Assistive Technologies and Other Supports for People With Brain Impairment
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Assistive Technologies and Other Supports for People With Brain Impairment

by

Marcia J. Scherer, PhD, MPH, FACRM
For individuals with brain impairments, their families, caregivers, and health care providers. The causes of brain impairment are many, each course unique, and support needs diverse. Keep looking forward!
Contents

Foreword David Braddock, PhD ix
Acknowledgments xi
Author’s Introduction xiii

1. The Aging Brain, When the Mind Dissolves 1
   Marjorie’s Recent Medical History
   Marjorie’s Psychosocial History and Life Course
   Marjorie’s Past Medical History

2. The Brain Born With a Disability, When the Mind Grows 19
   One Plus One Is More Than Two
   Two Minus One Remains a Better One
   Causes of Brain Injury in Infants and Children

3. How the Brain Works 33
   Acquired Brain Injury
   Neurological and Mental Conditions Associated Primarily
   With Behavioral Patterns
   “Cognitive Disability” As the Outcome of Any Brain Illness,
   Injury, or Condition
   The Inner Workings of the Brain

4. Treatment and Rehabilitation Practices: Intervening in
   Cognitive Disability 55
   Treating Developmental Disability
   Treating Degenerative Disability
   Treating Acquired Brain Injury
   Cognitive, Emotional/Behavioral, and Psychosocial Rehabilitation for
   Brain Impairment
   Community-Integrated Rehabilitation
   Participation in Desired Life Situations: Leading a “Good Life”

5. The Potential of Technology to Assist Individuals With
   Cognitive Disabilities 121
   What Are Assistive Technologies?
   Classifying Assistive Technology Devices
   The Value of Assistive Technology Devices and Services

6. Assistive Technologies for Mobility, Communication, Seeing,
   Hearing, and Activities of Daily Living 143
   Finding Assistive Technology Devices
Contents

7. Assistive Technologies for Cognition 159
   Strategies
   Specialized Technologies
   Everyday Technologies

8. Environmental Barriers and Enablers 193
   The Categories of Design, Construction, and Building Products and Technology in the ICF’s Environmental Factors Domain of Products and Technology
   The Category of Products And Technology of Land Development in the ICF’s Environmental Factors Domain of Products and Technology
   The Category of Assets (Financial, Tangible, and Intangible) in the ICF’s Environmental Factors Domain of Products and Technology
   Chapter 2 in the ICF’s Environmental Factors Component: Natural Environment and Human-Made Changes to Environment
   Chapters 3 and 4 in the ICF’s Environmental Factors Component: Support and Relationships and Attitudes
   Chapter 5 in the ICF’s Environmental Factors Component: Services, Systems, and Policies

9. Getting Support and Services 217
   Systems of Service Delivery
   A Support Selection Framework
   Conclusion

10. Matching Person and Technology 243
    Matching Person and Technology Model
    Matching Person and Technology Assessment Process

11. The Future Is Bright, But There Are Challenges 281
    A Model of Injury and Disability Risk Reduction Through Early Selection and Provision of Supports
    Some Solutions to Current and Likely Ongoing Needs

Notes 301

References 305

Appendices
   A. Glossary 329
   B. Examples of Assistive Technology (AT) and Cognitive Support Technology (CST) Resources 339
   C. Finding and Funding Assistive and Cognitive Support Technologies 353
   D. ISO 9999 With ICF References for Code 05
      Assistive Products for Training in Skills 359

Index 369
Visualize, if you will, an ornate hearing room in a United States Senate Office Building. It’s 24 years ago and AI Cavalier is presenting testimony before what was then called the United States Senate Subcommittee on the Handicapped. Mr. Cavalier headed the Arc-United States’ Bioengineering Program at the time, and in his testimony he emphasized an unfortunate but widely prevailing belief in the assistive technology field and across society generally, that people with cognitive disabilities such as intellectual disability, were simply not “appropriate consumers” of assistive technology or of any other technology for that matter.

He argued in his testimony that because of this unfortunate misconception they should be designated by the Federal Government as a traditionally underrepresented group and that affirmative action was necessary in the implementation of the then proposed 1987 Technology Act legislation to insure their right to inclusion in its benefits. Unfortunately, that affirmative designation didn’t happen and it has been up to leaders in clinical applications of rehabilitation technology like Professor Marcia Scherer to advance the field by “Scherer determination,” pun intended.

But dramatic and unforeseen general advances in technology soon followed Cavalier’s testimony—in semiconductors, personal computers, and server technology, and in smart phones, web services, and wireless networks, to name a few. Information accessibility for people with and without cognitive disabilities also improved as dependence on rote memory decreased, more complementary visual, audio, and multi-graphic formats were developed, and user complexity was reduced in requisite vocabulary and organizational skills. On the hardware side, according to Kurzweil, there were 22 doublings of price-performance in raw computing capacity between 1967 and 2003, and processor speeds increased from .25 MIPS to 1,000 MIPS. An MIP is one million instructions per second.

In this exceptional book, Professor Scherer displays a deep understanding of the potential capacity of technology to improve the quality of life of people with cognitive disabilities in our society and throughout the world. However, she does not underestimate the intense discrimination faced by people with cognitive disabilities when she remarks that “you can legislate community re-entry, but you cannot legislate community re-integration or acceptance.” Fear, distrust and rejection impact self esteem
and have emotional and behavioral consequences. Her grasp of the present state of the disability field, from both clinical and assistive technology perspectives, is impressively broad and deep. Her “Matching Person and Technology Model,” so capably described in this book and in a stream of her earlier works dating back to 1986, remains a foundational contribution to the clinical application of assistive technology.

