About Those Dementia Villages

Honorable Intentions and A Still Hellish Road

July 4, 2023 By Mike Barr

Of course, the Times headline on the growing trend of "dementia villages" caught my eye last night. I am all for this heart-breaking (I would argue misunderstood and not so quietly politicized) issue attracting all the keenest journalistic minds around, but it also crushes me to see these mostly Groupthink, lemming-like analyses. (Joann, maybe a follow-up piece?)

> “Over the past decade, as the number of dementia cases has exploded worldwide, more ’dementia villages’ and senior ’microtowns’ have opened across the globe. But experts worry that if the senior-care community is going to keep pace with diagnoses, there will have to be another major paradigm shift, and quickly,” the article explains.

Obligatory statistics from Alz.org and WHO note that, "When [Holland’s] Hogeweyk first opened its doors (which turns out to have been in 2008), there were about 35 million people living with dementia around the world. Today that number is more than 55 million, and WHO envisions 78 million by 2030.

If you have HIV (or HSV-1 for that matter) or periodontal disease or O2 saturation or insulin sensitivity issues or chronic constipation or insomnia or sinusitis or even undiagnosed gut flora imbalances, you can likely count yourself in among these numbers. Unless of course a stroke or neoplasm gets your first.

Rather than dementia villages, what we really need are dementia spas: you and your S.O. check in, you learn, you implement & hone, you heal, you go home.

Norway’s Carpe Diem opened in 2020, boasting 136 communal housing units and 22 high-care dementia units. Grenoble’s Village Landais, in June of 2020. Even Australia is in on the action. And truth be told, reading this made me physically sick to my stomach: celebrating or seeming to

celebrate colossal failure— capitulation, really— on an epic scale. I'm hoping I don't know all the details, and that unsuspecting dupes aren't sent here (or to Hogeweyk or Carpe Diem for that matter) as a life sentence:

> "Half a world away in the town of Bellmere, Australia, NewDirection Care describes itself as the world's first 'microtown' dementia community. Residents live in what resemble typical single-story homes — there are 17 in four different styles, with seven residents per home. The town center includes a corner store, cafes, a salon and a cinema.
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> 'It's very much like a suburb in Australia,' said Natasha Chadwick, the facility's founder and chief executive. This 'microtown' is fully inclusive, mixing dementia patients, including younger ones suffering from early onset dementia, with senior residents who haven't been diagnosed with dementia at all."

Rather than dementia villages, what we really need are dementia spas. (Call them "retreats" to take the snooty, exclusive edge off.) We have at least four of them now, and the movement is growing. You and your S.O., friend or other family member check in for a month or two. You learn about all the various— imminently modifiable— inputs that go into determining cognitive health. You apply them. You hone them. You get better. You go home. Please watch: "New Clinical Trial Achieves Reversal of Cognitive Decline." In a nutshell those inputs, as currently understood, include:

- restoring insulin sensitivity & teaching the body to burn fat for fuel
- optimizing nutrient & hormone support (often involves active stress mgt)
- resolving inflammation
- identifying & treating pathogens (oral, nasal, gut)
- assessing & addressing toxin exposure
- optimizing sleep (including nocturnal oxygen saturation)

For the majority of folks, this requires changing the way one eats (both food choices & frequency) and being more active. Sitting the new smoking, and all that. Many folks too will need time to allow their palates to change, and science seems to indicate that this can take up to two months. (Detecting and treating possible zinc deficiencies— and other possible nutritional imbalances— can also help wake up old taste sensations. (I love the word dysgeusia that many of us first encountered during Covid.)

I would add to the above list assessing & addressing digestive sufficiency: stomach acid, bile flow, pancreatic enzymes. There's little value in focusing on more nutrient dense foods if the body is not breaking them down and absorbing them.

You (and your support team) are coached and supported through adoption of these changes. And then, appreciably or fully recovered, you are sent on your way to continue this new way of thinking and living chez vous.

This is the "paradigm shift" I want to see. This is the paradigm shift we need.

I know this first hand because I have worked with clients who just couldn't seem to marshall the forces (and/or lacked the household support or omnipresent guidance & reinforcement) required to turn things around. If there had been a place— a Canyon Ranch retrofitted to these very specifications and ultimately paid for by Medicare (I know, dream on)— I could send them to, even for a couple of weeks, to undergo a sort of crash course master class in the new daily routine we envision for them (and also long enough to see even the first glimmers of progress so vital for motivating continued behavioral changes), I suspect Dr. Bredesen's much maligned ReCode program would be batting close to 1,000 than the current .500 or so.

With the average lifetime cost of dementia care clocking in in excess of $400K, maybe these "dementia resorts" are not such a pipedream afterall?

