



The Tao of Connected Dementia Therapy (CDT): How digital tools are changing the dementia experience

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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 support. We call it ‘Connected Dementia Therapy’ (CDT); it’s a new category we’re proposing that describes the transition of the world’s best offline wellbeing strategies into online ones for a better quality of life and data-supported measures that quantify its value.

Mentia’s value proposition in this new environment is our ability to scale wellbeing activities while also providing organizations with tools to measure their impact, providing critical metrics in the face of spiraling costs and increasing older populations. Mentia’s signature product, DevaWorld™, embodies these aims and principles, and we’ll use it as an exemplar later on in this white paper.

1. Setting the scene



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

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] Implicit in the definition is that people living with dementia are doing the best they can. The goal of assistive technology (AS) should be to support those impacted to participate more actively in their own care. Traditionally, AS is sensors, alarms, and mobility devices but not care *itself*. CDT-thinking changes that.

What is dementia ?



"one's own unique coping
mechanisms in the face of internal
devastation"

(Christine Bryden, 2002)

2. Delivering and Measuring the quality of care

Family and friends play an essential role in our dementia journeys. In North America, some 15.5 million 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 families actively care for loved ones for 9.5 hours per day, equating 18.8 billion hours of unpaid care annually. If we put a \$15 value on every hour spent, caregivers contribute \$282B worth of care, often overlooking their own health and wellbeing.

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 information on care management [7] Furthermore, caregivers commonly become isolated, 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 often complex path to be navigated, the entire families need support, especially at times of transitioning from home to hospital or long term care. In the era of longevity, entrepreneurs and intrapreneurs have massive opportunities to reimagine care to better meet older adults' diverse needs. Unlike services in the bricks and mortar world, the size of their digital pie doesn't diminish, no matter how often it is consumed. With the critical shortage of care workers, new systems can energize and upskill non-traditional caregivers, such as community volunteers, students, and retirees. Finally, the digital trace of that consumption leads to measurable waste – as well as efficiencies - across the health care system.

3. Eco-psycho-social¹ approaches to improved wellbeing

Dementia can undermine a person's confidence and self-esteem. However, as the dementia culture-shifter pioneer Tom Kitwood pointed out in the 1990s, a person can live relatively well despite their dementia when they are accorded respect and choice. 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 thinking 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 emotions and our reward, autonomic and motor functions. [9] Companion robots and VR experiences help to reduce isolation. 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 system captures the essence of these activities and delivers them through a unique interface that is acceptable to the target user group – people living with dementia. However, as newspaper publishers found when they first transitioned to online news, merely porting a facsimile of the traditional version is not enough. Moving into the digital realm changes the nature of care and the ecosystem that supports it. Digital therapy is not merely 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 treatments do not have the full sensory dimensions of physical world ones, they nonetheless have other characteristics that overcome usual limitations:

- **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, resource-heavy, and usually require a trained facilitator. In the digital space, however, costs are much lower, and activities can be customized to meet individual preferences. Digital therapeutic activities can easily accommodate a person who prefers not to join in a group activity.

- **Skill sets of care staff and supporters**

Traditionally, a roster governs when and where an activity session takes place. Should the recreationist be absent, volunteers and aides may not have sufficient training to take their place, nor is recreational therapy part of 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 not only engage but 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 for which they can be rewarded. Session data, such as duration times and interaction levels, bring

hitherto hard-to-collect insights which can be shared with families and allied health teams. In short, connected dementia therapy dynamically impacts people and environments.

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. CDT and the Connected Health Ecosystem

The pool of gerontechnologies that help people live well with dementia is rapidly expanding, exciting investors who committed \$11Bn to digital health in 2017[10]. The market is awash with digital reminders, alerts and smart calendar systems. Smartphone apps help people listen to music, navigate daily activities, share agendas and communicate with their families. Physical and cognitive snapshots are taken by phones and wristbands throughout the day. AI-driven detectors prevent falls. VR headsets deliver bucket-list travel destinations to chair-bound residents. Mechanical pets purr and swoon when touched. A host of devices and

services are being built around smart voice-activated appliances, with voice, arguably, the most natural interface of all.