Scherer’s multidisciplinary knowledge base also stems from her extensive experience as a practicing, doctoral trained, clinical psychologist. That experience includes extensive work directly with people with mental health disorders, developmental disabilities, and physical disabilities. She writes movingly in this book, most touchingly so when describing her lived experience as the daughter of a beloved family member with a brain disorder. I palpably felt the author’s deep compassion throughout the book. I admired her clinical competence and commitment as she provided detail about her close working partnerships with numerous people with varied abilities to use technology to help themselves achieve greater independence and self-confidence.

Dr. Scherer skillfully guides us in how to develop and apply reasonable, measureable clinical goals using assistive technology, and to step back frequently and revise those goals as deeper insights about what works with a given client are more fully recognized and understood. My familiarity with Dr. Scherer’s work has stemmed in part from her productive participation in the research and development activities of the University of Colorado’s Rehabilitation Engineering Research Center on Cognitive Technologies and in the Coleman Institute for Cognitive Disabilities’ 11 annual technology conferences to date, I know her to be a thoughtful and uncommonly creative writer and presenter. Her new book does not disappoint.

The most powerful insights she offers students, clinical colleagues, and general readers in this book flow directly from the several excellent case study presentations she offers. They display her extensive clinical experience, compassion, and realism in setting goals and evaluating attainment of those goals collaboratively with the consumer. But I am most impressed by two powerful ideas that rush to mind after reading this book: that cognitive technology is a byproduct of the human spirit and imagination and it will continue to surprise us in ways we cannot now fully envision; secondly, thanks to Marcia Scherer and this book, we have a new compass to inspire and guide us on this exciting journey of the imagination. Bon voyage....

David Braddock, PhD
Coleman-Turner Chair and Professor in Psychiatry
Executive Director, Coleman Institute for
Cognitive Disability
Associate Vice President, University of Colorado
Acknowledgments

Writing a book of this depth and breadth required that I have my own supports. Mary Brownsberger, a rehabilitation neuropsychologist affiliated with Bancroft Brain Injury Services in New Jersey, and Lauren Taylor, holder of a graduate degree from the London School of Hygiene & Tropical Medicine, served as my “development editors.” They kept a close eye on each chapter’s structure, content and tone, and pointed out where there needed to be better bridges within or between chapters. Dan Davies, founder and president of AbleLink Technologies Inc. in Colorado; Ed Lopresti, president of AT Sciences in Pittsburgh, Pennsylvania; Clayton Lewis, professor of Computer Science, University of Colorado at Boulder; and Cathy Bodine, associate professor in the Department of Physical Medicine and Rehabilitation, University of Colorado Health Sciences Center and Co-Principal Investigator of the Rehabilitation Engineer Research Center for Advancing Cognitive Technologies, all contributed information and insights on specialized and everyday technologies for individuals with cognitive disabilities. Steve Lowe, associate project manager of AbleData; and Yvonne Heerkens, program manager of Terminology & Technology for the Dutch National Institute of Allied Health Care, provided invaluable help with the classification of assistive technology products and its fit with the World Health Organization’s International Classification of Functioning, Disability, and Health. Colleagues in the University of Rochester Medical Center’s Department of Physical Medicine and Rehabilitation and in the university’s computer science department, were generous with time and support as were colleagues affiliated with the Burton Blatt Institute at Syracuse University.

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Last but foremost, I owe much more than words can convey to John Scherer, who as an electrical engineer and loving husband, provided me with substantive assistance as well as moral support and encouragement. He endured without complaint many take-out dinners and lonely evenings while I worked at the computer. Thank you, John—you are truly the love of my life.
Introduction

Brain injuries have been in the news a lot lately. We’ve read news coverage of professional football legend Terry Bradshaw’s rehabilitation efforts for traumatic brain injury, numerous reports of young people with sports-related concussions, the brain injury recovery process of U.S. Representative Gabrielle Giffords (D-Arizona) after she was shot in Tucson, and accounts of scores of wounded service members returning from wars in Afghanistan and Iraq with brain impairments. What doesn’t get as much press are the thousands of people with other forms of brain impairment—those who have survived a stroke, who struggle in school because of autism or an intellectual disability, who live with an emotional or behavioral disability, or who are living their last years with dementia or Alzheimer’s disease. The term brain impairment, thus, refers to the consequences of damage to the functions and structure of the brain as an outcome of a wide range of causes.

Enter technology to the rescue. Advances in injury diagnosis and emergency treatment, imaging, and medical and rehabilitation interventions have not only saved lives, but also made recovery and community living possible.

Ah, technology! It can be frustratingly complex at times, confuse and overwhelm us, but we can’t seem to live without it. Or even want to. On a recent flight, as I walked from row 10 to the back of the plane to use the lavatory, I saw people:

- Reading newspapers and magazines
- Reading paperback and hardcover books
- Reading Kindle
- Doing crossword puzzles in the airline magazine
- Playing computer games
- Watching the airline’s movie
- Watching movies on their iPad
- Doing work on their PCs
- Talking with a seatmate
- Sleeping.
Just how does technology affect the way we work, accomplish tasks, and relate to other people? How has it helped our quality of lives? These topics have been my area of research for the past 20 years, but particularly in the ways technology has affected those living with disabilities. No one is more affected in a personal way than people who must use technology to accomplish a task or get from place to place.

