USING ADAPTIVE TECHNOLOGY TO OVERCOME DEMENTIA'S BOREDOM AND FRUSTRATION

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Aging in Place Technology Watch

For this white paper, interviews were conducted with Juliet Holt Klinger, VP Dementia Care, Brookdale Senior Living; Dr. Judah Ronch, Dean of the Erickson School, University of Maryland; Karen Love, Founder of FIT Interactive; Dr. Murthy Gokula, Associate Professor,Program Director, Promedica St.Lukes Hospital Geriatrics Fellowship Program/University of Toledo; and Jack York, Founder and CEO of the software company, **It's Never 2 Late** (iN2L).

Following various studies about inappropriate use of antipsychotic medications for nursing home residents with various degrees of dementia, efforts were begun in 2005 to reduce the use of such drugs. At that time, this usage level (22%) of residents on antipsychotic medications in nursing homes was viewed as problematic, increasingly visible to regulatory agencies and the public.

A goal was set to reduce use of such drugs in nursing homes by 15% by the end of 2012. A bill to do this (S. 3604) was introduced in the Senate in 2012, but never enacted.[1] Additionally, in settings that lack appropriate training and proven approaches for dealing with dementia, there are ongoing behavioral issues with residents who have dementia. And although not quantified in broad-based public research, experts interviewed believe these behavioral issues and thus the use medications to deal with them is likely to be just as prevalent in assisted living facilities (ALFs) as it has been documented to exist in skilled nursing homes (SNFs).[2]

Why do residents with dementia have certain reactions?

According to experts interviewed, problematic behaviors -- such as wandering, calling out, crying, or attempting to harm other residents -- may result in the use of antipsychotic medications to mitigate them. These reactions may include:

- **Inability to articulate unmet needs:** When individual residents are disruptive to activities or to each other, staff members typically have struggled to manage these reactions and also do other assigned work. As a result, first a nurse or a doctor (or other health professional) becomes involved and may introduce a medication rather than analyze and address the individual's underlying and unspoken needs.

  "Meds are ordered when folks have disruptive 'behavioral expressions,' but meeting the unmet need is really what is required." – Juliet Holt Klinger, VP Dementia Care, Brookdale Senior Living

- **Inability to discern what to do next.** Residents with dementia may require cueing and staff direction to guide them in activities of daily living (ADLs) like eating, dressing, and participating in group functions. If staff is unavailable or occupied, confused individuals are left to their own devices and may be unable to self-direct towards an appropriate next activity.

  "Procedural memory is the last to go – how to do this or that task. If you get bored with TV, you can change the channel, make choices and critically analyze. For people with dementia, fine tuning of critical thinking goes away, so they get up from their chair, but there is no new target." – Dr. Judah Ronch, Dean of the Erickson School - UMBC

- **Anxiety of residents who cannot self-direct to activities – and remain idle.** Residents who are stuck in a repeating cycle of boredom and frustration may become anxious and agitated, looking for something or someone to gravitate towards – but not finding what they need. Included among behavioral symptoms are apathy and withdrawal, anxiety, irritability, depression, agitation and aggression, activities such as wandering, purposeless behavior, socially improper behaviors, disturbed sleep patterns, and resistance to care.[3]

  "People with dementia retain motor memory and their mind continues to seek novelty in the face of the boredom which is intrinsic in many settings." – Dr. Judah Ronch

Too often, staff rely on medication to cope with reactions

Staff members who might be having difficulties understanding the reason why a person with dementia is acting in a certain way may turn to management for assistance. That management could be the director of nursing, a staff nurse, or on-call doctor – any of whom can respond by requesting or ordering an anti-psychotic medication as an alternative to permitting an unwanted resident behavior to continue. Typically this is a direct result of:

- **Lack of staff training in dementia-specific care.** While the senior housing industry growth rate overall remains relatively anemic, construction of facilities with memory care is a recent growth opportunity, reflecting the changing acuity of residents.[4] But despite the growth in numbers of memory care units, dementia-specific staff training is a challenge.[5] And while staff getting to know a specific resident in order to anticipate their needs is the hallmark of good dementia care, too often management changes, staff turnover, or the addition of new residents to the mix may result in staff members who are unable to effectively cope with resident behaviors.

