Foreword

In this excellent and informative book Verna Carson introduces the public to the concepts of retrogenesis and the importance of these concepts for understanding persons with dementia, especially the dementia of Alzheimer's disease. Retrogenesis has been defined as "the process by which degenerative mechanisms reverse the order of acquisition in normal human development." As Verna points out in this book, this process has long been recognized in a certain sense, for example, by some of the most famous playwrights of all time. Even before the playwrights, a famous mathematician and philosopher who gave the world some of the "a, b, c's" of mathematics, also provided the "a, b, c's" of life. In the sixth century B.C., Pythagoras famously stated that for a right angle triangle, the square of the abscissa (a^2), plus the square of the ordinate (b^2), equals the square of the hypotenuse (c^2) or "$a^2+b^2=c^2$." All of us who studied geometry in high school have learned these truths, still called "the Pythagoras theorem." However, what Pythagoras may ultimately be known for is having provided us with the "a, b, c's of life." As a philosopher, Pythagoras stated that there are five phases of life. He said that the last two phases of life are "the senium" in which the brain returns to the first epoch of its infancy.

In the 1980s, I, together with my associates, systematically described the stages of brain aging and Alzheimer's disease. These descriptions have been proven to be scientifically valid, and also very useful. For example, our Global Deterioration Scale is used by the Alzheimer's Association to help the public understand the course of brain aging and Alzheimer's disease (www.alz.org/AboutAD/Stages.asp). Shortly after we developed the Global Deterioration Scale, we realized that functionally it was possible to describe the course of progressive brain aging and Alzheimer's disease in particular detail and we showed that a total of 16 successive "functional" stages of brain aging and Alzheimer's disease could be described with a measure called the "FAST," the Functional Assessment Staging Tool procedure. In the process of developing the FAST, we recognized that these functional stages are a very precise reversal of the order of acquisition of the same stages in normal human development (Reisberg, *Geriatrics*, 1986).

With these insights we set out to answer three questions: (1) In what other ways does the aging and Alzheimer's disease process reverse normal human development?

(2) How can these insights help in the care of persons with Alzheimer's disease? and (3) How do these discoveries relate to the cause of Alzheimer's disease?

The first and foremost question that we addressed was: do thinking abilities also reverse normal development, and if so, how close are the parallels? Working with investigators in Japan, especially Kenichi Meguro and Masumi Shimada, we showed close relationships between decline in Alzheimer's disease on a well-known intelligence test and the progression of functional loss on the FAST, and that these losses closely mirrored the corresponding developmental ages (Shimada and colleagues, *Psychogeriatrics*, 2003). Also, because in the later portion of the FAST scale persons with severe AD are untestable on traditional tests designed for children, we took infant intelligence test measures and adapted them for severe Alzheimer's disease patients. When we tested the severe Alzheimer's disease patients we found a very close correspondence between the performance in the severe Alzheimer's disease patients and that of infants at the corresponding points of Alzheimer's functional losses and infant functional attainment (Sclan and colleagues, *Psychiatric Journal of the University of Ottawa*, 1990 and Auer and colleagues, *Journal of the American Geriatric Society*, 1994). Most recently, investigators in Spain led by Jordi Peña-Casanova and Rubén Muñiz took the final, conclusive step. They, directly compared Spanish school children from ages 4 to 12 with elderly persons with normal aging, mild cognitive impairment, or progressively more severe Alzheimer's disease. They found strikingly strong parallels between the losses in aging and Alzheimer's disease and the corresponding acquisition patterns in children for both thinking (cognition) measures and functioning measures (Rubial-Álvarez and colleagues, *Journal of Alzheimer's Disease*, 2013).

Also, we and others showed that in many other interesting ways, the progression of Alzheimer's disease reverses the normal human development process. For example, we showed that reflexes in infants emerge in Alzheimer's patients at the corresponding developmental age related Alzheimer's disease stages in a series of publications by Emile Franssen and our other colleagues. Also, in terms of brain structure (anatomy), the process of brain aging has been shown to reverse the normal human development pattern. For example, the brain contains cells called "neurons" which have extensions similar to arms or wires called "axons" that are used to communicate with other brain cells. These axons (the nerve cell wires) are progressively covered with a fat-like substance, similar to the rubber which insulates a wire, and which aides nerve cell communication with other nerve cells. The fat-like substance on the nerve extensions is called "myelin." The process of nerve cell "rubberization" called "myelination," continues from infancy to late life. Several early investigators in Alzheimer's disease brain changes noted that the unmyelinated and most recently and therefore, most thinly myelinated brain regions are the first to be affected by Alzheimer's type brain changes. These early investigators included Arne Brun, Elisabet Englund and Lars Gustafson in Sweden, Patrick McGeer in Canada, and Heiko Braak in Germany. With the advent of new brain imaging techniques called diffusion tensor imaging, we were able to begin to directly verify the validity of this process in Alzheimer's persons (Choi and colleagues including Kelvin Lim and Isabel Monteiro, *Journal of Geriatric Psychiatry and Neurology*, 2005).