In the late 1970s and throughout the 1980s, there was an explosion of technologies being developed as a result of technology transfer from aerospace and other science and engineering achievements. The ability to miniaturize components led to smaller and more powerful computers. One outcome was a burgeoning of products developed for the specialized needs of persons with disabilities. Unfortunately, designers of the products had not fully taken consumer goals, priorities and preferences and product usability into account. Thus, what was a brilliant engineering design was not always viewed by the user as a desirable form of support. Many had fear of use and avoided it altogether. Many devices were used for a time, but then were determined to be too complicated or uncomfortable to use and were relegated to the basement, closet, or drawer to never again see the light of day. Today, we see more common platforms that are customizable in order to present options. For example, to enter many hotels, you can use a revolving door, a levered door, or a door that automatically swings open with the push of a button.

It was in the context of rapidly evolving technology supports for people with disabilities that I developed my PhD dissertation proposal and grant application to the National Science Foundation. Up to that point, few had studied the myriad characteristics differentiating adults with disabilities who did use various technologies from those who did not use them. The characteristics identified in my research fell into three broad areas: characteristics of the person, environments of use, and the devices themselves. The influences were then organized into a format where they could be used to guide the match of person and technology as well as assess outcomes of the device selection and procurement process. The influences have been presented and discussed in earlier books, which are also biographical accounts of the lives and experiences of persons with disabilities and include those who can’t hear or see, can’t walk or talk, and can’t even sip a cup of coffee independently. These individuals must depend on other people, depend on technologies, or be stuck.

As time has progressed to 2011, there is much less fear of technology. Rather, for many devices, there is increasing reliance and, some might say, overreliance or dependence. We have evolved to the point where embracing technology is not an issue, but knowing how to choose the best of it and ignore what is distracting or useless is a growing concern.

For many products, the operations needed to control them have been streamlined. For others, there is more cognitive complexity because of
increased choice. For example, to operate early microwave ovens, one just turned a dial to the desired number of minutes. Now, one needs to decide if high or low wattage is best, operate the numeric keypad, and determine if one wants convection cooking, grilling, and browning.

How the power of today’s technologies is being harnessed to support people with brain impairments, and how people can best select the most appropriate support from a wide array of options, is a key reason for my writing this book. Assistive and cognitive support technologies are discussed along with an array of accommodations and resources as well as individualized blends of different forms of support. Examples are provided to base the points and ideas made in real-life situations with actual support users. Here are the individuals you will read about and their particular form of brain impairment along with the age when it typically occurs or becomes apparent:

<table>
<thead>
<tr>
<th>INFANCY</th>
<th>CHILDHOOD</th>
<th>OLDER AGE</th>
<th>ANY AGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual disability including Down syndrome Theresa (Chapter 2)</td>
<td>Learning disability Louisa (Chapter 6)</td>
<td>Dementia, including Alzheimer’s disease Marjorie (Chapter 1) James (Chapter 6)</td>
<td>Traumatic and acquired brain injury Delmar (Chapter 3)</td>
</tr>
<tr>
<td>Cerebral palsy Maggie (Chapter 2)</td>
<td>Asperger syndrome Ryan (Chapter 3)</td>
<td>Stroke Marjorie (Chapter 1)</td>
<td>Mental, emotional, and behavioral disabilities Louisa (Chapter 6)</td>
</tr>
</tbody>
</table>

Their experiences are told in their own words, or those of the professionals with whom they worked. In the example of Marjorie, conversations were not recorded or noted at the time they occurred, but have been reconstructed based on my recall and the concurrence of family members. Ryan’s experiences are related by his sister.

Now, on to the subject of the book: How to best match individuals who have a variety of forms of brain impairment with the most appropriate supports so that they lead productive and satisfying lives and achieve a high quality of life.
Working with individuals with cognitive disability of any age, and their families, can be very rewarding, exhilarating, challenging, frustrating, the whole package—usually within the same day. Even the best of professionals find this to be true. Families, caregivers, and individuals with cognitive disability themselves experience this, plus other factors can come into play such as denial, being unaware of needs, and emotional distress. Let me provide an actual example.

Back in the winter of 2008, I lingered outside of Marjorie’s room for just a minute. Just enough time to prepare myself, I made sure my demeanor conveyed confidence and my face had a smile. The day before, when I walked into her room, my eyes were still watering from the cold air (it was, after all, February in Western New York) and Marjorie noticed that right away. “Why are you crying?” she inquired. I told her I wasn’t, that my eyes were watering from the cold. She looked at me skeptically and asked, “Are you sure? You’re not crying because of some news about me, are you?” I assured her I was not. Then she looked me directly in the eye and snapped, “You need to be very careful, you know. You should never go into a patient’s room with watery eyes. It makes them think . . . it made me think . . . something is wrong.” Her next words were spat out. “Some PhD . . . jeez!” As a former nurse, Marjorie had no qualms about dressing down the “younger generation.” I felt as helpless as Marjorie believed me to be.

A week later, I visited Marjorie again. When I walked into her area, I reminded myself to be aware of what I saw and heard, and also what I
did not see and hear. People socializing? Crying or screaming? Too many TVs on? To be aware of what I smelled, and what I did not smell. Food? Cleaning fluid? Urine? Then I put all these bits of information together to form my impression of the entire place that day, assessing its general atmosphere and character. I used a gestalt perspective, where the whole is greater than the sum of its parts; a big picture beyond mere details, where one sees the forest for the trees.

When I walked into Marjorie’s room at noon, she was lying in bed and greeted me with a nonchalant look and with a chill in her greeting. There it was, that glob of anger creeping up my chest, up my neck, and into my throat and in place for a snippy retort. I swallowed the glob back down, made myself focus solely on her. I asked, “How is your pain today?”