“It doesn’t matter what the facility type is – you must have staff trained and willing to look at former patterns of coping and dealing with anxiety and stress. – Juliet Holt Klinger

- **Lack of resident-specific staff interactions and intervention.** Despite multiple scheduled activities during the day, they are typically one-size-fits-all group activities – and staff members may be too pre-occupied with the group to focus specifically on individuals. Instead, experts assert, these should be experiences initiated by a staff member who knows the resident and has therefore tailored the activity to his or her needs.

  “When you have people doing interesting things, activities that provide them with meaning in their life, you can observe little moments of connection and joy. String those days together and you replace boredom, agitation, idleness and frustration with a better quality of life.” – Karen Love, Co-Founder FIT Interactive

What kind of approach will engage individuals who have dementia?

Experts with experience in residential settings, both observing and working with individuals who have various levels of dementia, believe that person-centered approaches work best. That requires understanding the characteristics and background of an individual and tuning the activity and interaction based on his or her specific acuity, interests, and preferences. Comments from the experts assert that a person-centered approach supported by adaptive technology (such as It’s Never 2 Late – iN2L) can be:

- **Programmatically rich – plus staffing based on the needs of residents.** Too often the menu of activities for residents reflects a pre-developed calendar of group activities, fixed into time slots that can leave substantial idle time waiting for staff to do chores and for the start of the next meal. Further, in most facilities, staff levels per shift are fixed based on the numbers of residents – not taking into account their lack of mobility, frailty or degree of dementia. This sometimes leaves staff pre-occupied with a few residents, while other residents remain idle. Instead, leveraging the choices and personalization supported in technology like iN2L, staff can be better deployed to meet the needs of individuals, whether in a group or one-on-one setting.

  “All healthcare staffing should be based on the level of acuity of the residents – their physical plus behavioral – using that knowledge to adjust all tasks.” – Juliet Holt Klinger

- **Customizable to the needs of individuals – reflective of their previous lives.** In contrast to the one-size-fits-all calendar structure, a staff member who is trained and becomes a motivated ‘iN2L’ coach can use knowledge of a resident’s history and life to

provide them with a customized and engaging experience, replacing boredom and idle time with personal and meaningful activity.

"If you take the idea of 'stimulus-seeking' behavior -- that is wandering, rummaging – residents with deteriorating behaviors cannot find what they are looking for. I had a patient walking around who told me that she was looking for herself – but could not find her. But iN2L puts what they are looking for right in front of them. How powerful it can be that even if you can only remember a fragment of what you used to do, with iN2L-type technology, someone who used to garden, ride a bike or pilot a plane has an experience that recalls that fragment." – Dr. Judah Ronch

"I think it's more about common sense than it is about age or dementia, or any other variable. I'm in my early 50's, and it doesn't matter whether I'm my age now, 35, 70 or 90, I like Bruce Springsteen and I don't like the Carpenters. If you give me quick and easy access to Springsteen, I will have a positive reaction. Our goal as a company, or maybe I should say our obsession, is to try and get those individualized experiences to people in an easy, dignified way at the touch of an icon. We want to make it easy for the residents, for the staff and for the families. When you do that well the outcomes are staggering." – Jack York, Founder, It's Never Too Late (iN2L)

- **Engaging staff and residents with long-distance families.** While a primary caregiver family member may regularly visit a resident of assisted living or a nursing home, other relatives may be able to visit only rarely if at all. And families today are smaller and more dispersed than they were a generation ago.[6] This geographical separation can result in loss of communication between family members, but scientists have long studied and recognize the family closeness and the connections formed by those families who use technology, compared to those families who do not.[7] iN2L's technology platform enables connecting these long-distance families.

  "We have residents who will never be able to visit in person again – but a resident with advanced dementia can now see a 94-year-old sister and Skype with her daily. We need to get over the ageism that prevents us from introducing technology to older adults. - Juliet Holt Klinger

How does iN2L fit with improved programming?

The experts identified four areas that working with iN2L can enable for organizations that structure staff roles appropriately. These changes in work include providing training so that:

- **Staff acts as a catalyst – championing and coaching.** To gain the greatest benefit from the use of iN2L in a dementia care context, a champion should be identified who knows the residents and their backgrounds, learns about the system and leverages the system's

adaptability to adjust to the interests and needs of individual residents. This iN2L champion (or coach) can be an activities staffer, an aide, a nurse or other staffer in the community.