Subsequently, a large study in several US centers strongly supported these observations (Stricker and colleagues, *Neurology*, 2009). There is also evidence that other brain changes, especially the loss of brain energy, called metabolism, also reverses the normal brain developmental patterns. Building on these observations we (especially Sunnie Kenowsky, Stefanie Auer and I), developed a science of Alzheimer's disease management and treatment based upon the knowledge of the developmental age (DA) of the Alzheimer's disease (AD) person (Reisberg and colleagues, *International Psychogeriatrics*, 1999 and Reisberg and colleagues, *American Journal of Alzheimer's Disease and Other Dementias*, 2002). With this management science, we translated the AD stages into correspondingly developmental ages. We have shown that the management needs and care requirements of AD persons at the AD stages mirror the corresponding DAs. Many of the emotional changes, activity needs, and other aspects of AD persons also reflect the DA. We have also noted differences between AD persons and their DA "peers." For example AD persons do not undergo a physical retrogenesis, so they are, for example, larger and potentially stronger than children at the same DA. Also, AD persons are older and prone to the illnesses (comorbidities) of older persons, unlike children. Additionally, Alzheimer's persons have a history, for example, of speaking, which infants do not. Hence, the "science of AD management" includes differences in the model as well as similarities. Recently, in part by applying this retrogenesis model to AD person's management and care, Dr. Kenowsky and I, have been getting very dramatically positive results in persons with moderately severe AD (Reisberg, et al., *Neuropsychopharmacology*, 2013 [abstract]).

Finally, I believe these findings are moving us towards a better understanding of the "cause" of AD. Basic brain mechanisms including brain anatomy (structure) and physiology (energy utilization), appear to be reversing development. In many ways we have found that even the time course of AD losses reverses normal developmental attainments, although there are also some differences. These observations point to a brain developmental reversal, perhaps, fueled by losses in brain energy (i.e., metabolic decrements). Accordingly, conditions which interfere with brain energy utilization (for example, condition which are diabetogenic), such as obesity, inactivity, etc., are increasingly being found to be risk factors for AD. Ultimately, the cause of AD, of course, requires further investigation. In the interim, advances in our understanding of AD persons can help these increasingly needy and potentially increasingly disturbed AD persons, as the disease process advances, today. Because of these possibilities and findings, this year, in 2014, the National Alzheimer Society of Spain (CEAFA) implemented a care model requiring familiarity with the use of our FAST scale of the progression of Alzheimer's disease related functional losses, and the retrogenic concepts of care needs and care possibilities, as compulsory in all nursing homes in Spain.

Barry Reisberg, M.D.
Professor of Psychiatry

Director, Fisher Alzheimer's Disease Program
Clinical Director, Aging & Dementia
Clinical Research Center
New York University Langone Medical Center

Preface

This book is written by three providers who care deeply about and are intimately involved with caregivers who struggle on a daily basis to provide loving and patient care to those diagnosed with Alzheimer's disease or one of the other dementias. Dr. Harold G. Koenig is a professor, a geriatric psychiatrist, and a researcher who delivers care to patients afflicted with one of the many dementias, while at the same time providing support to the caregivers of these individuals. Dr. Verna Benner Carson is a psychiatric nurse and President of a consulting company, C&V Senior Care Specialists, Inc. She developed a program entitled *Becoming an Alzheimer's Whisperer* and along with her business partner, Katherine Johnson Vanderhorst, also a psychiatric nurse, they traverse the country training family as well as professional caregivers—nurses, occupational therapists, physical therapists, and social workers—to "think outside of the box" when trying to manage the challenging behaviors of those with dementia.

They accomplish this by teaching and applying the Theory of Retrogenesis, developed by Dr. Barry Reisberg. This theory posits that those afflicted with dementia regress in a backwards fashion from adulthood to infancy. The theory does not suggest that a caregiver should "talk down" to the person with Alzheimer's or use "baby talk" but it does guide caregivers towards an accurate appraisal of what the individual is and is not capable of doing. Anyone who has seen or cared for an individual in the end stage of Alzheimer's cannot ignore the fact that the individual has lost many of the skills we associate with being an adult—the person is in a fetal position, cannot speak, lift his/her head up, sit up or walk, is incontinent and requires complete care—very much like an infant. The theory allows caregivers to understand the challenging behaviors in a different and more acceptable manner and leads to a problem solving approach that opens up a wide range of interventions. Additionally, the theory is correlated with damage to specific areas of the brain, so that caregivers learn that when their loved one repeats the same question over and over again they do not intend to be troublesome but this repetition occurs because the hippocampus, the storehouse of short term memory, is broken. Once caregivers know and understand the physiological origin of a behavior, they are free to "think outside of the box" to arrive at behavioral strategies.

Our hope is that within this book there are enough examples of such creative thinking that caregivers feel encouraged to allow their own inventiveness to lead them to discover interventions that are loving, patient, and effective in managing the challenging behaviors that characterize Alzheimer's and other dementias.

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