“Awful. Awful . . . oh, just awful.” She shook her head slowly back and forth.

_Awful_ was becoming her most frequently used word.

“Did they give you your pain medication yet?”

“Yes. I guess so. I think so. It doesn’t do much good, though.”

“And did you walk this morning?”

“Not yet. Maybe later. My back hurts too much now.”

At this, she closed her eyes, wiggled a bit, and winced as if to provide physical proof of what she had just told me.

I wanted to say, scream it, actually, “Maybe your back would feel better if you walked. Don’t you care anymore? If you don’t walk now, eventually you won’t be able to walk at all. The less you do, then the less you can do. Don’t you want to get better?” Instead, I said what I always said to her. “Well, that’s too bad. I understand. Later then.”

Marjorie’s hair was snow-white, but you could never tell from her face that she was 94 years old, even though over the years, she had gone from 150 pounds to less than 100 and had shrunk several inches to 5’2”. In a few minutes, a tall, large-boned nursing assistant came in to help Marjorie into her wheelchair to go to the small dining room for lunch. This was an agonizing experience for all—Marjorie, who found it painful; the assistant, who could think of nothing else to try to make it easier; and anyone nearby watching and listening. Marjorie’s loud groaning was the worst part of it, even though to my trained eye, I could see nothing that would cause such a sudden onset of excruciating pain. I asked Marjorie about it once she had settled physically and emotionally into her wheelchair.

“Oh, it’s not that bad really. Tawny [the assistant] knows, don’t you, Tawny?” And she gave Tawny a conspiratorial look and a small smile.

Tawny gave a truly good-natured laugh and replied, “I know Marjorie. It’s just our routine.”

Marjorie was behaving like a manipulative and spoiled child, with some complicity from Tawny who believed that anyone “of a certain age”
earned the right to do just as they pleased even if that meant staying in bed all day. In other words, in my mind, that they had the right to give up.

Marjorie believed that she could moan and groan any time she wanted and everyone would understand. If they knew who she was and what she had endured over the past few months, they would surely excuse any behavior. The trouble was, they didn’t, and they wouldn’t.

**MARJORIE’S RECENT MEDICAL HISTORY**

Marjorie had broken her hip almost 3 months previously on Thanksgiving Day. Her sister had picked her up to bring Marjorie over to her house for the afternoon and dinner. They drove into the garage and Marjorie got out and stood waiting under the open door. Then her sister, not knowing where Marjorie was standing, pushed the button to close the garage door, which hit Marjorie on the shoulder and slammed her down onto the concrete floor. An emergency hip replacement was done that night.

How quickly life changes!

Back at Marjorie’s house, where she lived alone, her cup and saucer sat ready for the next morning’s coffee. Beside it was a banana leftover from the lunch brought the day before by Meals on Wheels. The Thanksgiving Day morning paper was by her chair for reading when she returned back home that evening.

But Marjorie would never return to her home again. Prior to breaking her hip, Marjorie had gotten very thin, but her primary care physician had said she was in good health otherwise—strong heart, lab results came back just fine, blood oxygen level was high. This was excellent news, especially because she had been hospitalized 6 years earlier for severe bronchitis and now had chronic obstructive pulmonary disorder (COPD), which is a progressive lung disease affecting breathing. She only rarely needed to use the inhaler her doctor prescribed for her.

She was admonished to eat more and to put on some weight for “cushioning,” for if she should fall and break a hip, that would be very serious. This she said she knew, and to prove it, she had widened her eyes and affirmatively nodded her head. But still she didn’t eat enough.

Then, there was the fall in the hospital after her hip replacement surgery when she woke up in the middle of the night and walked to the bathroom. An X-ray confirmed all was fine with her hip. But she had to stay in bed and this led to the development of decubitus ulcers.

In popular parlance, a decubitus ulcer is termed a bed or pressure sore. It is an ulcer in the skin caused by sitting or lying in one position too long. Blood circulation in the skin is reduced by pressure, particularly pressure over skin that is over bony prominences in the back and hips. At greatest
risk are those who are older adults and those who have diabetes, dementia, or conditions that weaken the immune system. Thus, a decubitus ulcer is a serious medical condition; when it doesn’t heal, it may get larger and deeper, cause considerable pain, become infected, and become life threatening.

Marjorie’s small frame and low weight contributed to this to a large extent. When she left the hospital for subacute rehabilitation, she had to spend time in bed to ease the pressure off her buttocks. By becoming more sedentary, she got weaker and she required assistance to go to the toilet and shower.

She resisted walking more and more in physical therapy because she said that it was too painful to walk. Her lack of progress meant that she could no longer remain in that status even though they did give her more time. Marjorie was then placed on nursing home status. Shortly thereafter, she developed pneumonia that required a return stay in the hospital. From that time on, she required the continual use of oxygen, which meant a large oxygen tank had to accompany her everywhere. This she hated.

**MARJORIE’S PSYCHOSOCIAL HISTORY AND LIFE COURSE**

Marjorie was born in 1913, just before World War I, the first child of four. She was pampered by her parents as well as her paternal uncle, a physician; aunt; and grandmother. She always presented it as an idyllic childhood until tragedy struck one sunny autumn day when she was 7. She and her younger brother were playing in a curbside pile of leaves with several other neighborhood children when a milk truck came along. The milk truck driver didn’t see the children playing so close to the edge of the road, and when he pulled alongside the curb, he ran over Marjorie’s brother who died instantly. She was then an only child until a sister was born 12 years later and then another brother.

