

1 February 29, 2012

2 **COMMENTARY RE: “DRAFT NATIONAL PLAN TO**
3 **ADDRESS ALZHEIMER’S DISEASE”**

4 With all due respect to the contributors and authors of this draft plan, I submit
5 that, if finalized as written, it will do more to destroy the Alzheimer’s community
6 and set back any hope of progress toward a solution than anything seen to date in
7 my lifetime.

8 WHY?

9 As written this is a blatantly politicized piece of campaign rhetoric. I, perhaps
10 surprisingly, am a life-long Democrat and strong supporter of liberal causes who
11 has burned a lot of shoe leather knocking on doors on behalf of liberal candidates
12 starting with Adlai Stevenson in 1952, but I am and have been also a dementia
13 caregiver for over 20 years. This Alzheimer’s Disease issue SHOULD BE TAKEN
14 SERIOUSLY! THE PROBLEM IS APOLITICAL, AND SO SHOULD BE THE SOLUTION!

- 15 1. Starting with the Vision Statement. There is NO better vision than that of
16 The Alzheimer’s Association - “A world without Alzheimer’s Disease”.
- 17 2. Certainly President Obama should be given credit for his support, and his
18 supporting statement deserves recognition in the plan, but other people
19 such as former House Speaker Gingrich deserve equal recognition for their
20 contributions toward developing and supporting these efforts as well.
- 21 3. This entire issue of age related cognitive impairment (I’ve read that there
22 are nearly 100 probable types/causes) deserves the support of EVERY
23 citizen, whatever their political persuasion, and this draft plan mitigates any
24 possibility of achieving that necessary broad level of support.
- 25 4. Further, in the 27 pages of text, I count at least 8 specific references to the
26 “wonderful” AFFORDABLE CARE ACT. Why? One should be more than
27 enough, Zero would be better since a) The administration is wavering on
28 implementation with refusal to implement some parts of the law, b) the
29 administration is providing multi-state waivers to other parts, c) there

30 seems to be little agreement or consensus on interpretation of key
31 elements among those few who have struggled to review those nearly 3000
32 pages, and lastly d) this controversial law has yet to be reviewed for
33 constitutionality by The Supreme Court (partially or completely).

34 I suggest that the intent of those statements can be preserved in a much less
35 controversial way by simply replacing “Affordable Care Act” language with
36 something like “existing and proposed legislation”. I think that the PLAN might
37 also allow for the possibility for proposing new, additional legislation should it be
38 considered useful.

39

40 With respect to Strategy 1C, I feel it would be most appropriate to add an
41 additional action to address the legal and ethical aspects of early detection. What
42 about those people that show no signs of dementia but are discovered to have
43 major plaque accumulations? Should they be told?

44

45 I agree that measurement of the disease’s progression is extremely valuable to
46 the caregivers, researchers, and medical professionals, but I think that more than
47 imaging and biomarkers is needed. Today, the “gold standard” of American
48 neurologists and gerontologists is probably the MMSE (Mini Mental State Exam),
49 although many more assessment tools have been developed and found useful
50 around the world. Of even more significance is the Allen Cognitive Scale
51 measuring patients ability to contribute to their care in later stages. The PLAN
52 should include recommendations for assessment tool standards to be applied
53 nationwide in evaluating AD/Dementia progression for use in clinical trials,
54 medical reporting, and elsewhere.

55 Another observation formed from my having read the proposed draft report
56 numerous times is that the research portion, despite expressing some valid
57 points, still appears to be another somewhat disorganized “hip-shoot” relying on
58 far too much luck and too little deliberate, well thought out planning. Dr. Eric
59 Kandel said it best when he applauded the successes so far and recognized that

60 this whole issue was extremely complex and we had a lot more to learn. The
61 complexity of the challenges clearly represents a “system of systems” which the
62 late Russell Ackoff defined to be a “mess”. This entire program cries out for a
63 well-organized systems engineering approach if any progress is to be made in an
64 affordable, rapid manner. Ackoff would have been our guy, but perhaps a
65 colleague or student of his might be found to accomplish this task as soon as
66 possible. A few calls to the systems thinking community in Academia or the
67 International Federation for Systems Research might identify some key people.

