The TAO of CONNECTED DEMENTIA CARE

A different way to support the wellbeing of people living with dementia and their care companions

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The TAO of CONNECTED DEMENTIA CARE:

A different way to support the wellbeing of people living with dementia and their care companions

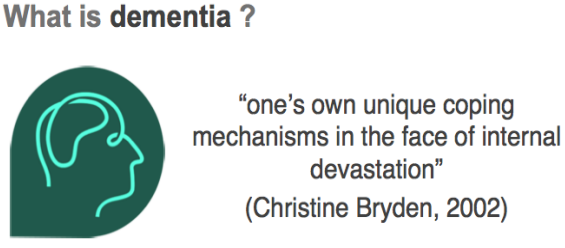
Welcome to Mentia's Q1 2019 white paper.
Why Tao? This paper spells out our 'way' forward in the digital transformation of services for receivers and providers of dementia-related care. We call it 'Connected Dementia Care' (CDC); it's a new category we're proposing that describes the transition of non-pharmacological care, which hitherto has been an offline experience, into the online environment, for better care, more enjoyable care, and data-supported care outcomes. The goal, is, in part, to enable organizations to measure the 'value' of care, a metric that may be hard establish, yet must be presented in CMS's new regulatory environment of value-based care.

Core to Mentia's value proposition is our ability to scale psycho-socially supportive activities, for which there is abundant evidence in the 'actual' world, while also providing organizations with tools to measure its impact. Deva World™, Mentia's signature product, embodies these aims and principles.

1. Setting the scene

With one person on the planet being diagnosed every three seconds, dementia touches more individuals, families, communities, and nations than ever before. Within thirty years, an expected 130-million of us will have dementia, and an estimated $2 trillion will be spent on our care.[1] One of the biggest shifts is occurring in low-income nations, where people are living longer than ever before.

Dementia's increasing prevalence is a story well-told by health authorities. Almost daily, media groups report on the anticipated 'tsunami' and pose questions about how society will cope. But behind the dramatic statistics and biomedical descriptions lies a person's private struggle to think, reason, remember, be safe and simply function, as Christine Bryden, herself living with dementia since 1995, poignantly describes it.[2]



[1] Alzheimer's Disease International https://www.alz.co.uk/research/statistics\

[2] Bryden (Boden),C. A Person-Centred Approach to Counselling, Psychotherapy and Rehabilitation of People Diagnosed with Dementia in the Early Stages Dementia 2002 1: 141

2. The toll on families

Family and friends play an essential role in our dementia journeys. In North America, some 15.5 million are currently caring for 6 million people.[3] With both high and low-income countries throughout the world struggling to provide services to their ever-growing elderly populations, families and extended households continue to provide unpaid care.[4]

Looking at US figures, AARP (USA) estimates that 9.5 hours per day are spent actively caring for a loved one, equating 18.8 billion hours of unpaid care annually. If we put a $15 value on every hour spent, caregivers are contributing $282-billion of unpaid care, often at great cost to themselves.

Unfortunately, we do not currently measure the *quality* of family care at home. Disturbingly, the National Institute of Health (NIH) found that most family caregivers lack the information they need to manage the care of a loved one.[5] Furthermore, caregivers commonly overlook their own wellbeing, becoming isolated, stressed and depressed, leading one landmark study to describe

[3] Alzheimer America < https://www.alz.org/facts/>; Alzheimer Society of Canada <http://alzheimer.ca/en/Home/About-dementia/>

[4] "Challenges of dementia care in China" <http://www.mdpi.com/2308-3417/2/1/7>

[5] Peterson, K., Hahn, H., Lee, A. J., Madison, C. A., & Atri, A. (2016). In the Information Age, do dementia caregivers get the information they need? Semi-structured interviews to determine informal caregivers' education needs, barriers, and preferences. BMC Geriatrics, 16, 164. http://doi.org/10.1186/s12877-016-0338-7

them as "the invisible second patient".[6] Given people's overwhelming preference to age in place, and the complex path that *both* members of the care partnership must navigate, providers seeking to bring high quality care to people living with dementia living at home must consider how best to support care companions too.