During the Depression, she enrolled in nursing school. She often talked about her memories of different patients on the wards, what medicine and health care was like then, and how the leftover food from the kitchen was taken outside to spoon into the dishes of those who had learned to patiently gather and wait for this daily occurrence. She told me that only 50% of those in her class actually passed and returned for their second year of study. They knew they had passed when they went to their classroom and they saw a cape draped on the back of their chair. No cape and you turned around, went back to the dorm room, and packed.

As a registered nurse, Marjorie was the first to administer sulfa in the hospital where she worked. She was very proud of this because sulfa was an early antibiotic that made it possible to control bacterial infections that up to that time had taken the lives of many of her patients. As much as
she loved nursing, she quit her profession when she married a mechanical engineer who owned a business, and only returned to nursing when he was drafted into the Army during World War II. Less than a year after her husband returned from the war, Marjorie’s father died of a cerebral hemorrhage, one more loss in her life. But then, things again became steady and calm. After several miscarriages, Marjorie and her husband had one child and settled into small town community life. It was a love-filled home, and Marjorie willingly made it her full-time job to care for the house, her husband, and their child.

Marjorie was never particularly outgoing and didn’t pursue an active social life. Even as a nurse, she had preferred night duty and the hours when most were sleeping and the typical buzz of the hospital was at its most quiet. She wasn’t shy or a loner, she just preferred things to be calm and steady, which they were until her husband died in 1972.

**MARJORIE’S PAST MEDICAL HISTORY**

Two years after her husband’s death, when she was 60 years old, Marjorie had a stroke.

**A Stroke Is a Brain Attack**

*Stroke* (or brain attack) is the third leading cause of death in the United States and a leading cause of adult disability. According to the National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (2010c), a stroke occurs when the blood supply to a part of the brain is suddenly interrupted, such as when a blood clot blocks a blood vessel to an area of the brain. This is called an *ischemic* form of stroke. A stroke may also be the result of a blood vessel in the brain bursting, thus spilling blood into the spaces surrounding brain cells; this is called a *hemorrhagic* form of stroke. Brain damage occurs when brain cells die because they no longer receive oxygen and nutrients from the blood (ischemic), or when there is sudden bleeding into or around the brain (hemorrhagic).

Stroke can occur at any age (even in utero), although it is most commonly seen in adults older than the age of 55 years. Both the American Stroke Association and the National Stroke Association (2010) list lifestyle risk factors for stroke such as substance abuse, obesity, as well as genetics, medical conditions (high cholesterol, high blood pressure, heart and circulatory disease), and injury to the head or neck. A stroke can also be a consequence of surgery, infection, or other health conditions.

To better describe the outcomes of stroke or brain attack, we could benefit from some visualization to accompany the text. Let’s use Leonardo da Vinci’s *Vitruvian Man* (Figure 1.1).² It is a familiar image and useful for
describing general aspects of what happens when there is a brain attack or stroke.

The consequences of a stroke are largely dependent on the side of the brain in which the stroke occurs. For example, if it occurs in the left hemisphere, the opposite or right side of the body is generally affected. This is known as the contralateralization of brain function (Figure 1.2).

There may be paralysis, typically on one side of the body, which is called hemiplegia, or hemiparesis if there is muscle weakness without paralysis. Thus, stroke results in brain damage which, in turn, can lead to difficulties with upper extremity control (fingers, hands, arms, shoulders) on the affected side. Lower extremity control can also be affected, resulting in difficulty with walking and mobility.

Stroke survivors may also have numbness or strange sensations. When present, the pain is often worse in the hands and feet and can be made worse by movement and temperature changes, especially cold temperatures. Compounding difficulties with such activities as walking, eating, reading, and writing are neurological and neuropsychological consequences such as spatial neglect and proprioceptive sense.

Spatial neglect typically occurs from injury to the right hemisphere (Bowen, McKenna, & Tallis, 1999). This causes the individual to “neglect”
sensory input from the left and treat as nonexistent what is on the left side of space (as shown in Figure 1.2). When, for example, individuals are asked to draw a clock, they may not include the numbers 6–12. They may neglect sounds coming into the left ear, not eat food from the left side of the plate, or fail to put a glove or mitten on their left hand.

Another possible outcome of stroke is the effect on the sense of proprioception, or the sense of where a particular body part (such as an arm or foot) is in space. It is related to kinesthesia or the perception of whether or not that body part is moving in space. Smith, Akhtar, and Garraway (1983) studied spatial neglect and proprioception in 287 stroke survivors and they found that proprioceptive loss indicated a more extensive lesion, more impaired intellectual function, and greater loss of upper and lower extremity motor power. Whereas proprioceptive loss had an adverse effect on the level of independence achieved and length of stay in the hospital, significant spatial neglect was associated with higher mortality and poor outcome for functional recovery.

Depending on the extent and side of damage, cognition, including remembering and learning as well as awareness, attention, and judgment, can be mildly to severely affected. Hearing and eyesight loss may be involved
and stroke survivors may have problems understanding speech (receptive communication) or speaking (expressive communication). A stroke can lead to emotional lability (instability) and other mental, emotional, and behavioral problems. Stroke patients may be less able to control their emotions or may express them inappropriately. Many stroke patients experience depression; in fact, depression is considered the number one consequence of stroke because approximately one third of stroke survivors experience it (Andersen, Vestergaard, Riis, & Lauritzen, 1994; Hackett, Yapa, Parag, & Anderson, 2005). It is thought in the medical and scientific community that depression can also be a contributor to the onset of stroke (Ostir, Markides, Peek, & Goodwin, 2001; Salaycik et al., 2007) as well as a leading consequence of it. Because depression can affect a person’s thinking, remembering, and learning as well as functional recovery and motivation to participate in rehabilitation, there have been efforts to identify the factors associated with depression in stroke survivors (Hackett & Anderson, 2005). There is some evidence to suggest that loss of functioning and expressive communication are predictors of emotional distress post-stroke (Thomas & Lincoln, 2008).