And maybe it isn't such a pipe dream. With the average lifetime cost of how our society currently cares for a typical "Alzheimer's" patient at just shy of half a million, I''m guessing there would actually be a significant overall savings were we (or maybe Sweden or New Zealand or Brunei, please!) to adopt my rehabilitation approach. (Looks like Village Landais is spending €55,000 a year per "dementia village" resident, calculated from reporting by Marion Renault.)

It's telling that in this week's Facebook Live conversation, Dr. Sandison actually shares the fact that the genesis of her study came from a well-to-do, philanthropically minded client who paid for the study.

(Are the Netherlands and Norway not speaking to Finland? Why not adopt even the FINGER trial tweaks? Yes, the FINGER study looked at prevention, but the same principles apply. Official FINGER trial website here. Clintrials link to FINGER publications and planned future analyses here. (Ten-year follow-up to be shared any day now.))

Years ago, I posted here about the project in Booth Bay, Maine. And in the intervening time three new ones, possibly more that I am not aware of, have opened. In contrast to the proliferation of Memory Wards and now dementia villages in this country and abroad, the activist minded, thinking man and woman's option here is rehabilitation— not so much accommodation.

Facilities like the newly opened Marama in Vista, CA need to (quickly) become real alternatives to

dementia wards and even villages. A sister site opened its doors in Wichita, KS of all places in April. And re-reading, just now, of Dr. Heather Sandison's undertaking, Solcere in Encinitas, CA, makes me not so much sick to my stomach but rather weepy with gratitude.

The Marama and Solcere model (and Booth Bay Health Center, for that matter) is for temporary— rehabilitation (and in many ways re-programming)— stays; the plan (or goal) being for residents to return to independent living. Marama provides the space, food, staff, amenities and experience to implement the lifestyle changes necessary to support cognitive health.

Re-reading just now of Dr. Heather Sandison's ballsy undertakings in Encinitas and Vista, CA rendered me teary-eyed with gratitude.

Where are the Musks and Gates and Thiels (insert fave VC or e-gazillionaire here, many whose names are less familiar to us) who will help to massively scale up these types of options for the seniors (and a growing number of not so senior folks) we are currently warehousing and committing to an end of life whitewashed hellscape? While the EU countries may have the funding infrastructure for these well-intentioned but ultimately Potemkin villages, the US, if nothing else, has turn-on-a-dime, get-it-done-overnight, value-free capitalism. Why not put it to good use?

After discovering two New Yorker pieces on this— Marion Renault's from last November but also Larissa MacFarquhar's ("The Comforting Fictions of Dementia Care" from October 2018— I realized this might not be the time-sensitive topic I initially thought it to be. I may need to update (or expand) this hastily composed exploration once I have had more time to dig into these long articles and all the new threads they might lead to. So please keep an open mind.

"What we're asking for is a miracle," Dr. Sandison concedes in the video, "so when we see someone even stabilize after six months on the program, we celebrate that— every day!"

Very few people should be getting all the way to dementia. We should be catching folks in the SCI stage, where they are easily reversible.

Just yesterday, Dr. Sandison's group's six-months results of a small (N=34) non-residential group were published in the Journal of Alzheimer's Disease. And they met to talk about it on July 15 (link

here). Seventeen of the 23 people who were able to stick it out for the entire six months showed improvement, both upon testing as well as by subjective changes noticed by them and their loved ones. And remember, this is something— stabilization and actual reversal/improvement (as opposed to only a slower deterioration, if we can even believe the analyses of Eisai/Biogen, Roche and Lilly)— that no drug trial has ever been able to do. Nutritional and lifestyle interventions typically take time to turn things around, six months historically being the time point where a sort of light goes on (or switch flips; choose your analogy): participants begin to heal and continue to improve thereafter. That's why it would be super interesting to see the 1-year follow-up of Dr. Sandison's group, although on July 15th call it sounded like this isn't going to happen. Towards the end of the conversation, Dr. Bredesen noted that for folks who come in with MOCA scores in the 12-13 range (and lower) may end up needing a second, follow-on strategy of neurotrophic support (e.g., intranasal trophic factors, peptides, stem cells) to help rebuild the lost synapses. So while goosebump exciting, this is all still clearly a work in progress with everyone still learning.

If you've made it to the end, this must be a topic that interests you, so I will also share here two or three parting resources:

- Dr. Bredesen's team recently began recruiting for a new multi-site dementia reversal study called Evanthea, and are actively recruiting interested study participants at study sites in Hollywood, FL; Nashville, TN; Rocky River (Cleveland), OH as well as three sites in CA: San Rafael, Walnut Creek, Folsom (Sacramento). Read more about it here
- Link to Dr. Bredesen's "PreCode" prevention screening and support program ($39/month with minimum 6-month commitment + $335 for labs if you cannot get them from your PCP) here
- And finally, the new pTau181 blood test (reportedly reimbursed by Medicare) that is so far appearing useful as a preventive brain atrophy screening tool: read about it here and here

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