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The Tao of Connected Dementia Care (CDC): How digital tools are changing the delivery of dementia care

A Mentia White Paper, July 2019

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Welcome to our vision for dementia care in a connected world.

This paper spells out our 'way' (the Tao) 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 'eco-psycho-social interventions' [1] from offline experiences to online ones for better care, more enjoyable care, and data-supported outcomes. The goal, also, is to show that data can help determine the value of care, a critical metric in the face of spiraling costs and the expanding size of older populations.

Mentia's value proposition in this new environment is our ability to scale ecopsycho-socially supportive activities, for which there is abundant evidence in the 'actual' world, while also providing organizations with tools to measure impact. Deva WorldTM, Mentia's signature product, embodies these aims and principles, and we'll use it as an exemplar in this monograph.

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 130millions of us will have dementia and an estimated \$2 trillion will be spent on our care. [2] One of



the biggest shifts is occurring in low-income nations, where people are living longer than 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. Christine Bryden, who has lived with dementia since 1995, poignantly describes it as "one's own unique coping mechanism in the face of internal devastation." [3]:

What is dementia ?



"one's own unique coping mechanisms in the face of internal devastation" (Christine Bryden, 2002)

2. The toll on families

Family and friends play an essential role in our dementia journeys. In North America, some 15.5 million are partner in the care of 6 million people.[4] With both high and low-income countries throughout the world



struggling to provide services to their ever-growing older populations, families and extended households continue to provide unpaid care.[5]



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 care partners lack vital care management information.[7] Furthermore, caregivers commonly overlook their own wellbeing, becoming isolate, stressed and depressed, leading one landmark study to describe them as "the invisible second patient".[8] Given people's overwhelming preference to stay in their homes and the complex path that both members of the care partnership must navigate to do so, savvy



providers ought to be considering the wellbeing of entire families not just the traditional 'client'.

By thinking digitally, entrepreneurs and intrapreneurs have limitless opportunities for new high-quality services that meet the diverse needs of aging populations. Critically, digital tools mitigate caregiver shortages because a) non-traditional caregivers may be motivated to become involved and b) when digital tools are used, the size of the digital pie doesn't diminish, no matter how many times it is consumed. Further, the digital trace of that consumption produces data that organizations can use to improve efficiencies and measure outcomes.

3. Eco-psycho-social approaches to improved wellbeing

Dementia can undermine a person's confidence and self-esteem, however, as dementia culture-shifter, Tom Kitwood, pointed out in the 1990s: when such needs are met, a person can live relatively well despite their dementia. But he was quick to add that it is we healthy others who must step up and assist if 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.[9]



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 memories, which are hardwired to human experience and often stay with us to the end of life.[10]

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 feel the structural challenges that come with doing things differently.

4. How digitally-delivered therapy is different

While digitally-delivered therapies do not have the full dimensions of physical world experiences (although sensory and fully immersive experiences are emerging), they have distinct characteristics, which, when well designed, can overcome 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". [11] 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 artifacts that hold special meaning to an individual.

• Skill sets of care staff

In traditional activity 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, tend to work outside the activities loop given their focus on medical-related tasks.

On the other hand, digitally-based therapies can contain modules that assist workflow and improve efficiency. 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 them. 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 of 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 close-up details of the work and suggest different pathways for interaction.

5. Connected Dementia Care (CDC)

The rise of digital tools that help people live well with dementia, though nascent, is no longer new. Apps help detect the early signs of dementia. Music therapy systems coordinate singalongs for individuals and groups. AI feeds falls detection sensors, reminders, alerts and smart calendar systems. Smartphone apps help people navigate daily activities, share agendas and communicate with their families. VR headsets deliver immersive bucket-list destinations to chair bound residents. Robotic pets purr and swoon when touched. A host of services are 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, robotics, voice-enablement)



- An enthusiasm for behavioral self-management and 'the quantified self', as evidenced by catalogs of wearables, including wrist bands and smart fabrics
- The social web
- Fueling the fire, the FDA has recently defined ten criteria for digital health [12]and digital therapeutics for addiction, diabetes, and autism [13] now bear the FDA stamp. Within this paradigm, lies the new category of dementia care we call 'Connected Dementia Care (CDC)', so named because captures the idea that through connectivity, knowledge flows. US-based consultant, Karen Coppock, has placed this category within the wider ecosystem of connected senior care [below].



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



6. Best Practice CDC

It is disturbing that the digital world offers we healthy-others a plethora of customizable apps to extend our online identities yet sets adrift those who need help to amplify their sense of self. When people critically need support on that front, the tech world turns its back. CDC 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

• Relationship-centered: keeping the connections between people and things alive to combat isolation

- Meaningful and purposeful occupation.
- Living well: living optimally albeit with a disability

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.



7. 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 merely replicating a non-digital activity and then redistributing digitally (e.g. a card game).
- A CDC is informed by non-digital engagement activities organized specifically for people with Alzheimer's and other related dementias

8. CDC's place in the assistive technology ecosystem

How well the world manages the increasing prevalence of dementia depends on the degree to which we embrace new ways to resource and scale the care for those living 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 give context to them.



1. Co-design

Co-design has long been a part of user experience (UX) design philosophy; however, only recently has there been a focus on how cognitivelychallenged people might contribute to software development. The catchcry 'nothing about us without us', enshrined by the disability movement in the 1980s, is now a founding principle of advocates working destigmatize dementia. Many advocates are themselves living well with the condition. CDC proponents honor the principle, for, without inclusive design, people impacted by dementia are unable to do-the-doing, and, instead, are 'administered to'. For *Deva World*, Mentia developed an iterative co-design methodology, termed 'Creative Engagement'. This system enables people with significant dementia to participate from the get-go. Mentia has also developed an instrument tool measuring digital engagement, which allows those participants to evaluate the developed technology, thus closing the design feedback loop.