We can use the Vitruvian Man to further illustrate aspects of functioning affected by stroke (Kelly-Hayes et al., 1998):

**Around the Head**
- Impairments in memory, attention, orientation, calculation abilities, visual–motor coordination
- Spatial neglect and proprioception
- Depression is common; emotional lability
- Monocular visual loss, homonymous hemianopia, or cortical blindness
- Loss of smell
- Increased sensitivity to light or sound
- Hearing loss
- Difficulty swallowing or speaking clearly (caused by disruption of facial nerves and muscles)
- Language difficulties include dysphasia or aphasia that may be exhibited by disturbances in comprehension, naming, repetition, fluency, reading, or writing

**Trunk, Arms, and Hands**
- Difficulty with precise motions, such as writing or buttoning a shirt
- Numbness, tingling, or altered sensitivity

**Legs and Feet**
- Balance, disruption of walking and gait, coordination
Marjorie’s stroke resulted from a hyperextension injury to the neck caused by a fall because of high alcohol consumption. Her type of stroke did not originate in a hemisphere of the brain. Rather, it came from a neck injury that affected the vertebrobasilar arterial system when the vertebral or carotid arteries became torn. The clinical features are different from those of hemispheric strokes; cerebellar signs are frequent (e.g., uncoordinated movement or dysmetria and poor coordination or ataxia) and aphasia and cognitive impairment are generally absent (Bogousslavsky & Caplan, 2008; Okawara & Nibbelink, 1974). Many such tears or lesions are small and specific, resulting in focal neurologic deficits. In general, the prognosis for functional recovery is better than with a stroke originating in the brain itself.

Mental Status: When the Mind Melts Away

After her stroke, Marjorie’s speech, thinking, and memory remained unaffected, but preexisting (and less than desirable) personality traits became amplified. For example, she became more judgmental and self-focused. This could be caused by stroke or undiagnosed depression. She had some weakness in her left hand, but her arm functioning and strength was good. Then her only child married and didn’t spend as much time with Marjorie as before. Marjorie, however, was determined to muster her “Yankee spirit” and be independent. She remained in her two-story home, mowed her acre of lawn herself, and would spend many summer hours in her flower garden and winter hours at the sewing machine. Marjorie enjoyed game shows on television and reading. She practically memorized the newspaper and knew all about every current event that was deemed fit to print.

Because it happens with everyone, as Marjorie aged, so, too, did all her organs and body structures. Marjorie adapted to small changes in her capabilities by using good strategies. For example, she used only lower shelves when she could no longer reach high ones instead of standing on her step stool.

And so life went on until she had bronchitis about 6 years before she broke her hip, the gradual loss of hearing, and weight loss that eventually resulted in her being enrolled in Meals on Wheels. By the time she was in her 90s, when she broke her hip, she had become reclusive. Her grooming deteriorated (she had a “falling out” with her hairdresser of 60 years and stopped going). One day her phone was shut off. The phone company said she hadn’t paid her bill.

What was happening? I quickly went to Marjorie’s house, an 80-mile drive, to try to determine what was going on.

I could see her through the window in the front door. Her head was on her chest and she was sound asleep in spite of the TV turned up to about 100 decibels. My knocking did rouse her, and when she saw my face, she smiled and came to the door, a bit surprised at this unannounced visit. The knot in my stomach told me this was not going to be easy.
I said in a calm and loving voice, for she was much loved, “Hey, Mom, how are you? What’s going on? I tried calling you but the phone company said they turned your phone off because you didn’t pay your bill.”

Yes, Marjorie is my mother.

The Insidious Nature of Deterioration

How could I so utterly fail to see what was going on with my own mother, and had been? What kind of a psychologist am I, anyway?

There had been another recent warning. The Meals on Wheels volunteer had reported that “Marjorie doesn’t seem to be taking proper care of herself.” I checked, the social worker checked, all seemed to be okay. Clearly, though, it wasn’t. Yet, when talking to Mom, it was difficult to notice that anything was wrong or needed attention. She stayed up on current events, always knew who she was speaking with and when and where she had been and was going. She was engaged and fully involved in conversations. Her physician never suspected anything was awry because there were no structural or biological indications. How would anyone know that she could no longer properly concentrate on tasks? Her strategies had worked so well that everyone was deceived into believing she was managing just fine.

It was the incident of the phone being cut off that finally did it. I went to get Mom’s checkbook and saw how many checks she had written, and then crossed off, and then written again. There was a sheet of paper with her record of additions that looked more like a third grader’s struggle than the work of an adult balancing her account. The mail was piled up on the table—bills, magazines, thank-you gifts including quite expensive ones from the World Wildlife Federation. Clearly, she had been giving the World Wildlife Federation substantial donations. The entire time I was going around the house assessing her state of affairs, Mom just stayed in her chair with her head down, looking both chagrin and whipped, knowing something was wrong but not exactly sure what it was. I knew now that something had to be done and stepped up my efforts to get more help for her. This was a month almost to the day before Thanksgiving.

Unlike the sudden onset of her stroke with the immediate visible signs that something was wrong, her dementia was so slow and progressive that the small changes it brought weren’t all that discernable. They were easy to miss—or rather, deny.