68

69 Speaking of complexity, I think we can rely on the following:

- 70 a) Age related dementias (other than major vascular events) are slow in
71 development (Some have said that AD may begin in a persons twenties).
- 72 b) AD mechanisms change as the disease progresses and as damage occurs.
- 73 c) Each stage may require markedly different treatments to achieve delay or
74 prevention.

75 Is it possible that we are discarding treatments because we are applying trials to
76 an inappropriate stage of the disease? (or even to those that may be incorrectly
77 diagnosed?) Can we confidently rely on the FDA to make the appropriate
78 treatment decisions for all stages of AD? I assure you that the “front-line”
79 families become more desperate as the disease continues it’s slow progression. I
80 further suspect that most people in the AD community care very little if the
81 treatment is “FDA Approved”. The issues really boil down to:

- 82 a) Is the treatment available (anywhere in the world)?
- 83 b) Is the treatment affordable?
- 84 c) Where, when, and how can I get it?

85 An example of a layman’s assessment of possible “treatments” as of today is
86 shown as Attachment 1 to this commentary.

87

88 With regard to rapidity, I also have seen other criticisms of the 2025 goal
89 suggesting that a 2020 goal might be better. Certainly, I would like to see a goal
90 of 2010, but I believe that 2025 might be attainable only if we restrict ourselves to
91 those things that are in the “pipeline” today, which in turn have no guarantee of
92 success. I would urge you to consider scheduling several goals, with separate
93 time objectives, recognizing that we are in a cancer or AIDS-like program that
94 might take 50 years to find a “cure”. By the way, I also noted that “finding a cure”
95 is not in the list of research objectives. Have you given up?

96 I would suggest starting as follows:

- 97 a) Identify and treat risks (2012) - Suggestions for good/bad environmental
98 and diet approaches (subject to vary with time and knowledge – remember
99 discarding our aluminum cookware?) This is like “No Smoking” in the fight
100 against cancer.
- 101 b) Slow and/or stop degradation (2015) This is partially available now for
102 those who respond to Aricept/Namenda combo treatment. Solutions are
103 needed for the large number of people who do NOT respond favorably.
- 104 c) Early Prevention (2020)
- 105 d) Minimize Symptoms (2022)
- 106 e) Delay Onset (2025)
- 107 f) Reversal of Afflictions (2050) - “THE CURE”!!!!

108 Of course, the above dates are unsupported figments of my imagination, but I
109 hope you see the concept here.

110

111 I also found some statements and titles in the described actions that gave me a
112 “where did this come from” moment. Namely, Action 1.B.3 that discusses clinical
113 trials and international outreach. Do you intend to request non-citizens, off-
114 shore, to participate in our clinical trials? This needs some explanation. Another
115 point that underwhelmed me was Action 1.B.4. Is this just pro-forma government
116 speak or is there a real point? Frankly, I am of the very solid opinion that
117 Alzheimer’s Disease is about as racially and ethnically diverse and unbiased in

118 selection as is possible in all of humanity. Are you implying that there is bias in
119 the clinical trial community? Is there managed selectivity in who gets the “stuff”
120 and who gets placebo? I highly doubt that! In fact, I doubt that your assumption
121 of higher risk for AD being either racially or ethnically related has any validity at
122 all. I submit that the REAL reason for those observations lie in differences in life-
123 long histories of environment, diet, and health care practices. For example, we
124 are fairly certain that Americans (of my generation) of Greek or Italian ethnic
125 heritage are at lower AD risk levels, most likely due to preferences for a mostly
126 Mediterranean Diet. This risk reduction may not apply to younger generations if
127 they’ve switched to Drive-Thru Bacon Cheeseburgers. In any case, I suggest that
128 tracking data on historical environment, diet, and health care practices will be
129 much more meaningful, and tracking racial/ethnic populations as suggested will
130 provide little or no contribution toward improved outcomes.