Gerontologist and age-tech commentator, Keren Etkin, put some order into the burgeoning ecosystem with her 2019 market map, nominating twelve categories, including ‘cognitive care’ [figure 1]. We propose that CDT be located within it, as a subset.

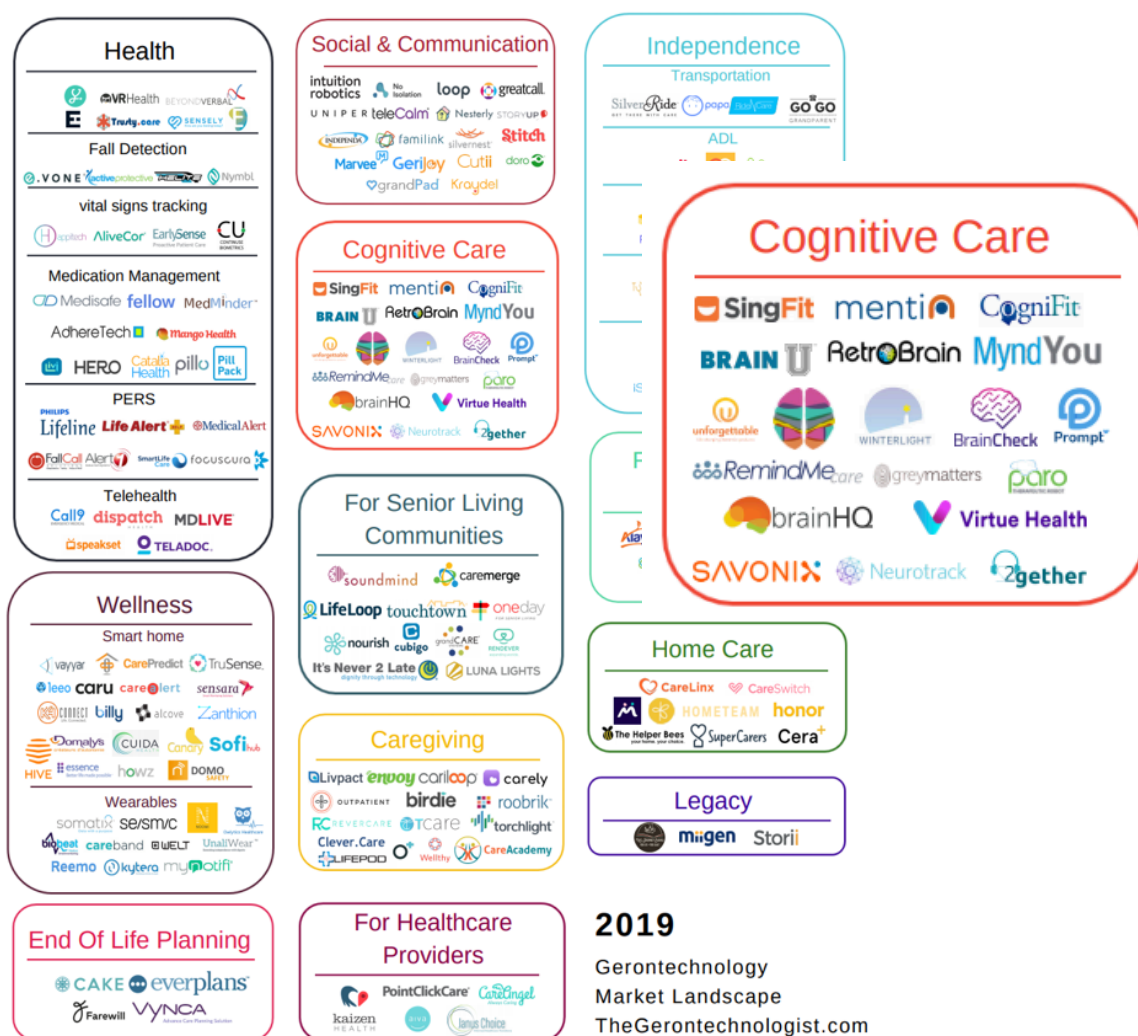


Figure 1: Keren Etkin's market map of connected senior services, ©2019
<<https://www.thegerontechnologist.com/>>