Advanced Dementia

Dementia is a general term used to connote changes in personality, behavior, thinking, remembering, and learning because of declining brain functioning, and it is usually associated with advanced age. There are many different
types of dementia, of which Alzheimer’s disease and Lewy body dementia are two, and dementia involves multiple parts of the brain. Dementia can be caused by several factors, including aging, brain injury, vascular problems, exposure to toxic substances such as lead or chemicals, and substance abuse. Individuals with earlier brain injury, for example, from a stroke, are more likely to experience degenerative dementia. The diffuse and slow onset of dementia often leads to difficulties in recognizing it.

Separate surveys have come up with different prevalence figures because of variation in the criteria used to define dementia. In an attempt to directly determine the dementia prevalence rate in the United States, the Aging, Demographics, and Memory Study (ADAMS) was funded as the first population-based study of dementia to include individuals from all regions of the country (Plassman et al., 2007). The researchers state that their ADAMS sample was composed of 856 individuals aged 71 years and older from the nationally representative Health and Retirement Study (HRS). Participants were evaluated for dementia using an in-home assessment. An expert consensus panel used the assessment data to assign a diagnosis of normal cognition, cognitive impairment but not demented, or dementia (and dementia subtype). Using sampling weights derived from the HRS, they estimated the national prevalence of dementia, including Alzheimer’s disease and vascular dementia, by age and gender. The results of the ADAMS project showed that the proportion of persons with dementia increased by age; 37.4% of individuals aged 90 and older had dementia and 70% of this group had Alzheimer’s disease.

Internationally, the prevalence of dementia varies by country. A team of 12 experts (Ferri et al., 2005) reviewed data from all world regions and all types of dementia (i.e., they didn’t separately look at Alzheimer’s disease, Lewy body dementia, vascular dementia, etc.). They reached consensus on the proportion of the older population likely to be affected by dementia in each region and then used United Nations population estimates to produce prevalence figures for both men and women in five age groups (the oldest being “85 and older”). In the international comparison, the United States came in with the third highest proportion of its citizens with dementia. China was first, followed by the European Union. Overall, the experts estimated a prevalence of 24.3 million people with dementia in the world, with 4.6 million new cases of dementia annually (or annual incidence), and with Alzheimer’s disease being the most prevalent. This means that approximately every 7 seconds, someone in the world receives a new diagnosis of dementia.

Ferri, Ames, and Prince (2004) studied the behavioral and psychological symptoms of dementia (BPSD) in a sample of 555 individuals with known dementia in developing countries (low- and moderate-income countries). They found that at least one BPSD was reported in 70.9% of their sample. Depression syndromes (43.8%) were most common, followed by anxiety disorders (14.2%). However, depression (pseudodementia) can
produce similar symptoms as dementia in an older person. Thus, a careful examination is needed as the treatment of depression in older adults can be quite effective—and ameliorate cognitive effects associated with depression. The key distinguishing factor is self-awareness; someone with depression is more likely to notice and complain about cognitive issues. A person with Alzheimer’s disease is less likely to be aware of one’s own cognitive decline.

Behavioral and psychological symptoms are significant contributors to caregiver strain and require much further study and intervention. These and other functional impacts of dementia include the following:

### Around the Head
- Depression and poor outlook
- Anxiety
- Loss of motivation to do activities
- Memory loss
- Disorientation in time and place
- Loss of skill in reasoning and judgment
- Communication difficulties
- Inadequate amount of food consumed

### Trunk, Arms, and Hands
- Inability to perform routine tasks such as self-care and preparing a meal
- Congestive heart failure
- Shortness of breath
- Need for oxygen therapy
- Bowel incontinence

### Legs and Feet
- Physical inactivity
- Difficulty walking without support

As dementia advances, there is increasing memory loss, communication difficulties, disorientation to time and place, loss of skill in reasoning and judgment, and a steady decline in the ability to perform such routine tasks as shopping, preparing a meal, and various self-care activities. Motivation to do these activities also diminishes. The rate at which dementia progresses is highly variable but is often exacerbated by a change in living situation or family circumstances, medical conditions, surgical interventions, a hospital stay, and so on.
Four months before Marjorie’s death, 2 months after her hip fracture, she lost interest in everything: her favorite television shows, reading, and sewing. Her cognitive world had become so small that it was difficult to carry on any semblance of a conversation. News about the people back home, even the family, was met with “Oh, so what?” “Current events?” “Who cares?”

Although it can be difficult to discern what loss of functioning is because of pain, medications, the underlying disease, and the disruption
in lifestyle from nursing home placement, there are effective interventions. Treating the aging adult with dementia is very complex and requires both medical and psychological care and attention.

Dementia and Mortality

One thing I recall very clearly after my mother’s hip replacement was the surgeon calling me into the recovery room and cautioning that, although my mother came through the surgery just fine, “You should know that the 1-year mortality rate is 30%.” He said no more about why this was so and I didn’t ask. At the time, I felt resentment toward him for saying this and immediately thought to myself, “Oh yeah? Well then, you’ll be pleased and perhaps surprised to see that we’re in that 70% group of survivors.”

Indicators of mortality in those with advanced dementia have indeed been studied. One group of researchers longitudinally followed a group of newly admitted nursing home residents (Mitchell et al., 2004). They derived what they called 12 indicators of 6-month mortality:

- Significant impairment of activities of daily living
- Male gender
- Age older than 83 years
- Cancer
- Congestive heart failure
- Shortness of breath
- Need for oxygen therapy
- No more than 25% of food eaten at most meals
- Unstable overall condition
- Bowel incontinence
- Bedfast
- Sleeping most of the day

Using these variables, a risk for mortality is calculated. The more variables that apply and the more severe they are, the higher the risk of death. Please note, however, the absence of explicit behavioral and psychological indicators.