131 A small, but significant, item that I have some issues with is the stated expected
132 cost of nursing home care at \$78,000. A much more representative (and far more
133 meaningful) number can be shown if it were expressed as a range of state cost
134 averages (\$70,000 to \$150,000) and further adjusted to determine the level of
135 pre-tax retirement income required to sustain the nursing home option (don’t
136 forget to include costs for incidentals like toothpaste, shaving cream, haircuts as
137 well as Medicare parts B,C, and D with those costs adjusted for “means testing”).

138 I suspect you will be looking at \$150,000 to \$250,000 per year. Thus it will be
139 much easier to understand the future economic pressures on Medicaid and will
140 go a long way toward determining the adequacy of an individual’s long-term-care
141 planning.

142

143 Also, I am very disappointed that this draft plan promulgates the social stigmas so
144 dreaded by those in the Alzheimer’s community. I understand the enticement to
145 encourage high funding levels and popular support through fear, but I believe this
146 is counterproductive to the tasks of living with and caring for those with AD. I am
147 also a strong supporter of redefining those people as being “deeply forgetful” as
148 opposed to “Alzheimer’s victims”, “Alzheimer’s sufferers”, “Senile individuals”,

149 “People with Dementia” or “Cognitively Impaired”. Please realize that NOBODY
150 wants to be diagnosed with Alzheimer’s. It WILL rapidly result in loss of life-long
151 friendships, loss of independence, loss of self, loss of peer respect, etc. This is
152 clearly why early diagnoses seldom happen, and why public education is SO
153 important. The stigma extends and becomes tragic when overzealous and
154 uneducated agents of Adult Protective Services who believe the unsupported and
155 unproven claims spread throughout the Elder Abuse channels of government that
156 “most elder abuse comes from spousal and parental relatives/caregivers”.
157 I believe that too many malicious prosecutions are executed throughout the
158 country due to proliferation of this myth. Occasionally, States have admitted to
159 errors, documented those errors, and revised state policies (see “HANDCUFFED”
160 by Wisconsin DHS). Other states rigidly support their mistaken beliefs, and I have
161 seen personally the destruction of families, and early, wrongful patient deaths not
162 to mention large legal costs to these families or to the states if public defense is
163 necessary.

164 Many caregiving families are threatened daily by the health care/ adult protection
165 bureaucracy. Has no one heard of self-inflicted injuries due to agitation? This is
166 why nursing homes use Posey Mitts (soft handcuffs) and load their patients with
167 unwanted drugs. Should patients be arrested and confined if a caregiver is
168 injured? Should caregivers be arrested and confined if a patient exhibits self-
169 inflicted injuries? Should a caregiver be arrested and confined if a patient is
170 inadvertently injured or bruised during an effort to protect another innocent
171 person? Or attempting to protect the general public? Should families be
172 destroyed, Power of Attorney ignored, and spouses of 50 years be separated
173 without visitation upon arrest, with NO conviction? The Plan’s legal advisors
174 would provide a great service to the community by prioritizing for both home and
175 professional caregiver’s a list of who should get protection/arrest first: a) the
176 general public, b) close bystanders, c) professional caregivers, d) home caregivers,
177 e) spouses and children/parents, or f) the “deeply forgetful” themselves.

178

179 Lastly, some comments on caregiving support needs. The PLAN needs to clearly
180 state as part of Goal 2 that the priority is to provide for in-home care as long as
181 possible in order to provide more favorable outcomes, extend life and quality of
182 life at less cost to both families and government taxpayers. My own personal
183 experiences indicate that respite care for family caregivers and supervised
184 productive day care experiences for the “deeply forgetful” are absolutely
185 mandatory to the achievement of this objective. The only successful application
186 that I have seen was a 1991-1992 experimental program in the State of Georgia
187 with several counties participating. While I understand this program has ended, I
188 believe it was well documented, and I guarantee that as implemented it was
189 indeed a lifesaving experience for participants and caregivers.