> *Mentia's view is that by thinking digitally, we can build new services to help meet the demand for high quality care for the world's increasingly aged populations and those caring for them. Digital tools offer the possibility to scale best practice wellbeing support care – unlike traditional care, the size of the digital pie doesn't diminish, no matter how many times it is used. Further, the digital trace is a ready source of data or organizations looking to improve efficiencies and demonstrate value-based care.*

3. Non-pharmacological approaches to improved wellbeing

Dementia undermines a person's confidence and self-esteem, however, as Tom Kitwood, the pioneer of modern-day dementia care pointed out in the 1990s, when such needs are met, a person can live relatively well despite their dementia. But he was quick to point out that it is we healthy others who must step up and assist those impacted are to live optimally. Kitwood's influence has permeated dementia care centers around the world, and today there is abundant evidence that tailored activities that promote meaningful engagement contribute greatly to a person's wellbeing. Better-known interventions involve music and reminiscence, physical therapies like exercise and dance, occupational activities such as gardening and cooking, and sensory activities, like massage and aromatherapy. Music is effective because it stimulates not only our auditory processing center but also our emotion, reward, autonomic and motor functions.[7]

Activities that tap into long-term memories are essential to our sense of self and a life well-lived. These memories are stored in areas of the brain that are less prone to deterioration. Exercise increases blood flow to the brain and produces endorphins that energize us and improve our moods. Occupational activities give a sense of purpose. Sensory activities stimulate embodied

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[6] Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, *11*(2), 217–228.

7 Zatorre , R. and Salimpoor, V., 2013. From perception to pleasure: music and its neural substrates. Proceedings of the National Academy of Sciences of the United States of America 110 2 pp: 10430-7

memories, which are hardwired to human experience and often stay with us to the very end of the life.[8]

At Mentia, our digital approach is to capture the essence of these activities and deliver them in a way that is acceptable to users. However, as newspaper publishers found when they transitioned to online news, a facsimile of the traditional version is not enough. Moving into a digital realm entails transformation and this includes the ecosystem within which the transformation occurs. Digital therapy is not simply a new intervention, it brings systemic change, and care providers are only just beginning to explore its nature.

4. How digitally-delivered therapy is different

While digitally-delivered therapies do not have the full dimensions of physical world experiences, (although touch, smell and immersion are areas of emerging research), they have distinct characteristics, which, when well designed, can overcome significant limitations of their physical world counterparts:

- Person-centered care
  As Dawn Brooker, the noted British authority on dementia care quipped, "person-centered care is easier to talk about than to achieve".[9] Personalized activity programs are costly and resource heavy. In the digital space, however, costs are low, activities can easily be customized to meet individual preferences; for example, working one-to-one should a resident prefer not to join a group activity, or tailoring an activity with digital artefacts that hold special meaning to the person.

- Skill sets of care staff
  In traditional therapy sessions, a skilled recreationist needs to be involved and sessions tend to be organized by roster. Volunteers and aides may not have sufficient training to run these activities, nor is delivering activity therapy considered to be their job. Certified nursing assistants (CNAs), too, are out of the activities loop given their focus on medical-related tasks. On the other hand, digitally-based therapies can contain modules that

[8] Hume, C. Wright, J., Crocker T. et al. 2009, 'Non-pharmacological approaches for dementia that informal carers might try or access: a systematic review' International journal of geriatric psychiatry, 25: pp 756 - 763 <https://www.ncbi.nlm.nih.gov/pubmed/19946870>

[9] Brooker, D. (2007). *Person-centred dementia care. Making services better*. London: Jessica Kingsley Publishers.

assist work flows and improve efficiencies. Also, the tool can carry a pedagogical load such that care companions are guided and supported through new or extended care practices; this may mean less stress for care companions. And, they could be doing continuing education units while working with their clients. Other added efficiencies can be built around data collected during sessions, such as duration times and interaction levels; these indicators can be sent to care circles to promote family communication and to deepen a provider's understanding of systems of care and client wellbeing.

- Logistics

  Taking a memory care group on an outing, say to a museum, requires considerable organization. Several staff members must accompany the group, who may have a variety physical challenges including the ability to walk or sit comfortably. Numbers are limited to the capacity of the bus. For some, travel can provoke anxieties. Then, the gallerist must choose the right painting, know how to draw out stories from the participants, and so on. A virtual gallery on the other hand, can mimic the experience, provide closeup details of the work and suggest different pathways for interaction.

Connected Dementia Care (CDC)

The rise of digital tools that help people live well with dementia, though nascent, is no longer new. The app, *Sea Hero Quest,* helps detect the first signs of dementia. The music therapy system *SingFit* provides cued singalongs for individuals and groups. IoT systems are being used for falls

prevention and detection. Reminders, alerts and smart calendar systems help people to manage daily activities, share agendas or activities in real time and communicate with their families. There are a host of new services being built around voice-activation, with voice, arguably, the most natural interface of all.