6. Best Practice CDT

CDT captures the idea that through connectivity, expertise flows. It is disturbing that the digital world offers we everyday internet users a plethora of customizable apps to extend our online identities yet sets adrift those who need help to amplify their status and connections. Despite people with a diagnosis needing support on that front, the social-tech titans chose to ignore them. CDT crashes through that digital divide by bringing people experiencing dementia in at the design phase. Why so late? Could it be nothing more than the societal stigma that has kept their UX voice silent?

CDT 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

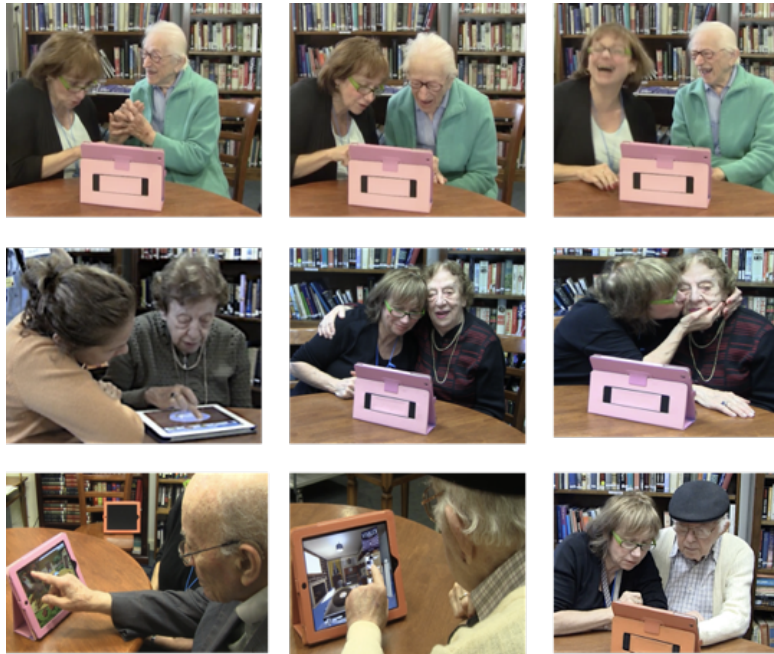
It is no coincidence that these elements are also the best practice pillars of non-digital strategies for supporting wellbeing. What is new, however, is understanding how to transfer this ethic into an app, keeping core values, while at the same time, incorporating the characteristics and possibilities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

7. DevaWorld™ as a CDT

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. CDT sits within an emerging set of digital practices and technologies that indicate a care renaissance is upon us; Here's how our signature product, *DevaWorld*™, fits in:

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 cognitively challenged people might contribute to software development. The catch-cry 'nothing about us without us', enshrined by the disability movement in the 1980s, is now a founding principle of [advocates](#) working to destigmatize dementia. Many advocates are themselves living well with the condition. CDT proponents must honor the principle, for, without inclusive design, people impacted by dementia are unable to do-the-doing, and, instead, are 'administered to'. For *DevaWorld*, Mentia used a novel co-design method to build a system that people with significant dementia use intuitively. We also developed an instrument for measuring digital engagement, which enabled participants to become evaluators of the very system they helped to develop. We continue to use these methods today as we extend our system.