190 As to Nursing Homes, reducing the inappropriate use of anti-psychotics is a good
191 start, but further improvements are necessary, and should begin with significant
192 modification to the criteria by which state licensing authorities evaluate these
193 facilities. Current criteria covers physical safety very well, but ignore many quality
194 of life issues that affect the “deeply forgetful” residents. We often need to remind
195 ourselves that the deeply forgetful are NOT “empty shells”, but simply require
196 unique communication techniques. The Plan should look specifically at the
197 results achieved by advanced compassionate thinking in facilities modeled after
198 Lakeview Ranch, those practicing The Eden Alternative, Montessori based care for
199 the “deeply forgetful” and suggest significant modifications to existing licensing
200 and evaluation criteria that could be addressed by all State Licensing Authorities.
201 Also, I am told that many facilities consider it to be too costly to maintain and
202 update resident’s care plans, apparently in direct violation of federal laws. This
203 may be lack of education, but certainly indicates lack of enforcement.

204 Hospitalization offers additional caregiver challenges. “Deeply forgetful” patients
205 require special care, and have special needs above and beyond normal
206 expectations. Electronic (although privacy protected) records are a great idea but
207 should be expanded to include primary caregiver advice and concerns. Hospital
208 personnel need to understand time, behavior, and observation problems as well
209 as the patient’s inability to express needs, particularly if in discomfort and pain.

210 Similar observations might be made about any social situation that is not a part of
211 daily routine and familiar people. Examples such as travel (particularly by air),
212 home care visitations, family outings, and especially holidays come readily to
213 mind. People that interact with the “deeply forgetful” need to know that respect
214 and personal dignity are paramount.

215

216 If you made it this far, thanks for listening.

217

218 If readers would like any clarification or would like to further discuss any issue I
219 may have raised in this commentary feel free to contact me at any time.

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235 **Reported “good” for AD/MCI from various sources:**

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- 237 1. Heart healthy diet (Mediterranean) or New Nordic Diet (Real Rye Bread,
238 Cabbage, Carrots, Apples, Pears, and Berries)
- 239 2. Raw fruit and vegetables
- 240 3. Control high blood pressure (Prefer angiotensin II receptor blocker – ARB)
- 241 4. Avoid statin drugs (use policosanol and/or Red Yeast Rice)
- 242 5. Cruciferous (Broccoli/cauliflower) and leafy green vegetables (Vitamin K)
- 243 6. Physical and mental exercises and exergames like “cybercycling”
- 244 7. Good, sound sleep
- 245 8. Light Therapy (blue-green/6000K) to address circadian rhythm related
246 issues (Sundowning, etc.)
- 247 9. Socialization, Stress Management, and maintain friendships, HELLO
248 dinners (dubbed “socialceuticals” by Richard Taylor, PHD; diagnosed with
249 AD over 10 years ago) and Improvisational Theater Classes/Dancing
- 250 10. Prescription Drugs – Aricept, or Exelon, or Razadine, and/or Namenda,
251 etc.
- 252 11. Music, music, music
- 253 12. Meditation (Check Chakra’s), Kirtan Kriya yoga exercise, and Laughter
254 Yoga
- 255 13. Regular dentist visits
- 256 14. NeuroAD – electromagnetic stimulation (Israel – on test in Europe/USA)
- 257 15. Surgery – omentum translocation (Germany)
- 258 16. Deep Brain Stimulation (Canada)
- 259 17. Stem Cell Injections (Europe)
- 260 18. “Memryte” implants (Curaxis Pharmaceuticals – In Trial)
- 261 19. etanercept (Trade name: Enbrel) : anti-TNF therapeutic
- 262 20. Dual n-back tasks (Brain exercises – see [www.dual-n-
263 back.com/nback.html](http://www.dual-n-back.com/nback.html))
- 264 21. Other mental exercise (DAKIM, Sudoku, crosswords)
- 265 22. Supplements:
- 266 a. AXONA (prescription required - food product)
- 267 b. Huperzine A (Chinese med of choice – OTC)