The energy in the digital health space, illustrated by some $11Bn invested in 2017[10], is being driven by the alignment of three vectors:

- New tech (Internet of things, AI, GPS, nanotech, voice-enablement)
- An enthusiasm for behavioral self-management and 'the quantified self', as evidenced by catalogues of wearables, including wrist bands and smart fabrics
- The social web

Fueling the fire, the FDA has recently defined ten criteria for digital health[11] and has approved a small number of apps[12]. Mentia lives within this paradigm, exemplifying a new category of dementia care that we call Connected Dementia Care (CDC). US-based consultant Karen Coppock has placed this category within the wider connected ecosystem of senior care [see Figure 1, p12].

5. What makes a technology CDC?

It is troubling that the digital world offers healthy others a plethora of customizable apps to extend our online identities, yet it sets adrift people with dementia, who experience a diminished sense of self at the very time they could most do with some support. CTD puts an end to that.

By leveraging best practice dementia-friendly design thinking with cloud-based and a socially aware Internet, we have built a CDC schema.

CDC values:

- Person-centered care: recognizing the full spectrum of an individual's needs, including their psychological, emotional, spiritual and social needs, rather than focusing on the neuropathology.
- A person's sense of self: amplifying the "I am" which exists but may be difficult to express
- Engagement: keeping the connections between people and things alive.
- Meaningfulness: offering purposeful occupation.
- Living well: living optimally albeit with a disability.

[10] https://gumroad.com/l/FOSGD
[11] https://www.fda.gov/MedicalDevices/DigitalHealth/ucm575766.htm

[12] https://peartherapeutics.com/wp-content/uploads/2017/09/Pear-letterhead-FDA-Clearance-FINAL-FINAL-9.14.17.pdf

It is no coincidence that these elements are also the best practice pillars of non-digital strategies for supporting wellbeing. What is new, however, is understanding how to transfer this ethic into an app, keeping core values, while at the same time, incorporating the characteristics and possibilities that digitally-based systems offer.

6. Characteristics of a CDC

- A CDC is an experience rather than a service
- A CDC is designed for doing, not merely for viewing
- A CDC supports participants' individual psychosocial needs
- A CDC is the outcome of participatory design so that the product mitigates the impact of reduced cognitive function and other commonly experienced age-related conditions
- A CDC is a digital native in the sense that connection is inherent to its design as compared to replicating a non-digital activity and then redistributing digitally
- A CDC is informed by non-digital engagement activities organized specifically for people with Alzheimer's and other related dementias

7. CDC's place in the assistive technologies ecosystem

How well the world manages the increasing prevalence of dementia depends on the degree to which it embraces different ways to resource and scale the care of those who live with it. CDC sits within an emerging set of digital practices and technologies that indicate a care renaissance is upon us; robotics and voice-enabled technologies amongst them.

Here are the main innovation actors. We use our own product, Deva World, to contextualize them.

1. **AI**:
   When the Internet arrived, information became available everywhere at low cost. Then, Web2.0 made knowledge available everywhere at low cost. Now, with the rise of artificial intelligence, *expertise* becomes available everywhere and at low cost. Introducing AI into Deva World enables us to have a deeper understanding of participants' needs, delivering culturally relevant just-in-time content, smarter suggestions and responses, and enriched services to providers.

2. **Scalability:**
   A characteristic of the digital age is the capacity to scale any activity and have it available to users anywhere, anytime, on any device. Content, invariably, is cloud-based, preferably with open APIs so that other digital systems such as assisted living management programs can talk to it. There is no room for silos, and the inefficiency that comes with systems that don't talk to each other. A theme day, for example, celebrating a British royal's marriage, might involve fabric purchase, or particular kinds of foods. Great fun in a

care home or day center – but living at home can be isolating, and there may be no opportunity for a care companion to prepare or shop. With Deva World, digital and media artefacts could be pulled from the internet straight into an interactive scene.

3. **Intangible economy**:
   When one shares a tangible good, it divides. When one shares an intangible good, it multiplies. Digital transformation moves an economy of scarcity to an economy of abundance. Deva World gives creative and dynamic therapists, whose actual presence is usually required, the opportunity to amplify their therapies, and support multiple geo-diverse communities across time zones and at times that suit participants. No more the notion of appointed times for therapy. While therapists would need to respect the engagement protocols that we, as platform creators and administrators, have set, these rules are not designed to be restrictive, simply effective.

