

Richard Taylor. *Alzheimer's from the Inside Out*.  
Baltimore: Health Professions Press, 2006.

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### RÉSUMÉ

Le Dr Richard Taylor est devenu le héros et le modèle de rôle de ce réviseur, à titre de psychologue qui entreprend maintenant son voyage dans les étapes intermédiaires de la maladie d'Alzheimer. Même si cela peut sembler improbable, M. Taylor est de fait le parfait exemple du modèle scientifique-praticien en psychologie qui mise beaucoup sur son expertise en recherche (compilant systématiquement ses notes et les classant à l'aide de l'informatique), et il est comme un observateur attentif et un professeur qui l'aide à formuler sa « méthode d'enquête » afin de créer une étude phénoménologique de son expérience comme participant-observateur dans un milieu naturaliste. Ici, les milieux autour desquels s'articule sa documentation comprennent notamment l'esprit de M. Taylor (ses pensées et ses sentiments), les liens de rapports mutuels avec sa famille, ses amis et ses fournisseurs de soins professionnels, et son environnement physique. Il associe toutes ces données à un excellent matériel documentaire d'appoint, et envoie aux fournisseurs de soins de santé professionnels, aux membres des familles et aux personnes souffrant de la maladie d'Alzheimer le message qu'il faut prendre des mesures visant à défendre et à faire valoir les intérêts de ces personnes, afin de mieux comprendre la maladie et les soins à donner aux personnes qui en sont atteintes.

Richard Taylor writes to document his thoughts, feelings, and insights in order to help himself better understand his behaviour, his future, his seemingly unanswerable questions, and his continuous observations of himself and his caregivers. *Alzheimer's from the Inside Out* (2006) is a compilation of essays he has written to express these findings and to share his experiences of the world in which he now lives. Dr. Taylor is a retired clinical psychologist who found that, by writing down his thoughts (a process made easier by the use of computer) and organizing them by theme, he was able to "weave an essay" (p. xvii) that helped him feel more confident about problem solving and ultimately gave him a "confirmation to me, of me, and by me" (p. xviii). The author began writing the pieces included in the collection shortly after his diagnosis of "dementia, probably of the Alzheimer's type" (p. 9) and continued up to and including his fourth year post-diagnosis, making for a remarkable work. Testament to the value, benefit and/or relevance of the book for persons diagnosed with Alzheimer's disease and their caregivers as well as for medical, psychological, and allied professionals is unanimous, as reported in the "Praise for ..." section of the book. The preface, written by Taylor's wife, is itself an insightful and open description of her experience as a caregiver and as the wife of this "remarkable man" (p. xxi). Two pages of photos offer a glimpse of the man Linda Taylor wishes the reader had known before the diagnosis was made (e.g., intellectually gifted, a clinical psychologist, a professor, a father of two, and now 62 years of age).

In addition to the essays, Taylor includes a few lists that combine humour and relevant pointed recommendations for improved care (e.g., in the list entitled "If I Were an M.D. instead of a Ph.D.", Taylor suggests that he "would always direct my remarks to the

patient" (p. 223). The book ends with a well-sourced list of Web sites and also cites Web sites throughout the book that give more impartial information and suggestions for care. Unfortunately, the Web site information is limited in being apparently all American (with the Alzheimer Disease International site the possible exception). The Web site list still has utility, in that Canadians (or others around the world) can likely find links to similar sites in their own countries. Taylor includes several Web sites "for people living with the disease" (p. xxi), including several in which he is directly involved.

The body of this work contains the essays, which are from one to four pages in length and which are organized around several themes, although Taylor is clear that they were not written in this order chronologically and explains—without apologizing for—the repetition and sometimes tediousness that this creates. This reviewer suggests reading the book from start to finish (as I confess I initially did not); this may avoid confusion over material repeated in different sections of the book.

The first section of essays is entitled "What Is It Like to Have Alzheimer's Disease". I, as a psychologist who, over the past 18-plus years, have asked this question of people diagnosed with Alzheimer's disease, am not surprised by Taylor's revelations. In his case, though, his verbal skills lend an exquisite metaphorical and poetic quality to his answers that helps us fully appreciate his experience. He acknowledges that his experience is unique, but it is also, perhaps, more common that he realizes; for example, 2 years after the diagnosis was made, he says that his life is "like looking through the world with lace curtains" (p. 16). This is a variant of the veil, curtain, or fog description this reviewer has heard several