Let’s see how Marjorie fared on these criteria 1-month preinjury, before her hip fracture (exactly 6 months before her death), and then 1-month posthip replacement. Significant impairment of daily activities? Preinjury, not really. She got up every day, dressed and bathed, fixed herself a small breakfast, and had an established daily routine. She walked more slowly now and got out of breath quite often, but she still drove her car—and not badly either. I had actually witnessed her driving from the passenger seat when I asked her to drive us to the grocery store and the post office for exactly the purpose of assessing her driving skills.
There is a home movie of me as a toddler trying not to lag too far behind my mother as we were walking in the yard and garden. On my face is a look of plucky, good-natured determination to catch up to her. A look that said, “Don’t worry, I’m coming.” Her face, turned back to see just where I was, had a smile of loving patience. I recalled that moment vividly when we went grocery shopping that day. I had gotten ahead of her to get the shopping cart, and when I turned around to see where she was, she had that same plucky, good-natured look of determination to catch up to me. I so hope I looked at her with the same patience and love she had shown me.

Post hip replacement, Marjorie’s entire lifestyle and daily routine changed, which represented a major life disruption. Then she did not make the progress in rehabilitation she needed to remain in rehabilitation. To discuss the next steps, a team and family meeting was scheduled. There the doctors told her that she would likely never walk again. This news totally devastated her. I could see it impact her physically as I watched her expel all the air out of her lungs, curl into herself, and cast her eyes down fighting not to cry. I could hear it in her trembling question as she choked back her tears, “Do you mean I’ll always have to use a wheelchair?”

And that was the moment she gave up her will to live. I could not only see and hear it, but I could also feel it. And it tore my heart right out of my chest.

Mom’s appetite decreased. She stopped reading and showed no interest in talking with any of the other nursing home residents. She enjoyed the visit from Marty, the therapy dog, and liked to attend the events when volunteer choral groups came in. But her world was becoming smaller and smaller, with nothing to share in a conversation. She retreated first into the past and then into silence, broken only by moans of pain, utterances of awful... awful, and the occasional angry or hostile statement. She was depressed but unaware of her cognitive decline, so her dementia was indeed advancing.

But let us return to the mortality predictors. Male gender? No points here. Neither did she have a history of cancer or congestive heart failure. However, she did have COPD.

After her hospitalization for pneumonia, her diet was changed to soft foods and liquids, which she said were tasteless so she consumed less of them, too. Now she was eating “No more than 25% of food at most meals.” So we check that one on the list.

The less you do, the less you can do. This was certainly true in my mother’s case. The downward spiral was well underway and then the last four applied to a more or less extent:

- Unstable overall condition
- Bowel incontinence (not really—she just stopped bothering to call for the bed pan)
Bedfast (not until the last week of her life did the nurses stop getting her up and into her wheelchair)
Sleeping most of the day (only the last week of her life)

Although these criteria applied to varying degrees for my mother, as with all such guidelines, they will apply differently from one person to another. That is why it is so important to use such guidelines with a healthy dose of reservation. As the history of science and medicine has taught us over and over, there are precious few absolute, without-a-doubt certainties when it comes to dealing with the individualistic and idiosyncratic nature of human beings.

To see someone die of dementia is very much like watching a snowman melt. A typical snowman has three round sections from the head (the smallest) to upper and then lower torso (the largest). The snowman may have milk bottle cap eyes and a smile made of pebble teeth pushed into its face like a string of pearls in the form of a smile. Fallen sticks picked up off the ground make good arms. When the temperature warms, first the bottle cap eyes droop and fall, and then the teeth start dropping out. The head gradually gets smaller and smaller, and then the torso and the lower body get thinner and thinner. Finally, the snowman is just an indistinct pool of water that is absorbed by the earth.

Death certificates may list immediate, secondary, and underlying causes of death. The immediate cause is typically heart or respiratory failure. According to the American College of Physicians (1998)

The cause-of-death section of the certificate has three main parts: the chain of causation from immediate to underlying causes, the interval between onset of each of these conditions and death, and other contributing conditions unrelated to the underlying cause. . . . The underlying cause, which usually provides the most important epidemiologic information, may predate the immediate cause by several years. For example, acute myocardial infarction (the immediate cause) is produced by arteriosclerotic heart disease (the underlying cause). (p. 172)

The underlying cause of death is the one reported in the New York State vital statistics database. It is classified by medical code from the World Health Organization’s International Classification of Diseases (ICD, 10th Revision). Here is what is listed on my mother’s death certificate:

Immediate cause: Respiratory failure/multiorgan failure
Due to or as a consequence of: advanced dementia
Due to or as a consequence of: hyperkalemia (excessive potassium in the blood), hypernatremia (excessive sodium).
Is this right? The American College of Physicians has found that “death certificates are often inaccurate” and that a significant error rate exists in how underlying causes are reported. As I read it, I thought to myself, “For the underlying cause, why not write just plain old age? Or how about sick and tired of pain, complete lifestyle disruption, loss of independence and freedom, and the will to live”?

Dementia is a deterioration of brain function and cognition, and as we’ve seen, it can be fatal in and of itself. There are many other forms of damage and injury to the brain; however, they are not all progressive and certainly not fatal. In fact, many stroke survivors (like my mother) and individuals with traumatic brain injuries recover to lead, if not their complete preinjury lives, at least satisfying and productive ones. In the next chapter, we will meet two very interesting women who were born with their particular forms of brain impairment.