- 268 c. Lithium Aspartate or Lithium Orotate
269 d. Lysine (enzyme-yellow corn)
270 e. Bromelane (pineapple)
271 f. Lycopene (tomatoes)
272 g. CoQ10 (see www.drstinatra.com)
273 h. Omega-3 oil (3000 mg) + Alpha-lipoic-acid (600 mg)
274 i. Potassium (20 + meq tabs, prescription required)
275 j. Magnesium (with potassium)
276 k. Cranberry Extract (for UTI prevention)
277 l. MCT Gold (medium chain triglycerides – coconut oil)
278 m. Vitamin D (50,000 units once or twice a week – Rx reqd. or use
279 multiple 10,000 unit tabs OTC)
280 n. Vitamin B-12, B-6, Folic Acid (5,000 units daily)
281 o. Welch’s Concord Grape Juice
282 p. Green Tea plus L-theanine
283 q. Vitamin C (oranges)
284 r. Vitamin E (600 IU per day)
285 s. Beta-Carotene (25,000 IU of Vitamin A)
286 t. Sniffing Insulin (not yet available)
287 u. Club moss extract, alpha-lipoic acid, PS fatty acid, etc.
288 v. Astragalus Root (immune system)
289 w. Spices: Turmeric, Curcumin and Cinnamon
290 x. DHA
291 y. DHEA
292 z. Vinpocetine
293 aa. Cognizin
294 bb. Alpha GPC
295 cc. Caffeine (coffee)
296 dd. Astaxanthin
297 ee. Symbiotropin
298 ff. Prevagen
299 gg. Ayurvedic medicines (ashwaganda, bacopa, gotu kola, mucuna,
300 salep orchid, morning glory,) MINDCARE includes all these.
301 hh. MINDMENDER
302 ii. Phosphatidylserine (PS)
303 jj. Gantenerumab (entering Phase 2 trials in U.S.)
304 kk. Flavenoids (blueberries, citrus, dark bitter chocolate)

- 305 **ll. Dimebon (rejected by FDA in two clinical trials)**
- 306 **mm. Seanol (Alginol) powerful antioxidant**
- 307 **nn. Astaxanthin (anti-oxidant, anti-aging)**
- 308 **oo. Resveratrol (red wine) or pterostilbene**
- 309 **pp. Dark Chocolate (limit to 1-2 oz. twice weekly)**
- 310 **qq. Methylphenidate (prescription for AD apathy)**
- 311 **rr. Ginko Biloba (some controversy here, but reportedly loaded with**
- 312 **helpful flavonoids)**
- 313 **ss. MELATONIN (10mg) nightly for sleep**
- 314 **tt. Phosphatidylserine**
- 315 **uu. Alpha GPC (Increases acetocholeline in brain)**
- 316 **vv. Pirocetam (Not available in USA – order on-line)**
- 317 **ww. Black Cohosh (herbal by Satori Pharmaceuticals)**
- 318 **xx. Citicoline (marketed as Cognizin)**
- 319 **yy. Thiamet-G (A Tau enzyme modifier)**

321

322 **Reported “BAD” for Alzheimer’s from various sources:**

323

- 324 **1. Diabetes**
- 325 **2. High Blood Pressure**
- 326 **3. Obesity**
- 327 **4. Depression !!!**
- 328 **5. Being Sedentary**
- 329 **6. Smoking**
- 330 **7. Low education levels and lack of mental stimulation**
- 331 **8. Statin Drugs (Lipitor, etc.)**
- 332 **9. Drug interactions (See Beer’s list!)**
- 333 **10. Restricted life space**

334