times from persons in early stages of Alzheimer's disease (and interestingly, the description is often offered in the context of the curtain's having lifted after someone has been on an Alzheimer's drug for a few months). Taylor encourages those diagnosed to write, even long after their verbal skills diminish: "Writing about things can be immensely helpful when talking about them is no longer working" (p. xviii). I take the liberty here of referring to some Canadian writing, similar to Taylor's, to illustrate and support how his recommendation has value for "patient" and family: the Nova Scotia Alzheimer's Society Web site offers several examples of people living with dementia who have expressed what their experience means to them. I draw particular attention to "Bob's poems," written by a non-writer (unlike Taylor) whose poignant poems reveal the emotion and thinking behind his experience (like Taylor's). In this first part of the book, Taylor describes the historical focus of work in dementia care; that is, on working with the caregiver and, most importantly from his perspective, on what the caregiver says is going on with the "patient". Taylor maintains this focus still exists, the frustration of which is shown in one of his most consistent points, repeated throughout the book—that is, to treat him (and others diagnosed) with respect and with the dignity of an adult.

The next two sections, entitled "From the Inside Out" and "From the Outside In", reveal Taylor's experience intra-personally and interpersonally, respectively. He shares insights into his redefined understanding of hope once he learns he has Alzheimer's disease: "[knowing] motivates my focus on actively making today better than yesterday, not hoping tomorrow will be better than today" (p. 88). He also shares his emotional responses, including depression, fear, grief, and anger, as well as his moments of joy (e.g., "I am going to do more singing. I feel safe, sound, healthy, and alive when I sing" [p. 100]). He explores his belief system and how his sense of spirituality changes but not necessarily because of his disease. Taylor's relating his experience of others' reactions to him (e.g., "[I]t embarrasses me when others act differently around me" [p. 153]) is followed by many suggestions regarding how someone can (should) interact with him (e.g., "Please accentuate the positive with my recollections. Don't lie if I'm not accurate" [p. 155]). Taylor reveals his awareness of, sadness about and sometimes frustration with his increasing reliance on his wife ("my independence is morphing into dependence on Linda" [p. 165]). These sections are essentially about what helps and what does not help Taylor

in his living with himself and the disease as it progresses through his mind.

The book's last section, "Dear Doctor . . .", emphasizes Taylor's strong belief that the medical profession (and similarly, psychology and any health care group) needs to change to ensure the patient (and the caregiver) receive the best care possible. The critical tone of his implicit message is that not a good enough job is being done to deliver this "best care". The major change means involving patient, caregiver, doctor, and other health care professionals in developing the best care plan; that is, one that addresses the patient's symptoms, abilities (rather than disabilities), and fears. Although Taylor's list of "obtuse answers physicians give to direct questions" is qualified as not representative of all physicians (or other health care professionals), it does highlight the ways in which they [we] need to pay better attention to the detail and delivery of responses to patient's questions (e.g., "Will this almost former hippie become aggressive?" Answer: "I can say with a great degree of confidence that the answer to your question is yes or no. We will have to wait and see what happens" [p. 232]). Taylor wants the physician (or care provider) "to explain things . . . as many times as it took for the patient to be able to explain it back . . . in his or her own words" (p. 223). Taylor's "eight minute" presentation to a group of "noted internists and gerontologists" on "[w]hat it's like to have Alzheimer's disease" is included verbatim in this section, and, in it, he reveals a highly personal account of his feelings and thoughts about, for example, having a doctor tell his wife "in front of me that I need to come back to see him only after I have pulled down my pants and peed in the middle of my living room". Taylor challenges physicians to imagine what it would be like to have early-onset Alzheimer's disease and gives his own description of what it is like living with it (i.e., "having to die twice in front of my family. First comes the death of who I am, and the second is the death of who I will become" [p. 227]). He makes his awareness of his progression clear in reporting that

I have moved from dozens of scraps of articles, each with an important "note to self" on it, to to-do lists, to multiple computer generated to-do list alarms, to lists of to-do lists, to one day at a time, to simply caring less about what is and is not happening to me and my obligations to others. (p.227)

Taylor writes to explore his own experience, but he also educates and raises awareness of "poor practice" issues, from his perspective at least. This reviewer's

experience with patients in the early stages of a dementia corroborates many of Taylor's points, and from a phenomenological viewpoint, his issues are considered valid in any case. While keeping in mind that not every person with Alzheimer's disease will have the exact same experiences, the book is invaluable in suggesting what it might be like for many with the disease and for helping professionals become a little more mindful of whom they are treating. I highly recommend this book to professionals at all levels of experience and expertise

and to the patients and family members who would like validation and/or some understanding of the nature of the experience of living with Alzheimer's disease.

### **Note**

1 The author wishes to acknowledge Sarah Douglas for her helpful comments in the preparation of this review.