2. AI

When the Internet arrived, *information* became available everywhere at a low cost. Then, Web2.0 made *knowledge* available everywhere at a cost. Now, with the rise of artificial intelligence, *expertise* and *data* becomes available everywhere and at low cost. AI in *DevaWorld* equates deeper understandings of participant needs, and the ability to respond just-in-time. Collected data drives insights and efficiencies.

3. Scalability

A characteristic of CDT 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 with other digital systems such as management programs and electronic health records. Silos come down. Scaling also reduces the need for external resources; for example, special days can be celebrated with artifacts pulled from the internet and placed contextually into a *DevaWorld* scene.

4. Intangible Economy

When we share a tangible good, it divides. When we share an intangible asset, it multiplies. Digital transformation moves an economy of scarcity to an economy of abundance. *DevaWorld™* delivers ever-expanding creative and dynamic therapies on demand. No more the notion of therapy-by-appointment.

5. Community

In the digital age, “horizontal” relationships within communities blossom. Connections self-propagate around spheres of interests and the sharing of knowledge and resources. As we build out *DevaWorld*, becomes 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, or those with a preference for Latvian folk-dancing can each be accommodated by visiting culturally-specific 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. Staff may view new processes with suspicion: “Extra work for me? I can’t get through my to-do list as it is.” But what if caregivers see their residents at ease with a new technology? Resident acceptance could drive workplace

change more generally, accelerating, for example, the shift from paper-based handover notes to digital ones.

7. Learning

A digital tool can have many facets and serve different masters all at once. In the case of *DevaWorld*, knowledge is embedded in the play experience, reinforcing dementia care practices. Staff learn by doing. They are hands-on rather than book-bound.

8. Scientific Research

Our preliminary observations show that when a player is walking, playing the piano, and trying on clothes in *DevaWorld*TM, their real-world communication is enlivened. Why is this so? Which parts of the brain are being recruited? Digitally-based systems collect data that help us better understand the impact of cognitive stimuli. As knowledge develops, these activities will be finely calibrated for each individual, just as precision medicine within the bio-medical field does.

8. Summary

New technologies shift the status quo.[14] To providers wedded to legacy systems, we say now is the time to open the door to innovators who come knocking. Gerontech startups need long-term care providers to be bold, 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 is demanding a different aging experience to that which their parents endured. New tools are needed not only to meet their

expectations, including a preference to thrive in their own homes - but also supplement a shrinking care-worker force.

Fortunately, gerontechnologies are driving change, with CDT being part of this broad shift. As a category of care, CDT makes expert cognitive care available everywhere. It affords new ways to communicate and interact; teach, learn, and build knowledge. It enlarges a shrinking world. Plus, unlike actual-world endeavors, digital activities *flow*; bricks and mortar can't contain them. CDT is part of healthcare's digital renaissance, which, like its historical namesake, causes both instability and enlightenment. This is the Tao of Connected Dementia Therapy, 'the way' forward in a world where dementia care must transform if we are to meet the cost and care challenges that lay ahead – and respect the right of persons living with dementia to play a greater role in their care.

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About the Authors

Mandy Salomon is CEO at Mentia, a digital therapeutics company focusing on age-related brain health and cognitive wellbeing. She received her Ph.D. at Swinburne University of Technology in Melbourne (Australia) for developing communication systems for people with dementia. Stirling University's Dementia Services Research Centre (UK) described her work as 'digital empathy'. She was also the recipient of the Smart Services Cooperative Research Centre's CEO award for Best Ph.D. Mandy brings a large body of work in theatre and media production to her practice. She is an active member of the Dementia Action Alliance (USA), Creative Aging San Francisco, and Aging 2.0.

Serge Soudoplatoff, CTO at Mentia, 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 recent monographs are on the topics of digital health, artificial intelligence and the blockchain.

Mentia was born in 2017. Its vision is a world where people with cognitive disabilities live independent and purposeful lives. Please visit www.mentia.me to learn more about Mentia's product, sales and partnerships.

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