4. **Community:**
   In the digital age, the "horizontal" relationships inside communities are amplified. Connections self-propagate around spheres of interests, and the sharing of knowledge and resources. As we build out Deva World, it will become a network for sharing ideas and experiences. For example, one community's decision to create a place of worship can benefit other communities that share the same faith. Veterans, LGBTIQ groups, people who love *Led Zeppelin*, each can be accommodated by visiting specific virtual places that other like-minded folks have commissioned. Indeed, there may be a payment model whereby original 'world builders' can be reimbursed by those who want to visit their places.

5. **A path to wider digital adoption:**
   Whenever digital transformation occurs, there are some for whom the switch is not easy. Care staff who are reluctant to try products like Deva World may be weighed down by past failures, like out-of-date devices, inconsistent wifi, or hardware that is locked away in cupboards and forgotten.

   But what if caregivers, seeing the person with dementia completely at ease walking inside a digital 3D world, start to realize that, after all, going digital is not that complex? It may signal a new attitude to technology tools inside the workplace; for example, towards a management system that handles rosters and handover notes. Deva World, with its universal design, can bring communities of care staff more fully into digitally-based work practices.

6. **Pedagogy**:
   A digital tool can have many facets and serve different masters all at once. Deva World can be used to educate and create knowledge. Care companions can play in a virtual world that mirrors best practice care of the actual world. Care companions who are inclined

to learn visually are 'hands-on' and having fun. They learn by stealth about bathing a client in a way that limits anxiety, or the importance of a well-lit corridor, because in Deva World this knowledge is embedded. And, they and their player *experience* it.

7. S**cientific research:**

   Digitally-based systems collect data that can be used to better understand the neuroscientific aspects of non-pharmacological therapies. Our preliminary observations show that when a player is walking, playing the piano, and trying on clothes in Deva World, their extra-world communication is also enlivened. How does Deva World promote such engagement, what parts of the brain are being recruited? These questions can be scientifically explored. Our cloud-based platform already captures significant data, and as numbers on the platform grow, we will accumulate data that could help neuro-cognitive and biomedical scientists acquire deeper understandings.

Like the technology outcomes of the historical renaissance, printing foremost amongst them, innovation destabilize old systems and methods.[13] Even though providers may be wedded to legacy systems, and there can be many good reasons for this, now is the time to open the door to innovators who are building the new care ecosystem when they come knocking. Those bringing digital transformation to a complex and unsustainable system need the industries' support. Change will not happen overnight, nor without pain. Our aging tech communities want to work with providers to ensure their products make the difference they envisage.

8. Summary

Boomer-agers, many of whom are digitally literate, are demanding a different aging experience to that which their parents (often) endured. New tools are needed not only to meet their greater expectations, including a preference to age-(well)-in-place but also to resource a shrinking care workforce.

Fortunately, a new set of technologies is driving change, with CDC being part of this broader paradigmatic shift. As a category of therapy, it harnesses the affordances of the digital renaissance, which are: expertise available everywhere and at low cost; the power of cooperation; scalability and reach; cloud-based, an economy of abundance; and a way to teach, learn and research. Unlike actual world therapeutic activities, digital therapy *flows*. This is the Tao of Connected Dementia care, 'the way' forward, in a world where different dementia care solutions must be found.

[13] Soudoplatoff, S. 2018 L'expertise partout accessible à tous ("Expertise available everywhere and to everyone") http://www.fondapol.org/etude/lintelligence-artificielle-lexpertise-partout-accessible-a-tous/

Figure 1 Karen Coppock's diagram on connected senior services in California. May 2018.

9. About the authors:

Mandy Salomon's PhD, 'Finding 'Self' in a virtual world: Digital engagement for people with moderate to advanced dementia' (Swinburne University of Technology, Melbourne, 2016) propelled her from media-maker in her home country, Australia, to a first-time entrepreneur in the Silicon Valley. Teaming up with French digital transformation expert, Serge Soudoplatoff, they are the co-founders of Mentia, the home of Deva World, which is a dementia-friendly interactive digital world for cognitive care. Salomon and Soudoplatoff bring fresh eyes to dementia care through a combination of creative thinking and technological know-how. They can be contacted at **hello@mentia.me**.
Please visit **www.mentia.me** to learn more about Mentia's product, sales and partnerships. The author's peer-reviewed papers on digital transformation are available at http://swinburne.academia.edu/mandysalomon and http://www.fondapol.org/etude/le-numerique-au-secours-de-la-sante/ ; http://independent.academia.edu/SergeSoudoplatoff.
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