"It is not about buying the system -- it is about knowing the system. Staffs don't need to be creative and come up with these programs – they simply need to a) learn how to use the system, b) show the resident what to do, and c) contact the family to obtain material." – Karen Love

- **Staff uses iN2L type of technology to actively replace reliance on the TV.** TVs in dementia units benefit staff-- but often programming is left on that is disturbing to residents. Experts note that if residents are anxious and are physically capable of wandering away from it, they will. Instead, using engagement technology like iN2L can replace traditional over-reliance on TV, instead providing social and engaging experiences.

"I can see dementia units replacing their over-used TVs with this. Everywhere there is a TV, but broadcast programs make no sense to the residents, thus aggravating behaviors. With iN2L, the user experience could be to walk up and engage by touching the screen." – Dr. Murthy Gokula

- **Using iN2L, staff helps residents engage with each other.** In a 2010 Mather Lifeways study conducted about the use of iN2L, two nursing home resident groups were compared, one provided with iN2L systems and training, the other group's environment was unchanged. The iN2L-studied groups demonstrated higher functioning ADL levels, greater social engagement, higher cognitive levels, and lower levels of depression in comparison to the non-iN2L group.[8]

"I think something like this is best deployed in an individual's room where a resident can spend time touching pictures on the screen, but I've seen iN2L deployed where there are multiple people in a room accompanied by a nurse's aide – that works. They sing, move, dance, engage with each other in ways that they haven't done in years. In comparison to nothing, that's a big leap forward." – Dr. Judah Ronch

- **Person-centered engagement becomes possible.** Organizations with multiple communities and dementia care settings may find, as Brookdale Senior Living is now finding, that iN2L can be an enhancement of person-centered engagement in dementia care – and that it is this person-centered care which in turn enables reduction in reliance on medication to mitigate behaviors.

"We are in our second year of a pilot – with iN2L in 255 locations. We see this as a tool to increase our ability to provide person-centered engagement. This technology puts us further along that path, not just honing in on interests, history, and preferences – but enabling relationships." – Juliet Holt Klinger

"I think there is fundamental shift underway in how families want to see their loved ones with dementia treated, and technology is a big part of that. Ten years ago aesthetics played a key role in influencing the decisions that adult children made in helping place their mom or dad into a community. Today keeping them engaged and connected, regardless of where they are cognitively, is becoming a critical factor in deciding which community to choose. Families know about technology, they are starting to demand it. Brookdale, to their credit, understands that, and it's a major reason why they have deployed iN2L throughout their entire dementia network." -- Jack York

For more information about It's Never 2 Late, go to www.iN2L.com.

Other references:

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Mentions multi-sensor media system in treatment of dementia:
http://www.tara.tcd.ie/bitstream/2262/49835/1/Technology%20in%20dementia%20care.pdf

http://socialaccessiblemobile.files.wordpress.com/2012/06/touchscreen-evaluation-from-strategy-to-practice-2012.pdf

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[1] https://www.govtrack.us/congress/bills/112/s3604

[2] One theory is that these issues may appear to be less obvious because ALFs are not subject to federal regulation and related oversight and scrutiny – however, some incidents have received a great deal of negative publicity PBS Frontline Documentary, Life and Death in Assisted Living aired in July, 2013, was one exception, scrutinizing care standards for residents. The Miami Herald series, Neglected to Death is another.

[3] http://www.nursingcenter.com/lnc/CEArticle?an=00000446-200507000-00028&Journal_ID=54030&Issue_ID=591242#P141%20P142

[4] http://www.alfa.org/News/3200/Housing-Fundamentals-and-Trends-in-Senior-Housing

[5] The Alzheimer's Association offers training programs for staff in Assisted Living and Nursing Homes. https://www.alz.org/national/documents/brochure_dcprphases1n2.pdf

[6] http://www.nbcnews.com/id/14942047/#.UnjpmBCzKjw

[7] http://ecap.crc.illinois.edu/eecearchive/books/fte/internet/aidman.pdf

[8] http://fileresource.sitepro.com/filemanager/215/filecollections/1436/green_house_project.pdf