured in the next year you will.
Points to Ponder…..

“Together, we have the power to change people’s lives and perceptions.”
Interactive Exercise

- What will you be doing in your 50’s-60’s and what does your career look like in your 50’s-60’s?

- What age will you retire, what does your retirement look like, what are your dreams for your retirement?
Organizational Structure

Continuum of Care

Community Services-4 Year Expansion
• Adult Day Center
• Community Education Workshops
• Caregiver Support Group
• ReCharge! Brain Health Enhancement Class
• SPARK with Jewish Museum - Milwaukee
• Memory Café at McKinley Marina and Miss Katie’s Diner
• R+R: ReCharge! and Renew Social Outing Club
This Is Why We Developed The R+R: ReCharge! and Renew Club.....

• Picture of Mark on Bike, helmet fit active pictures

...And for all the “Mark’s” we weren’t ready for!
Mark and Colleen’s Story

Mark
• Drummer
• In his youth sang for the Philharmonic Boys Choir
• Amateur Bicycle Racer
• Headmaster of Private Schools in N.Y.
• Secondary School Administrator
• Teacher of U.S. History and Economics
• Double Master’s Degree
• Loves the “Talking Heads”
• Lives in Milwaukee

Colleen
• Mark’s Wife
• Born in Green Bay, Raised in Milwaukee
• Master’s Degree in History and Teaching
• Founder of Academics Matters in N.Y. Private Practice
• Advocate for Mark
• 3 Beautiful Children
• 2 Adorable Dogs
• Likes Pilates and Knitting
• Lives in N.Y.
Family Photo’s
Meet Mark

• Work and retirement ….ideal vs reality

• Story of living in Milwaukee and how it came to be

• Thoughts on R+R Club: Connections and support

• Personal Life’s Challenges
Colleen’s Thoughts

• “New York is like a prison for individuals with MCI.”
• “Going from teaching to early stage programs and getting there was Hell.”
• “Ideal vs Real is a constant struggle.”
• “Friday is his favorite day of the week.”
• “Since Mark started these programs he reads again without hesitation, I re-ordered the N.Y. Times for him, he has completed his first book in 2 years, and he beat us at a board game.”
Why the R+R Club?

• Statistics- 5% of the 5+ million American’s, approximately 200,000, have Young-Onset Alzheimer’s Disease
• Change in demographics of the AA Support Groups and Memory Assessment Clinics
• Identified as a gap in services by the community and Alzheimer’s Action Network
• Early Memory Loss programs not meeting needs
• No other programs specifically designed
Jack’s Story

• Video Clip
Different Needs/Commonalities

• Generally under age of 65
• Physically active
• Job Loss
• May not drive/transportation issues
• Home all day while spouse work
• Looking for fun/meaningful things to do in community
• Language difficulties yet extremely perceptive
• Visual spatial and writing difficulties
• Frustrated in Brain Health Enhancement classes
• Difficulty with unfamiliar settings and people
• Seeking to connect with those in similar circumstances
• Disease trajectory seems extreme
• Small everyday tasks frustrating (ex: fastening bicycle helmet, opening pills)
R+R Club Background Information

- Received 2 year grant of $50,000 from the Helen Bader Foundation. Thank You !!!!
- Called a “club”- less threatening, meets weekly, started in October of 2016
- Components- community involvement, stress/anxiety reduction techniques, and relaxation and socialization
- Focus- community fun and connecting with others
- Self-directed by group
- Adaptation of ReCharge! brain health enhancement class
R+R Club Model

Program Schedule

- 9am -10am: meet in Oasis Cafe for coffee and sweets/fresh fruit
- 10am -12:00pm: community outing, support group, relaxation technique, or SPARK program
- Lunch 12pm -1pm

Warm environment
Meets every Friday
Ongoing club- desired capacity of 12 club members
Enrollment process and fee
Free “Try-it“ day for informal assessment
Collecting anecdotal and empirical data
Consistent staff and trained volunteers/ clinical students
Never Miss The Sweets!
The Club Members Decide!

Community Events

- Pabst Mansion
- Museums
- Elk Farm
- Ethnic Restaurants
- Tour of Port Washington
- Movie and Pizza
- Glass fusing and pottery class at GLAZE
- Black Historical Society
- 3 session watercolor workshop with artist Nancy Lohmiller

Stress/Anxiety Reduction

- EFT-Emotional Freedom Tapping Technique
- Nia
- Yoga
- Gong Therapy
- Tia Chi
- Mindfulness
- Hoola Hooping
- Flute Meditation
- The club requested support group every 4-6 weeks with MSW Social Worker
GLAZE GLASS FUSING AND POTTERY
VERANDA YOGA and
CHUDNOW MUSEUM OF YESTERYEAR
From a Social Workers Perspective
How is it Different?

• Stressors and Dynamics

• Support Group
  • My expectations/reality
  • Value
Patty and Tony’s “Story of Hope”

- Patty caught Tony’s attention when she was wearing a mini-skirt and Go-Go boots the rest is history!
- Patty is 68, loves horses, children, music and dance
- Patty is Irish and fun, Tony is Sicilian
- Tony has never left Patty alone except for close friends and family until the R+R Club
- Tony and Patty pick up Mark for community events
- The *Purple Canoe Club* has been a lifeline
- Instead of “traveling and pursuing interests”, Tony is developing a transitional plan for Patty
- “There is still a positive and happy life to live and take hold of what you CAN do.”
- “I miss Patty creating the sense of home.”
Anecdotal and Empirical Data

• Mood /Sense of Well-Being/Anxiety- How does the club member rate their mood before and after the club? What does the care partner see on club days at home?

• Care Partner Stress- Is there a sense of relief when loved one attends the R+R Club? Is it helpful to you and your partner? Is there a feeling of increased support being connected to an organization?

• Social Connectedness- Is there an increase in social activities and community involvement since joining the club?
What We Have Learned

• Have a strong philosophy of what the club is and who it is for
• Regular club attendance is essential but be prepared for absences such as vacations/hospitalizations/medication adjustments
• A warm/welcoming location is important and an excellent way to showcase your facility
• Families are very interested in club events but slow to return any needed enrollment items
• The group needs your time
• Consistent staff and trained volunteers are essential
• Confidentiality issues arise as the group becomes connected to each other
• Draw a clear line when the group starts getting together on their own
• This is an expensive program to run
What We Have Learned

• The club should become self-led as much as possible
• Offer volunteer opportunities within your facility
• Mixed cognitive levels is not an issue
• Individuals with Parkinson’s have been very interested
• Physical limitations require creative problem solving
• Transition plans are essential in the beginning of club membership and when the club member is no longer able to attend
• Transportation can be an issue
• Offer fun community event handouts
• Be prepared to look for cell phones, coats, purses…
• Be prepared for HEARTFELT MOMENTS! and don’t skip the sweets!
Contact Information Adult Day Services
at Ovation Communities

Dawn Adler, RT
Director of Adult Day Services Ovation Jewish Home
414-277-8838
Dadler@ovation.org

Dana Rubin-Winkelman, MSW,CAPSW
Social Worker Ovation Chai Point and Adult Day Services
414-721-9249
DRubin-Winkelman@ovation.org
Questions ???

We will be happy to stay and answer questions!