2. 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 a deeper understanding of participants' needs, delivers culturally relevant just-in-time content, makes smarter suggestions and responses, and enriches services to providers.

3. 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 is cloud-based. Open APIs integrate it to other digital systems such as management programs and electronic health records. Silos come down.



Scaling also reduces the need for external resources; for example, there may be no opportunity to prepare for a special day on the calendar. With Deva World, digital and media artifacts can be pulled from the internet straight and placed into an interactive scene.

4. Intangible Economy

When we share a tangible good, it divides. When we share an intangible good, it multiplies. Digital transformation moves an economy of scarcity to an economy of abundance. Deva World gives in-demand creative and dynamic therapists, whose actual presence is sought, the opportunity to amplify their presence and support geo-diverse communities across time zones and at times that suit participants. No more the notion of therapy by-appointment. Therapists would need to respect the platform's protocols however rules are not designed to be restrictive but, simply, effective.

5. Community

In the digital age, "horizontal" relationships inside communities are blossom through connections that 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, and why not people with a predilection for Latvian folk-dancing can each be accommodated by visiting culturallyspecific places that other like-minded folks have already commissioned. Indeed, there could be a payment model whereby original 'world builders' can be reimbursed by those who want to visit.



6. A Path to Wider Adoption

Whenever digital transformation occurs, there are some for whom the switch is not easy. Care staff who are reluctant to try new products may be weighed down by past failures, out-of-date devices, inconsistent Wi-Fi, or hardware that is locked away in cupboards and forgotten.

But what if caregivers, on seeing residents at ease with a digital 3D world start to realize that, after all, going digital is not so bad? Resident-led acceptance could be a driver for workplace change more generally. CDC products could help accelerate the shift from, say, paper-based rosters, records and handover notes to digital ones.

7. Pedagogy

A digital tool can have many facets and serve different masters all at once. *Deva Word*, for instance, can be used to educate and create knowledge. Care companions can play in a virtual world that mirrors and reinforces best practice care for the actual world. Care companions who are inclined to learn visually are 'hands-on' and having fun, learning 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.

8. Scientific Research

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. Why is this so? Which parts of the brain are being recruited? Digitally-based systems collect data that can be used to better understand the cognitive impact of certain activities on the brain over others. As knowledge develops, these activities could be finely



calibrated to each individual, just as precision medicine within the bioclinical field does. And as cloud-based platforms grow, so, too, does data, leading to fresh insights into how best to optimize cognitive function.

9. Summary

Like the technology outcomes of the historical Renaissance, printing foremost amongst them, innovation destabilizes old systems and methods.[14] To providers wedded to legacy systems, we say now is the time to open the door to innovators who come knocking. Senior-tech startups need senior- care providers to lend support, and that means dollars as well as time, for without such help, new solutions will fail and the rate of change will slow. Innovators need champions.

The 'boomer' generation, 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 the preference to thrive in their own homes - but also to fill holes made by a shrinking care workforce.

Fortunately, a new set of technologies is driving change, with CDC being part of this broad shift. As a category of therapy, CDC captures the spirit of the digital Renaissance, on the one hand causing instability and fear, and on the other, Enlightenment: expertise is available everywhere and at low cost; new modes of communication bring a sense of agency and develop selfesteem, new ways to distribute and scale activities cloud-based, an economy of abundance over scarcity, and new ways to design, teach, learn and build knowledge. Plus, unlike actual-world endeavors, digital activities *flow*; they can't be contained by bricks and mortar. This is the Tao of Connected



Dementia Care, 'the way' forward, in a world where dementia care solutions must transform if we are to meet the challenges of cost and care that lay ahead.

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11. About the Authors

Dr. Mandy Salomon, CEO at Mentia, is an entrepreneur working at the intersection of creative media, human-computer interaction and cultural gerontology to build next-generation tools for people living with dementia and those who support them. She received her M.A. and Ph.D. at the Swinburne University of Technology in Melbourne (Australia) for work on inclusive design for people with dementia, and for developing digital systems that enable them to participate. While there, she conducted studies that showed the acceptance of 3D virtual worlds for people living with dementia and the psycho-social advantages of using them. Stirling University's Dementia Services Research Centre (UK) selected Dr. Salomon's research for 'Ideas today that will impact tomorrow' describing her work as 'digital empathy'. She was also the recipient of the Smart Services Cooperative Research Centre's CEO award for Best PhD. Dr. Salomon also holds a BA in Drama and Visual Arts and brings a large body of work from theatre and media production to her practice. She is a Research and Industry Fellow at Swinburne University, a member of Creative Aging San Francisco, and an Alliance member of Aging 2.0.

<u>Serge Soudoplatoff</u> is an authority on digital transformation. As CTO at Mentia, he brings fresh eyes to dementia care through a combination of creative thinking and engineering. Soudoplatoff trained at École Polytechnique, Paris, in computer science and mathematics. He is a regular contributor to the French think-tank, *Fondapol*. His <u>recent monographs</u> are on the topics of digital health, artificial intelligence and the blockchain. The author's peer-reviewed papers on digital transformation are available at <u>http://swinburne.academia.edu/mandysalomon</u> http://www.fondapol.org/etude/le-numerique-au-secours-de-la-sante/;

Mentia was born in 2017 and is a portfolio company at Launchpad Digital Health in San Francisco. The focus of Mentia's work is to apply innovative technologies to solve the large-scale senior care challenges: scaling expertise and up-skilling care staff for better health outcomes. Please visit <u>www.mentia.me</u> to learn more about Mentia's product, sales and partnerships.

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